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A Study of Learning Activities of Selected Caregivers of Alzheimer's Patients in East Tennessee

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A study of learning activities of selected caregivers of Alzheimer's patients in east Tennessee

McLaughlin, Jeannette Goss, Ed.D.

East Tennessee State University, 1989

A STUDY OF LEARNING ACTIVITIES OF SELECTED CAREGIVERS OF ALZHEIMER'S PATIENTS IN EAST TENNESSEE

A Dissertation
Presented to
the Faculty of the Department of Supervision and
Administration
East Tennessee State University

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Education

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by
Jeannette Goss McLaughlin
December, 1989

APPROVAL

This is to certify that the Graduate Committee of

JEANNETTE GOSS McLAUGHLIN

met on the

fourth day of August, 1989.

The committee read and examined her dissertation, supervised her defense of it in an oral examination, and decided to recommend that her study be submitted to the Graduate Council and the Associate Vice-President for Research and Dean of the Graduate School, in partial fulfillment of the requirements for the degree of Doctor of Education.

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Signed on behalf of the Graduate Council

James H. Potts
Associate Vice-President for Research and Dean of the Graduate School

ABSTRACT

A STUDY OF LEARNING ACTIVITIES OF SELECTED CAREGIVERS OF ALZHEIMER'S PATIENTS IN EAST TENNESSEE

by

Jeannette G. McLaughlin

The problem of this study was to identify and describe the individual learning activities of caregivers of people with a diagnosis of Alzheimer's disease and to develop an analytical description of the patterns of learning of these adults.

An instrument was not available for use; therefore, a focused interview guide was developed. The interview guide was developed through consultation with several spouses or adult children caring for Alzheimer's patients, professionals in the health care field, and a review of the literature.

The major analysis procedure for the study was the constant comparative method, an inductive method that has been used most systematically by Glaser and Strauss (1967). Grounded theory is discovered or generated from data. It is developed by entering the field work phase without a hypothesis, describing what happens, and formulating explanations as to why it happens. Five research questions were explored dealing with the caregiver's support system, reasons for seeking medical help, learning at the time of the diagnosis, learning activities, and learning patterns.

Caregivers, as adult learners, showed the capacity to conduct self-directed learning activities. While the content was greatly determined by the patient's progression of the disease, caregivers identified six learning processes: (a) professionally guided, (b) informal conversation, (c) observation, (d) solving problems, (e) change in perspective, and (f) facilitating understanding for others.

The informal support system was significant in providing information to caregivers. Sixty percent of the friends and 50.5% of the family provided information, resources, and discussion. An extensive informal support system showed a greater use of a problem solving process.

IRB FORM NO. 106 PROTOCOL NO. 86-888

EAST TENNESSEE STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

PROJECT TITLE: A Study of Learning Activities of Selected Caregivers of Alzheimer's Patients in East Tennessee

PRINCIPAL INVESTIGATOR: Jeannette G. McLaughlin

The Institutional Review Board has reviewed the above-titled project on (date) October 17, 1986 with respect to the rights and safety of human subjects, including matters of informed consent and protection of subject confidentiality, and finds the project acceptable to the Board.

Ernest A. Daigneault
(CHAIRMAN)

DEDICATION

"I'm lost within my own mind;
I cannot find myself-"

Jeannette Heller Goss
3/26/09 - 3/25/86

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A very sincere thank you to the 30 caregivers and their loved ones with Alzheimer's disease who allowed me to share part of their lives.

CONTENTS

Chapter Page

LIST OF TABLES

Table Page

Table Page

CHAPTER 1

Introduction

The incidence of having Alzheimer's disease is five to seven percent at age 65 and over. Currently, there are more than 22 million in this age group in the United States, so Alzheimer's affects approximately 1.5 million people (Cohen, 1979; Mortimer, Shuman, & French, 1981). This number will increase as the older population size increases in the decades to come.

To date there is no known cure for this degenerative brain disorder. First, the mind dies, and then the body dies. Each patient progresses through an early, middle, and late stage. There is not a predictable rate of progression. Alzheimer's disease is characterized by severe memory loss. It is the fourth leading cause of death for people over 75 (Gwyther, 1985).

Families, especially the spouses and adult children of Alzheimer's patients, become responsible for financial and legal arrangements and health care. Shanas (1979a, 1979b) supported the significance of the role of the immediate family during the time of an elder's illness. Other studies showed that most long-term care of older persons was provided by families and other informal resources (Brody, Poulshock, & Masciocci, 1978; Carrilio & Eisenberg, 1983).

The impact on the family of caring for an Alzheimer's patient is significant. With the increase of medical costs and the possibility of job loss on the part of the patient or caregiver, financial responsibilities increase. The physical and emotional strains have been documented in the literature related to caregiver strain and the burden of caregiving (Gilhooley, 1984; Poulshock & Deimling, 1984; Robinson, 1983; Zarit et al., 1980).

The health care system is increasingly aware of the problems confronting the family caring for an Alzheimer's patient. Studies on the use of support groups, management strategies, and intervention techniques were found in the professional journals of medicine, nursing, and social work. Greater awareness on the part of health professionals of the caregiving family has resulted in the family being included in the treatment plan (Aronson & Lipkowitz, 1981; Barnes, Raskind, Scott, & Murphy, 1981; Breen & Reifler, 1983; Reifler & Wu, 1982).

Caregivers learn in a very special environment. As the disease progresses, the patient reacts to successive changes. The caregiver is aware of both the disease changes and patient's reaction to them. The caregiver must deal with the loss of a loved one, a new and different role, potential financial insecurity, the caregiver's own fear of aging, and other components in the caregiving environment unique to individual cases. Regardless of the situation, informal interviews with Alzheimer's caregivers revealed significant learning on their part in order to better care for their relative or friend.

Research within the field of adult education has documented the independent learner and self-directed learner (Brookfield, 1984b; Knowles, 1980; Knox, 1977; Penland, 1979). Tough's research (1971, 1982) on adults' learning projects and its many replications were based on the idea that learning was a natural part of adulthood and was carried out primarily in informal and independent ways. The relative lack of formal learning provided for caregivers suggests that informal or independent learning should exist among caregivers.

The literature has documented approaches to learning used by adults. Within the context of the Alzheimer's patient/caregiver environment the literature suggested that the learning conducted by caregivers as adult learners should be mainly self-directed; problem oriented; and experience based, with learning resources, including human and material, chosen from the immediate environment. Other orientations or approaches to learning possibly exist.

Statement of the Problem

The problem of this study was to identify and describe the individual learning activities of caregivers of people with a diagnosis of Alzheimer's disease and to develop an analytical description of the patterns of learning of these adults.

The Purpose of the Study

The purpose of the study was to identify and describe the learning activities of adults caring for patients diagnosed as having Alzheimer's disease. The total population aged 65 and older in the eight upper East Tennessee counties was 46,997 (1980 census). Applying the 5% figure of possible Alzheimer's disease patients, there are approximately 2,350 persons who have Alzheimer's or some form of dementia. These patients, for the most part, have family members who are caring for them.

Significance of the Study

The significance of this research is the contribution it makes to the knowledge of adult learning and education. Within the area of research on self-directed learning the emphasis has been on the features of individual learner control over the planning, conduct, and evaluation of learning. The importance of the social context in which the learning takes place and its relevance to learning is lacking in the literature. This study attempts to investigate the individual learning of adults within a specific setting. It recognizes the possibility of both formal and informal learning.

The results of this research have implications for the existing programs and support group activities designed to increase the caregiver's ability to care for an Alzheimer's patient. Current educational practices could be supported or questioned, thereby providing direction for future activities.

Research Questions

1. What is the caregiver's support system (e.g., formal supports used, informal supports of family and friends, support group affiliation)?
2. What specific situation(s) resulted in the caregiver seeking medical help?
3. What initial information was given to the caregiver at the time of diagnosis?
4. What are the learning activities after diagnosis that a caregiver can identify in his/her caregiving role?
    a. What triggers or causes a learning activity to occur?
    b. What is the process of the learning activity (e.g., steps involved, material and human resources, how and why they were chosen)?
5. What patterns of learning activities evolve among the caregivers sampled?

Limitations of the Study

The following limitations were imposed on the study:

1. Medical records for identification of patients diagnosed with Alzheimer's disease are not public record. Therefore, a random sample of the population was not possible.

2. The study was limited to the extent that subjects were asked to volunteer due to the personal nature of the study.

3. Subjects in the sample were limited to Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, and Washington Counties.

4. The sample was limited to 30 caregivers.

Assumptions Relative to the Study

The following assumption was made relative to the study: The caregiver's statement that the person he or she is caring for was diagnosed by a physician as having Alzheimer's disease is valid.

Definitions of Terms

Alzheimer's Disease

Alzheimer's disease is a specific type of dementia or organic brain disease where brain cells (neurons) of the neocortex die prematurely. The specific cause of this death of brain cells is not yet known, but the brain changes are typical and recognizable by neuropathologists as distinctive and indicative of Alzheimer's disease. The neuronal depopulation of Alzheimer's disease results in progressive memory impairment and intellectual decline. At the present state of knowledge, the decline is irreversible and at this point in medical science untreatable (Middleton, 1984).

Caregiving

Archbold (1981) divides caregiving into care-managing and care-providing. Care managers identify needed services and manage their provision by others. Care providers identify the services needed and then perform them (cited in Gilleard, 1984, p. 84)

Dementia

Dementia is a generic term and not a specific disease. It refers to memory loss and intellectual decline due to the loss of brain cells or brain tissue. It is essentially permanent, irreversible, and it can be caused by a variety of diseases or conditions (Middleton, 1984).

Learning

Brookfield (1984a) noted two features which seem to be central to most definitions of learning: that learning involves change, and that such change is permanent in that it leads to altered behavior. Permanent behavioral change is usually identified in terms of newly developed skills, i.e., in the psychomotor or cognitive areas or a combination of both (p. 11-12). Brookfield (1986) also recognized "learning in which adults come to reflect on their self-images, change their self-concepts, question their previously uncritically internalized norms (behavioral and moral), and reinterpret their current and past behaviors from a new perspective."

Learning Activity

For the purpose of this study, a learning activity refers to the content and process the caregiver identifies and describes as learning in his or her role as caregiver.

Lifelong Learning

Lifelong learning is a process of learning that continues throughout one's lifetime, based on individual needs, circumstances, interests, and learning skills (Heimstra, 1981).

Self-Directed Learning

Knowles (1975) defines self-directed learning as a process in which individuals take the initiative, with or without the help of others, in diagnosing their learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes.

Procedures

A review of the literature was conducted in Sherrod Library and the Department of Learning Resources (Quillen-Dishner College of Medicine at East Tennessee State University. Various computer searches included MEDLINE, AGELINE, and ERIC. Research specific to Alzheimer's disease and caregivers was conducted at the Center on Aging, University of Maryland in College Park, and the American Association of Retired Persons (AARP) in Washington, D.C.

An instrument was not available for use; therefore, a focused interview guide was developed. Five pilot interviews were conducted to pretest the instrument. The non-random sample consisted of 30 caregivers. Participants from eight East Tennessee counties were identified through the first Tennessee Development District Area Agency on Aging Alzheimer's Caregiving Training Program held in the Fall of 1986 and Spring of 1987. Subjects were asked to volunteer.

The major analysis procedure for the study was the constant comparative method, an inductive method that has been used most systematically by Glaser and Strauss (1967). Grounded theory is developed by entering the field work phase without a hypothesis, describing what happens, and formulating explanations as to why it happens on the basis of observation (Bailey, 1978). The grounded theory approach, or constant comparative, method employs systematic coding and analysis. It is necessary to systematically compare similar, and sometimes dissimilar, events or situations.

Organization of the Study

Chapter 1 contains the introduction, statement of the problem, purpose of the study, significance of the study, research questions, limitations to the study, assumption relative to the study, definitions of terms, procedures, and organization of the study.

Chapter 2 includes a review of the literature relevant to the study.

Chapter 3 presents the research methodology and instrumentation.

Chapter 4 contains a presentation, an analysis, and an interpretation of the data.

Chapter 5 includes the summary, findings, conclusions, and recommendations.

CHAPTER 2

A Review of the Literature

Introduction

The number of persons afflicted with Alzheimer's disease is significant. The incidence of the disease is five to seven percent at age 65 and over. Currently, there are 22 million in this age group in the United States, so approximately 1.5 million people have Alzheimer's or another form of dementia (Cohen, 1979). Katzman (1976) suggested that Alzheimer's could rank as the fourth or fifth most common cause of death in the United States. The trend towards an increase of persons in the age 65 and older group in the next few decades will result in an increase in the number of Alzheimer's patients. The incidence of the disease increases with age. By the age of 80 the incidence is 15% to 20% of this elderly population (Mortimer, et al., 1981).

In the State of Tennessee the 1980 Census showed 11.3% of the population was over age 65. The eight upper East Tennessee counties were slightly higher, with 11.97% of the population over age 65. Many elderly persons, two-thirds of whom were women, live alone in rural counties in Tennessee (Postma, Hastings, & Jacobsen, 1984). Applying the 5% figure to the eight counties showed approximately 2,350 persons over 65 as possible Alzheimer's patients.

Patient/Caregiver Environment

Concepts about senile dementia in general have varied and evolved for more than 2,500 years. In 1906 a German physician, Alois Alzheimer, described a 51-year-old patient with a characteristic set of clinical and neuropathological findings. In an autopsy he found senile plaques and another pathological lesion he called neurofibrillary tangles. Subsequently, this presenile dementia was referred to as Alzheimer's disease (Schneck, Reisberg, & Ferris, 1982).

Three major phases of the disease were noted in the literature by Reisberg (1986), Schneck, Reisberg, and Ferris (1982), and others. Strub and Black (1981) provided a more detailed description of four stages. They divided each of the four stages into emotional, social, and cognitive changes.

In the initial stage, the emotional changes are often the first clue. Some of the changes include loss of interest in work and family, increased irritability, increased complaining of minor aches and pains without a physical basis, or the total denial of any problem with health, depression, and anxiety. High activity level, and restlessness and wandering were other changes.

Social changes in the initial stage show an accentuation of previous personality traits. Cognitive changes involve the beginning of memory loss with significant difficulty in forming new memories. Things are misplaced and names are forgotten. General problem-solving ability wanes, mainly with new problems. However, the ability to perform routine well-established skills and strategies remains. Comprehension and expression of complex ideas, thinking in abstract fashion, and making critical judgement are all dulled.

In this stage of memory difficulty the routine neurologic examination remains normal. A diagnosis is dependent on the clinician's ability to carry out a careful mental-stage exam and to recognize early behavioral signs.

The second stage shows an accentuation of the emotional, social, and cognitive changes of the first stage. Language becomes very concrete and tangential. Speech remains fluent at first but contains paraphasias, word-finding pauses, and a surprising lack of substantive words (nouns and action verbs). Many are upset at night and wander about. Restlessness is seen when they pick imaginary bits of lint on their clothes (carphologia) or constantly manipulate objects in their hands. During this stage, the patient often retains sufficient insight into his or her condition to develop secondary anxiety and depression which can make dementia appear to be more severe.

In the third stage patients begin producing unmistakable aphasic speech. Spontaneous speech decreases and there is a tendency to echo what is said to them (echolalia). Comprehension is greatly reduced. There exists an inability to recognize once familiar objects. Patients may sometimes appear to be aware of their loss and at other times totally oblivious to their condition. Primitive or infantile reflexes such as the snort, root, grasp, and palmomental begin to show themselves. Limbs begin to resist passive motion which is a result of a loss of the patient's ability to exhibit his natural reflexes. Lint-picking is more prominent and may include chewing movements. Urinary and fecal incontinence begins. Occasional emotional outbursts coupled with periods of agitation and shouting may occur.

The fourth or final stage shows evidence of involuntary emotional expression, either crying or laughing, aimless wandering, and little meaningful social interaction. Patients are very noncommunicative, uttering only short phrases or undirected babbling. They become peevish if bothered, delusional, and finally completely apathetic and withdrawn. Flexion of the lower extremities causes the body to form the fetal position. Death results from pneumonia, aspiration, or urinary infection.

The individual perceives and reacts to his or her losses long before a diagnosis is made. Recognition of phases or change in the patient can be significant considerations in developing plans and actions to assist the patient and family. Cohen, Kennedy, and Eisdorfer (1984) conceptualized a series of six psychologic reactions or phases in the cognitively impaired individual. The phases were identified from clinical interviews with several hundred persons afflicted with Alzheimer's. The phases are: recognition and concern, denial, anger, guilt and sadness, coping maturation, and separation from self. The authors noted a similarity to the work of Elizabeth Kubler-Ross in that dying was a process involving a series of psychological phases.

Alzheimer's patients are coming to terms with a degenerative disease process and a psychologic as well as physical death. Recognition and concern exist in the pre-diagnosis phase. Symptoms may have already caused family and social disruption through marital conflicts, job changes, automobile accidents, alcohol abuse, depression, and stress. This is the care-seeking phase--something is wrong. After diagnosis comes denial, anger, guilt and sadness, coping, maturation, and separation from self. Not all patients go through all stages, nor in the above order.

Several studies demonstrated that most long-term care of older persons was provided by families and other informal resources (Brody et al., 1978; Brody, 1981; Carrilio & Eisenberg, 1983). The work of Shanas (1979a, 1979b) supported the significant role of the immediate family during the time of an elder's illness.

A poor understanding of the aging process and the impairment of the older person produced guilt, anxiety, and fear on the part of the caregiver. The diagnostic process with a progressive disease can be perplexing and difficult to tolerate. Once the diagnosis was clear, families were often angry with physicians and distrustful of them. Denial of the illness, particularly of the dementia types, often made it difficult for family members to understand or accept physicians' explanations. Character changes such as irritability, lack of initiative, or impulsiveness were difficult symptoms for family members to understand as the disease progresses. Also, the fact that even with the best care patients with Alzheimer's disease will continue to deteriorate was difficult to accept (Barnes et al., 1981).

The stress and emotional consequences of being a caregiver often led to "burnout" or exhaustion on the caregiver's part and early institutionalization of the elder. The institutionalization usually occurred at a point when the needs of the older relative outstrip the resources of his or her exhausted caregivers. It was often accompanied by strong feelings of relief and guilt (Carrilio & Eisenberg, 1983).

Research on caregivers experiencing strain found them describing their role with terms such as helplessness, uncertainty, anxiety, fear, resentment, frustration, guilt, anger, depression, and similar expressions. A number of causes led to serious strain on the caregiver. Having to face the aging and deteriorating loved one produced a deep sense of loss and sadness. Caregivers grieve for the loss of a "dead" elder who was still physically present and requiring care. Wishes and fantasies for the patient's early death were expressed by caregiving spouses (Barnes et al., 1981). These negative feelings were difficult to tolerate, produced guilt, and were hard to discuss openly.

As the patient's disability increased, the caregiver assumed new and often perplexing roles. Role confusion contributed to disruption within the family setting. Tensions increased as the patient begins to feel helpless, resentful, and angry about the provider's attempts to exert control and set limits. Adult children may assume a reverse relationship in becoming a parent-like figure to the elder. This can be intensified if the adult child is confronting his or her own problems of aging. Barnes et al. (1981) noted that some spouses spent so much time looking after the patient that they seemed to identify themselves with that person and often lost sight of their own personal needs and interests. Reifler and Wu (1982) found that families depended too much on logic and reason and expected too much of themselves.

The responsibilities for the care of an aged parent were perceived by many adult children to occur at an inopportune time. Those in need of care were largely 75 and over, and to an even greater extent, 85 and over. Most often their children were in middle and early old age.

Middle-aged women, who compose the great majority of caregivers, have multiple family responsibilities. They have their own spouses, children, and grandchildren. Some may have grown children still at home. For some, the empty nest was being refilled by a frail elder. Also, as Brody (1981) pointed out, an increasing number of women, many middle-aged, were in the work place. These women contributed to the economic lifestyle of the family unit.

Caregivers made many personal sacrifices in giving up time for themselves, socializing with friends, privacy, and vacations. Numerous changes in their daily routine and income increased conflict and tension among family and friends. The emotional strain of feeling alone and not having time for oneself or immediate family was greater than the demands of providing financial support or daily physical care. Adult children no longer received the accustomed support and love from a frail parent. Social isolation grows as opportunities to initiate activities were increasingly curtailed due to the time required in providing care. As the patient's condition worsened, friends often limited their social visits. Caregivers may be too embarrassed or physically unable to take the elder out (Barnes et al., 1981). Both the patient and the primary caregiver suffered from social isolation.

In his work in the field of psychiatry, Dr. Paul Teusink and Susan Mahler (1984), a social worker, identified a normal series of responses on the part of caregivers. They felt that if a caregiver got "stuck" in one of the following stages, he or she could be helped out of that stage and generally continue his or her progress towards acceptance.

Stage I is denial. The caregiver is overlooking the early signs of memory loss and may represent a defense against a variety of psychological issues in the family.

Stage II is over-involvement. The caregiver overcompensates when deterioration becomes apparent and is often unable to ask for assistance or does not know where to get help.

Stage III is anger. The caregiver feels anger at the "abandonment" of the family member with Alzheimer's and also at medical staff for not being able to "cure" the patient. There is a possibility that the family may withdraw the patient from treatment.

Stage IV is guilt. Self-blame is due to the anger directed towards the patient, to the unsolved issues, and for some, the possibility of feeling responsible for the patient's illness.

Stage V is acceptance. At this stage, the caregiver understands the disease and has found sufficient resources within the community to deal with the burden. The caregiver has worked through the anger and guilt and recognized that the loved one is no longer the person he or she once knew.

However difficult the problems may be for caregivers, studies (Breen & Reifler, 1983; Reece, Waltz, & Hageboeck, 1983) have found that most families willingly accept responsibilities for providing care and have a feeling of fulfilling an obligation by caring. To quote a positive statement from a physician concerning one patient with Alzheimer's:

> In day-to-day caretaking, the emphasis is necessarily not on the emptiness of the half-full cup but on its relative fullness. Although Mr. X is different from the person he once was, and to those who knew him in past years, may seem to be "less" of a person, to those to care for him day by day, he is a fullsome [sic] and substantial person, indeed. (Howell, 1984, p. 657)

The majority of the research on caregivers has focused on the impact of caring, the problems, and resulting stress and strain thereof. Although not as extensive an avenue of research as the impact of caregiving, studies related to the management strategies employed by caregivers were found in the literature. Archbold's study (cited in Gilleard, 1984) has analyzed caregiving strategies of women caring for a severely functionally impaired parent. She identified two roles: care-managing and care-providing. The care manager identified the needed services and managed their provisions by others, while the care provider identified the services needed and performed them himself or herself. The characteristics of care managers include a higher socioeconomic background and a social network that included physicians, lawyers, social workers, and nurses. Care providers tended to be poorer, had limited social networks, and if employed, had low-status jobs. These care providers were found to be under greater strain and found considerably less satisfaction in their caregiving roles.

Spouses were less able to be care managers as they often were not in a position to be so. Zarit, Orr, & Zarit (1983) and Gilhooley (cited in Gilleard, 1984) found that husbands were better able to adopt more effective coping strategies than women because they could opt out of, or at least reduce, many of the needed domestic and personal care chores associated with the traditional female oriented models of caring.

Johnson and Catelona (cited in Gilleard, 1984) in their study of adult children of infirmed elderly parents found two opposing styles of adaptation in caregivers. The two styles were referred to as distancing or enmeshing techniques. The distancing technique can take one of three forms. In the first, the caregiver ceases to visit or arranges the transfer of caregiving responsibilities to others, including institutions. The second form of distancing is to establish psychological distance while maintaining physical proximity. A third form of distancing is similar to care-managing where others are involved in the caregiving process.

The other, or enmeshing, style refers to supporting relatives who employ techniques which serve to draw caregiver and dependent into a closer, more interdependent relationship. Two particular enmeshing techniques termed social regression and role entrenchment are evident among spouse caregivers. Social regression refers to increasing isolation. Whether it is self-selected or forced upon the caregiving spouse is difficult to establish. Role entrenchment is defined as a situation in which the caregiver sees his or her exclusive caregiving role to take on the attributes of a new purpose in life.

The term coping or to learn to cope was used frequently throughout the literature related to caregiving of the Alzheimer's patient. An example was the study by Gilhooley (1984), who found a correlation between duration of caregiving and caregiver's morale and mental health. The longer the supporter had been giving care the higher the supporter's morale and the better the mental health. She presents two explanations: (1) the "survival" effect, and (2) "the greater time during which the supporter would have had an opportunity to learn to cope and adjust" (p. 42).

Lazarus and DeLongis (1982) explored the dynamics of stress and coping. They felt that the state of the art in the measurement of stress and coping was still primitive and that personal beliefs, values, and commitments, which develop from a person's unique history, shaped the appraisal of stress and the manner one copes with stress. The authors felt that the significance of any given event was embedded in the individual's personal, lifelong drama and it was important to examine stress and coping longitudinally. Absent in the literature was research on caregivers' reaction to stressful events prior to and after the role as a caregiver of an Alzheimer's patient.

Pearlin and Schooler (1978) defined coping as "behavior that protects people from being psychologically harmed by a problematic social experience" (p. 2). They identified three major types of coping.

The first type was a response that functions more for control of stress itself after it has emerged. This response did not alter the situation generating the stress-provoking strains or create more positive perceptions of the problematic experiences within the situation. Rather, it was a coping mechanism essentially to help people accommodate to existing stress without being overwhelmed by it. Some examples of this were: accept hardship because it is meant to be, try not to worry because time itself solves problems, take the good with the bad, and try to avoid confrontation. The orientation to life-problems included denial, passive acceptance, withdrawal, an element of marginal thinking, a hopefulness for living on blind faith, and belief that the avoidance of worry and tension was the same as problem solving.

A second type of coping was a response that controls the meaning of the strainful experience after it occurs, <u>not</u> before the emergence of stress. Threats were cognitively neutralized. The threat was dependent on how individuals perceptually and cognitively appraised the experience. Examples of this type fell into two areas. Positive comparisons included "count your blessings," or "we're all in the same boat." These comparisons may contain a temporal frame of reference and/or one formed by a significant other. A second area of this type of coping was selective ignoring, which includes identifying some positive attribute of circumstance and ignoring the bad. The gratifying part of the experience is magnified.

A third type of coping was a response that changes the situation out of which stressful experience arise. This was not a common type of coping possibly due to two factors. First, people must recognize the situation as a source of their problem before they can mobilize action towards modifying it. This recognition is not always easy. Second, even when the situation is recognized, people may lack the knowledge or experience necessary to eliminate or modify it.

Golden (cited in Lazarus & DeLongis, 1982) identified three coping styles by subjects who provided care over a period of time to an ill elder. The three styles were confrontation, denial, and avoidance. Of interest was the confrontational style, which involved the investment of a major effort to cope with the expression of anger, guilt, and sadness. These caregivers sought intimate confidants and used strategies that magnified or extended the experience of valued positive emotions. Similar to this style was Pearlin and Schooler's (1978) third type of coping in which people must recognize the situation as a source of their problem before they can mobilize action towards modifying it.

Common to both types of coping was a concept of change. To quote Lazarus and DeLongis (1982), "People are rarely passive in the face of what happens to them; they seek to change things if they can, and when they cannot, they use cognitive modes of coping by which they may change the meaning of the situation" (p. 248). Lazarus and DeLongis divided coping changes into emotion-focused and problem-focused. In emotion-focused coping an individual operated through a variety of cognitive acts, such as attentional avoidance, intellectualized detachment, denial, reinterpretation of the past, humor, magical or wishful thinking, and religious faith. The objective situation remained the same, although a more favorable emotional reaction was created. In problem-focused coping the disturbing person/environment relationship was changed which caused a person to no longer have any reason to be threatened.

Coping is a crucial factor which influences a person's ability to live well and should be recognized in any study dealing with issues of psychological stress. The issue of stress has certainly been identified in the role of caring for an Alzheimer's patient. Of significance to this study was the relationship between the more active type of coping, such as problem-focused coping, and accepted definitions of adult learning. Both recognize the element of change.

Caregivers as Adult Learners

The definition of learning used in this study is "that learning involves change, and that such change is permanent in that it leads to altered behavior" and "permanent behavioral change is usually identified in terms of newly-developed skills" (Brookfield, 1984a, pp. 11-12). Skills may be psychomotor; for example, a caregiver learning to change a dressing on a decubitus ulcer. Skills may be cognitive; for example, further understanding in the possible medical causes of Alzheimer's. Skills may refer to both psychomotor and cognitive; for example; understanding the language dysfunction of Alzheimer's patients allows for more creative approaches for one-to-one communication between caregiver and patient.

Brookfield (1986) also recognized that "personal learning might be defined as that learning in which adults come to reflect on their self-image, change their self-concepts, question their previously uncritically internalized norms (behavioral and moral), and reinterpret their current and past behaviors from a new perspective" (p. 213).

Brookfield suggested that adults cannot help but acquire new skills and knowledge as they proceed through life. For him, "it would be a highly perverse individual who managed to shield himself or herself from all those circumstances and life changes which necessitate the development of new competencies" (p. 1).

Alzheimer's support group activities were the closest to a formal type of learning. The concept received attention in the literature and is advocated by the medical professions. Most support group activity included information presented by professionals, physicians, nurses, social workers, lawyers, and others. In addition, it provided a means for interaction, sharing and support among caregivers. However, Steinberg (1983) noted in her work with groups that participants became intellectually knowledgeable about the many possible behavioral and personality changes that occurred in the Alzheimer's patient, but when these changes actually took place, family members experienced much emotional trauma. She feels it was rare for real acceptance to exist as the caregiver was never emotionally prepared for each new occurrence.

Adult learning in the caregiving environment was highly problem-oriented. Gilleard (1984) identified patterns of evolving problems, adaptations, then further new problems requiring further new adjustments. Problems merged one into the other, and their significance fluctuated according to the situation of the caregiver and the development of the dementia. Sanford (1975) researched the problems caregivers experienced in relation to their tolerance to the identified problems. He did not seek answers on how caregivers solved these problems.

According to Knox (1977) adults have the capacity to learn continually and informally as they adjust to role changes which occur throughout their lifespan. A life crisis was a significant cause and motive for adult learning. While adults have different strategies for coding information, cognitive procedures, mental sets, or learning styles, and learn in different ways, at different times for different purposes, they generally liked their learning activities to be problem centered and meaningful to their life situation.

Knowles (1980) has supported a problem-solving perspective as the most relevant reason for adult learning.

> Adults tend to have a perspective of immediacy of application toward most of their learning largely

> in response to pressures they feel from their current life situation. To adults, education is a process of improving their ability to cope with life problems they face now. (p. 53)

Cross (1981) also concluded that adults have many reasons for learning, the most common of which was application.

The documented isolation of caregivers and the relative lack of formal learning activities should create an environment for caregiver control of the learning process. Penland (1979), in a study of self-initiated learning projects, found that environmental factors such as lack of formal opportunity as a means of learning were often associated with self-initiated learning projects. Using a national sample Penland found that about 80% of the American population 18 years and older perceived themselves to be continuing learners and the percentage of adults involved in self-initiated learning projects was almost as high (76%).

Tough's research (1971, 1982) on adults' learning projects and its many replications were based on the idea that learning was a natural part of adulthood and was carried out primarily in informal and independent ways. Since his original study of 40 Canadian college graduates (1967), almost 50 follow-up studies were recorded as having been conducted based on a modified form of an instrument schedule developed by Tough.

Brookfield (1984b) observed that the research by Tough and others challenged the assumption that "adult learning can only occur in the presence of a fully accredited and certified professional teacher appropriately trained in techniques of instructional design and classroom management," (p. 60). In addition, he asserted that the research has "helped to breakdown the false dichotomy in which institutionally sponsored learning is seen as purposeful and deliberate and learning occurring in non-institutional contexts is held to be serendipitous, ineffective and wholly experimental" (p. 60). The capacity of many adults to conduct learning projects has been supported by research. Caregivers as a special group of adult learners should also show a capacity for self-directed learning.

Tough (1971) identified steps that adults take in many self-planned projects. Other research by Penland (1979) and Hiemstra (1975) has reported or implied the existence of detailed preplanning of self-directed learning by adults. Spear and Mocker (1984) in their research of 78 self-directed learners with less than high school completion found that while their subjects did not do detailed pre-planning, their efforts could not be characterized as random or nonrational. For this population they derived the concept of the "Organizing Circumstance" which stated that "self-directed learners, rather than pre-planning their learning projects, tend to select a course from limited alternatives which occur fortuitously within their environment, and which structures their learning projects" (p. 4). The sample selected for this study should include a variety of educational levels. It is possible that both the detailed preplanning noted by Tough and others and the concept of the organizing circumstance could emerge from the data.

Included in caregivers' environment was their social network. Luikart (1977) researched the relationship between an individual's personal social network and the amount, source, and type of assistance received during self-planned learning. He defined helpers as "the people who the adult learner used in order to gain information and assistance for his learning project" (p. 5). Luikart found that the "variation in the amount, source, and type of help received by self-learners was associated with differences in the size, density, and composition of their personal social networks" (pp. 172-173).

Hooyman (1983), Shanas (1979a & 1979b), Treas (1977), and Wentowski (1981) documented the importance of the informal social support system in maintaining an elder's ability to function within the community. Limited research has been completed on the informal support system of caregivers of Alzheimer's patients.

A related area of research was the role of "lay consultants" as described by Furstenberg (1985) in her study of "Health Practices of Older People." She defined lay consultation as the description of "the way people talk about and look for information from nonprofessionals about health problems they are experiencing" (p. 108). The use of lay consultation carried more weight and was sought actively when people felt ill-informed by their physicians.

Simpson (1980) stated that the two characteristics of adult learning most frequently advanced by theorists were the adult's autonomy of direction in the act of learning and the use of personal experience as a learning resource. Not only do past experiences affect their current learning, but so do the experiences which occur during their current learning. Boyde and Fales (1983) questioned whether a person repeated the same experience several times, becoming highly proficient at one behavior, or learned from experience in such a way that he or she was cognitive or affectively changed. It would appear, due to the number and variety of problems encountered by caregivers, that trial and error learning would occur.

The shift from one conceptual perspective to another (Brookfield, 1986) was similar to Mezirow's (1978) process of "perspective transformation." Mezirow (1981) stated the following:

> The traumatic severity of the disorienting dilemma is clearly a factor in establishing the probability of a transformation. Under pressing external circumstances, such as death of a mate, a divorce or a family breadwinner becoming incapacitated, a perspective transformation is more likely to occur. (p. 7)

For many primary caregivers the caring of an Alzheimer's patient is a "traumatic" and "disorienting dilemma." A changed conceptual perspective is possible as a result of the major life events caregivers must face during this time.

Summary

Two main points have been addressed in this chapter. The first was that caregivers of Alzheimer's patients learn in a distinctive environment. This environment included the phases of the disease the Alzheimer's patient progresses through, the unpredictable nature of the disease, the loss the caregiver experiences, and the stress of the caregiving role.

The second point was that caregivers as adult learners should be capable of conducting their own learning which should be self-directed, problem oriented, and experience based. The stress involved in the caregiver's role could lead to a change from one conceptual perspective to another.

Information as to the way the caregivers' informal support system affects their learning should emerge from the data. Caregivers of Alzheimer's patients have a significant cause and motive for adult learning.

CHAPTER 3

Methods and Procedures

Introduction

The purpose of this study was to identify and describe the individual learning activities of caregivers of people with a diagnosis of Alzheimer's disease, and to develop an accurate and analytical description of the patterns of learning of these adults. Emphasis was placed upon understanding the learning of individuals in a specific environment. The importance of the human perspective and the environment in which learning occurs were significant factors in the choice of research methods.

Five research questions guided the conduct of this study:

1. What is the caregiver's support system (e.g., formal supports used, informal supports of family and friends, support group affiliation)?

2. What specific situation(s) resulted in the caregiver seeking medical help?

3. What initial information was given to the caregiver at the time of diagnosis?

4. What are the learning activities after diagnosis that a caregiver can identify in his/her caregiving role?

a. What triggers or causes a learning activity to occur?

b. What is the process of the learning activity (e.g., steps involved, material and human resources, how and why they were chosen)?

5. What patterns of learning activities evolve among the caregivers sampled?

A variety of methods have been used in research related to the caregiving of elders. Horowitz and Shindelman (1983) studied 203 primary caregivers in order to determine the variation in caregiving commitment. They used an in-depth, structured interview containing open-ended, fixed-choice, and scale items. Sanford (1975) in his research of problems confronting supporters, or caregivers, interviewed 50 individuals using a standard form. He recognized that his use of a standard form might have limited the amount of information obtained. Wentowski (1981) conducted a two-year anthropological study of the cultural rules that underlie the helping that takes place in the support networks of some older people living in a community setting. Structured interviews and participant observation were used by Wentowski to obtain an insider's perspective. Hirschfeld (1983) in her study to explore the factors influencing a caregiver to continue caring for an old person with irreversible senile brain disease used qualitative analysis of interviews and participant observations. Field methodology and grounded theory (Glaser, 1978; Glaser & Strauss, 1967; Schatzman & Strauss, 1973) guided Hirschfeld in the development and analysis of the in-depth interviews and observations of a nonrandom sample of 30 demented elderly and their 30 family caregivers.

Brookfield (1984b) noted that the research into the activities of self-directed learners, in terms of methods of research, has been extreme in its commitment to measurement scales, structured interview schedules, questionnaires, and prompt sheets. He felt that one consequence was that quasi-quantitative instruments become self-defining regarding the learning activities they uncover. Quoting Brookfield, "If unequivocal quantitative measures of learning are sought by the researcher, it is likely that subjects will (perhaps unwillingly) concentrate on recalling learning projects which seem to meet the interviewer's expectations as enshrined in their methodology" (pp. 63-64).

Rockhill (1982), in supporting a qualitative approach to the study of adult participation, questioned whether the human perspective could easily get lost in the seeking of scientific precision: "With the ascendance of quantitative measures in defining 'acceptable' social science research, the understanding of reality as experienced in the lives of people has been sacrificed to methodological rigor" (p. 5).

According to Rockhill, when research is begun with "predetermined theories to be tested, other aspects that may be even more important are typically not noted because they are not looked for" (p. 6). She questioned "a research approach which seeks to interpret human behavior using constructs which are derived from the perspective of the research literature rather than from the perspective of the people being studied" (p. 8).

Grounded Theory

Consistent with the purpose and significance of this research, it was guided by an inductive approach based upon the principles of grounded theory as elaborated by Glaser and Strauss (1967) and Glaser (1978). The researcher enters the field without a hypothesis, describes what happens, and formulates explanations as to why it happens on the basis of observations. This approach begins at the empirical level and ends at the conceptual level. The only concepts used in the development of grounded theory are those that are generated through analysis of empirical data.

Grounded theory is rooted in data and not in an existing body of theory. In the deductive approach, Glaser (1978) argues, "Commitment to pre-conceived hypotheses may limit the kinds of observations, information and insights that the researcher makes and actually may have access to" (p. 38).

In the discovery approach, theory is gradually built up inductively from the progressive stages of analysis of the data. Glaser and Strauss note that "at the beginning, there is more collection than coding and analysis; the balance then gradually changes until near the end when the research involves mostly analysis, with brief collection and coding for picking up the loose ends" (1967, p. 72-73).

To discover the basic conceptual elements, the constant comparative method is used. Similar, and sometimes dissimilar, events or situations are identified by systematically analyzing data sentence by sentence. Glaser and Strauss (1967) described four stages in the constant comparative method: (a) comparing incidents applicable to each category; (b) integrating categories and their properties; (c) delimiting the theory; and (d) writing the theory.

In the first stage, comparing incidents applicable to each category, each incident in the data is coded into as many categories of analysis as possible. Incidents are significant pieces of data which are first compared to each other to identify commonalities and differences. As additional incidents are noted, they are then compared to the group of incidents in an emerging category.

The second stage is integrating categories and their properties. As coding continues, the constant comparative units change from comparison of incident with incident to comparison of incident with properties of the category that resulted from initial comparisons of incidents. Memo writing is the recording of theoretical ideas as the coding process continues. Memos, while based on description, are aimed at raising that description to a theoretical level. According to Glaser (1978), five important aspects of generating theory are accomplished in the use of memos.

(1) It raises the data to a conceptualization level;

(2) It develops the properties of each category which begins to define it operationally;

(3) It presents hypotheses about connections between categories and/or their properties;

(4) It begins to integrate these connections with clusters of other categories to generate the theory;

(5) Lastly, it begins to locate the emerging theory with other theories with potentially more or less relevance.

The third stage in the constant comparative method is delimiting the theory. Reduction occurs in the original list of categories as the researcher becomes more selective and focused on incidents applicable to a smaller set of categories. The terminology and text of the emerging theory are further delimited with a smaller set of higher level concepts. Theoretical saturation has been achieved when continued data collection gives no new information on the properties of the category.

The fourth stage is writing theory. At the completion of field work, the researcher should have a set of memos that together develop the core of the emerging theory. The writing of the report relies on the memos which contain the content of the categories and their properties and a description of their interrelationships. Coded data from the field reports and quotations from the actual incidents are used to illustrate categories and their properties.

Selection of the Sample

Participants were selected from the eight upper East Tennessee counties that are part of the First Tennessee Development District. Subjects were identified through programs sponsored by the First Tennessee Development District Area Agency on Aging to provide information and support to caregivers of Alzheimer's patients. In addition, senior center staff from the eight counties in Northeast Tennessee provided names of caregivers within their county. The benefit of using the resources provided by the Area Agency on Aging for selection of caregivers was the geographic diversity between rural and urban areas.

Due to the exploratory nature of the study, the in-depth nature of the interview, and the one to two hours involved in the interview, the sample was limited to 30 interviews. All interviews were on a voluntary basis and respondents signed an informed consent.

Data Collection

According to Glaser (1978) the initial decisions in data collection are based only on a general sociological perspective about a substantive area within a population prior to field research. While the grounded theory researcher avoids approaching a study with a predetermined hypothesis, he or she commonly has a flexible orienting framework or organizing concept to begin the study. Schatzman and Strauss (cited in Glaser, 1978) acknowledged selective sampling, which "refers to the calculated decision to sample a specific locale according to a preconceived but 'reasonable' initial set of dimensions which are worked out in advance for a study" (p. 37).

The initial set of dimensions for this study were based on the patient/caregiver environment and adult learning as reviewed in the literature. Consistent with the grounded theory methodology, the collection of data for this research was accomplished by the use of an interview guide.

Development of the Interview Guide

The development of an interview guide according to Merton, Fiske, and Kendall (1956) takes advantage of the subjective experiences of persons exposed to the preanalyzed situation in an effort to discover their definitions of the situation. Therefore, what began as a series of open-ended questions evolved into an in-depth structured interview guide. The initial interview guide was developed through a review of the literature, consultation with several spouses or adult children caring for an Alzheimer's patient, and professionals in the health care field. The inclusion of the caregiver's own summary of what a most recent day was like provided descriptive material on the current status of the patient.

The Interviewer

The researcher of this study was the interviewer. Significant works on interviewing techniques (Bailey, 1978; Merton et al., 1956) were read in order to understand the process of becoming a competent interviewer. Techniques such as probing, not altering the question to destroy comparability, exclusion of biased probing or wording, and accurate note-taking skills were practiced in the pilot interviews.

Conduct of the Interview

The interviews took approximately one to two hours. The respondent was informed of the nature of the study. A signed informed consent consistent with protection of human subjects was completed by each respondent.

The first part of the interview involved the completion of demographic information. The body of the interview solicited information about one or more learning activities and the process involved. The last part included the open-ended component of the daily activities. Collection of the data was on the interview guide.

Analysis of the Data

The process used for analysis was consistent with the constant comparative method. Significant pieces of data, incidents, were identified and written on notecards. These incidents were compared to each other to identify commonalities and differences. As categories emerged, incidents were compared with the properties of the categories through the use of preliminary charts and tables. Selected incidents and categories were looked at more closely in order to identify higher level concepts. Continuous memo writing provided ideas about connections between categories. Each research question was treated as an independent unit at the beginning. As the analysis continued, concepts from the individual research questions were integrated to generate one or more patterns of learning.

Within a day of each interview, the information gathered was transcribed from the interview guide to five by seven inch index cards. The use of a card system allowed for expansion of notes taken at the time of the interview. The cards also provided a means to manipulate the data in order to begin the coding process.

The cards were filed under the major heading of Demographic Data, Caregiver Support System, Reasons for Seeking Medical Help, Learning at the Time of Diagnosis, Learning Activities, and Learning Patterns. Each card was coded with a number designating an individual caregiver.

The Demographic Data consisted of information on the Alzheimer's patient and the caregiver. The statistical information was organized by using a table format on the index cards.

The Caregiver Support System consisted of the formal supports, including support group activity, and the informal supports. Information on formal supports was organized into a table format. As the cards relating to the informal supports were being sorted and organized, it became apparent that a variety of people were providing each caregiver with different types of support. Four helping or support functions emerged from the data: (a) sharing information about the disease; (b) providing emotional support; (c) helping to make decisions; and (d) giving day-to-day practical help. In order to arrange this data with the 122 persons identified by the 30 caregivers as providing informal support, a chart was created (see Appendix B).

This chart organized the type of support and the people providing the support for each caregiver. Use of the chart allowed for an observation of each caregiver's informal support system. It also provided a means to compile the total number and identities of those giving support and the type of supports provided by these people.

Additional index cards were used to record data obtained under the heading of "Reasons for Seeking Medical Help and Learning at the Time of Diagnosis." Similar pieces of data were written on individual cards. These cards were used later to create preliminary tables or charts which allowed for a comprehensive look at the caregivers as a group.

Learning Activities consisted of content areas and the learning process. To determine the content areas, the cards reflecting a common theme were placed inside separate, large, brown envelopes. The envelopes provided space on which notes and memos were written. The 185 learning activities were divided into five major content areas.

To determine the learning process, a chart format was developed. The headings included the trigger event, learning outcomes if identified, process or steps taken, and the resources selected by caregivers. The resources were divided into material and human. Space for why and how chosen and how used was included for each resource. This same chart was completed for each of the five content areas identified. The chart, provided a means to compare common themes in the process chosen by caregivers to learn. A separate note card containing the process and resources was completed for the six identified themes. These common themes were compared to the possible types of learning identified in the literature review. Labels were given to the six themes or processes of learning based on caregivers' descriptions and choice of words, and the review of the literature.

Writing memos and creating preliminary charts and tables were significant aspects in determining the pattern or patterns of learning. Thoughts and ideas were written on note cards or scraps of paper and filed for future reference. Charts and tables allowed for testing of ideas, comparison of data, and in developing higher level concepts. The patterns of learning were based on these concepts.

Procedures

The following procedures were followed in conducting the study:

1. A review of the literature was conducted in Sherrod Library and the Department of Learning Resources (James H. Quillen College of Medicine) at East Tennessee State University.

2. Various computer searches were carried out including MEDLINE, ERIC, and AGELINE.

3. Specific research related to Alzheimer's disease and caregiving was conducted at the University of Maryland, Center on Aging in College Park, and the American Association of Retired Persons (AARP) in Washington DC.

4. An instrument was not available for use; therefore, an instrument, a focused interview guide, was developed.

5. Five pilot interviews were conducted to pretest the instruments.

6. A nonrandom sample of 30 caregivers was interviewed. Participants from eight Northeast Tennessee Counties were identified through the programs of the First Tennessee Development District Area Agency on Aging and with the help of senior center staff. Subjects were asked to volunteer.

7. The major analysis procedure for the study was the grounded theory approach as described by Glaser and Strauss (1967). The constant comparative method is an inductive method which employs systematic coding and analysis to generate a theory which is integrated, consistent, close to the data, and in form clear enough to be operationalized for testing, using other methods.

8. A summary of findings and analyses was prepared.

9. Conclusions and recommendations were formulated.

CHAPTER 4

Presentation and Analysis of the Data

Introduction

The results and findings obtained from the data gathered in this study are presented in this chapter. The analysis of the data begins with a presentation of the demographic data for the 30 respondents. Following the demographic data, the five research questions presented in Chapter 1 are analyzed under the headings of caregiver support system, reasons for seeking medical help, learning at the time of diagnosis, learning activities, and learning patterns.

Demographic Data

The sample consisted of 26 female caregivers (86.6%) and four male caregivers (13.4%). Four male caregivers declined to be interviewed. All female caregivers who were asked agreed to be interviewed.

The age distribution of the 30 patients diagnosed with Alzheimer's was analyzed (see Table 1). The range of ages was from 63 years to 86 years. For female patients, the mean was 77.1 years. For male patients, the mean was 76.3 years.

The patients were cared for by daughters, wives, daughter-in laws, sisters, husbands, and sons (see Table 2).

Table 1

Age Distribution of Patients Diagnosed with Alzheimer's

	Female		Male		Total	
Age	N	%	N	%	N	%
60-69	4	21.1	1	9.1	5	16.7
70-79	11	57.9	8	72.7	19	63.3
80-89	4	21.1	2	18.2	6	20.0
Total	19	100.1	11	100.0	30	100.0

Note. Not equal to 100% due to rounding.

Table 2

Relationship of Caregiver to Patient

Relationship	N	%
Daughter	14	46.7
Wife	8	26.7
Daughter-in-law[a]	2	6.7
Sister[b]	2	6.7
Husband	2	6.7
Son	2	6.7
Total	30	100.2

Note. Not equal to 100% due to rounding.

[a] Wives assuming caregiving responsibilities for their spouses.

[b] A sister caring for another sister.

Ten spouses were caregivers. The years of marriage ranged from 47 to 55 years with a mean of 50.9 years.

The living arrangements for the 30 Alzheimer's patients were analyzed (see Table 3). The living arrangements for the 19 female patients showed more variation. The percentage for female patients in a long-term care setting (42.1%) was significantly lower than for males (63.6%).

The educational level of caregivers ranged from less than an eighth grade education to the doctorate level (see Table 4). A comparison with the _1980 Census of Population in Tennessee_ for years of school completed in the counties of the study area showed the sample to have a significantly higher number of people completing four or more years of college. Fourteen caregivers (46.6%) reported obtaining a college degree or more. In the more urban counties of Washington and Sullivan, 9.7% of the population completed four or more years. In the other more rural counties, 5.6% of the population completed four or more years. The majority of the sample population was selected through the Caregiver Training Program presented by the Area Agency on Aging in the eight northeast Tennessee counties. People with a higher level of formal education might have attended this type of program.

The age distribution of the caregivers was analyzed (see Table 5). The ages ranged from 28 to 79 years. The

Table 3

Living Arrangements of Alzheimer's Patients

	Female		Male		Total	
Living arrangements	N	%	N	%	N	%
Alone	2	10.5	-	-	2	6.7
With spouse	2	10.5	4	36.4	6	20.0
With daughter	5	26.4	-	-	5	16.7
With sister	2	10.5	-	-	2	6.7
Long-term care	8	42.1	7	63.6	15	50.0
Total	19	100.0	11	100.0	30	100.1

Note. Not equal to 100% due to rounding.

Table 4

Educational Level of Caregivers

Educational Level	N	%
8th grade or less	3	10.0
9-11th grade	2	6.7
High school diploma	7	23.3
1-3 years college	4	13.3
B.A./B.S.	10	33.3
Master's	2	6.7
Master's plus hours	1	3.3
Doctorate	1	3.3
Total	30	99.9

Note. Not equal to 100% due to rounding.

Table 5

Age Distribution of Caregivers

	Female		Male		Total	
Age	N	%	N	%	N	%
20-29	1	3.9	-	-	1	3.3
30-39	1	3.9	-	-	1	3.3
40-49	9	34.6	1	25.0	10	33.3
50-59	5	19.2	1	25.0	6	20.0
60-69	3	11.5	1	25.0	4	13.3
70-79	7	26.9	1	25.0	8	26.7
Total	26	100.0	4	100.0	30	99.9

Note. Not equal to 100% due to rounding.

mean age for female caregivers was 56.4 years and 59.8 years for males.

All 30 caregivers had other roles and responsibilities in addition to being a caregiver. The identified roles and responsibilities included maintaining a home, being a spouse, being a parent with children at home, and providing all or part of the income for their families (see Table 6). Half of the 30 caregivers interviewed were working outside the home. The average age for the 15 caregivers was 46.2 years (see Table 7). Major financial demands expressed by this group were mortgages, children's education, and saving for their own future. These caregivers said that it was necessary to work in order to provide for themselves and their families.

Caregiver Support System

Both formal and informal supports were used by caregivers. Formal supports included organized programs usually sanctioned by an institution with paid personnel. An informal social support system originated out of the social environment of the individual caregiver. It consisted of family, friends, and others who provided a variety of services to the caregiver without payment.

The four types of formal supports caregivers identified were (a) ACCESS, (b) in-home care, (c) day care, and (d) support group activity. ACCESS is a program through the

Table 6

<u>Other Roles and Responsibilities of Caregivers</u>

	Female		Male		Total	
Other roles	N	%	N	%	N	%
Homemaker	11	42.3	-	-	11	36.7
Retired	-	-	2	50.0	2	6.7
Spouse/parent[a]	2	7.7	-	-	2	6.7
Provider/parent/ spouse[b]	3	11.5	2	50.0	5	16.7
Provider/parent[c]	3	11.5	-	-	3	10.0
Provider/spouse[d]	2	7.7	-	-	2	6.7
Provider[e]	5	19.2	-	-	5	16.7
Total	26	99.9	4	100.0	30	100.2

Note. Not equal to 100% due to rounding.

[a] Parent with children at home. [b] Two males and two females are employed full-time and one female is employed part-time. [c] Two females are employed full-time and one female is employed part-time. [d] One female is employed full-time and one female is employed part-time. [e] All five females are employed full-time.

Table 7

Relationship Between Roles and Age

Roles	Number	Average Age
Homemaker	11	70.2
Retired	2	74.0
Spouse/parent[a]	2	42.5
Provider/parent/spouse[b]	5	44.9
Provider/parent[c]	3	48.3
Provider/spouse[d]	2	42.5
Provider[e]	5	49.2

[a] Parent with children at home. [b] Two males and two females are employed full-time and one female is employed part-time. [c] Two females are employed full-time and one female is employed part-time. [d] One female is employed full-time and one female is employed part-time. [e] All five females are employed full-time.

First Tennessee Development District Area Agency on Aging. The program identifies frail elderly individuals and provides support by referring them to available resources. Five caregivers and their Alzheimer's patients were involved in the program.

In-home care refers to someone coming into the patient's or caregiver's home to provide assistance. Fifteen caregivers used license practical nurses or nurse's aides to help with health needs. Most caregivers sought medical help through a recognized home health care agency. Paid sitters were used by seven caregivers to help prepare food and to provide companionship while the caregiver was away. One caregiver had a physical therapist twice a week for two months to maintain her mother's mobility after a fall.

Three caregivers took their patients to a day care setting. Day care through a hospital or nursing home was used to help with bathing, shaving, and other related activities. It was also used to provide respite for the caregivers.

Twelve caregivers participated in support group activities. Five were very active and attend all meetings if possible. They found the group helpful, shared in the planning of meetings, and reached out to new members. One caregiver mentioned that she was "one of a solid core" within one group. Four caregivers considered their involvement to be moderate. They attended special programs and tried to attend many of the group meetings. Three caregivers felt they were inactive. While they remained on the mailing list, they were very selective in attending meetings. One caregiver only attended "educational meetings with guest speakers." Two mentioned that "little new information was presented" or that "information was repeated."

Eighteen caregivers said they were aware of local support group activities but were not members. Twelve chose not to join a group. The six remaining caregivers gave a specific reason for not joining: two worked full-time; two attended one meeting and felt too uncomfortable to return; one did not drive; and one felt she had enough support.

The informal support system of the caregivers consisted of family, friends, and others who provided a variety of services to the caregiver without payment. To obtain data concerning the informal support system, caregivers were asked to describe the type of support provided and the relationship of the person providing the support. The level of support provided was identified by the amount of time spent by each person giving support in the period of one week. There were four types of categories of support activities identified by the 30 caregivers. The four categories were (a) information sharing, (b) emotional support, (c) decision making support, and (d) practical support.

People involved in information sharing provided reading material and usually discussed this material with caregivers. Other resources provided included information about television programs, workshops, and conferences. Many of these people attended these activities with the caregiver.

In providing emotional support people listened to the caregiver and tried to understand. Empathy and love were shown to both the caregiver and patient. Many patients and caregivers were remembered in prayers. Some caregivers mentioned hugs as a helpful support.

Decision-making support involved obtaining materials and resources related to a potential decision a caregiver needed to make, for example, placement in a long term care setting. Suggestions and advice were given to the caregiver, usually at their request. Caregivers could present their options and have others respond to them. A variety of options were shared and discussed.

Activities included in practical support were doing chores around the house for caregiver and patient, feeding the patient if necessary, helping to lift or bathe the patient, and driving the caregiver to a long term care setting. Visiting the caregiver and taking the caregiver out were other ways of providing practical support.

A total of 120 people provided one or more of the four types of informal support to caregivers (see Table 8). With 30 caregivers, this averaged to four people giving support to each caregiver. The 120 people were engaged in 303 informal support activities. Of the 303, 105 (34.7%) were emotional support, 77 (22.4%) were practical support, 65 (21.5%) were sharing information, and 56 (18.5%) were decision-making support.

The people who provided the informal supports included the immediate family, extended family, and friends. The 65 (54.2%) immediate family members consisted of parents, spouses, siblings, and adult children of the caregivers. The extended family included 15 (12.5%) aunts, uncles, nieces, cousins, and in-laws. Of the 40 friends providing support, 22 were accessible within the caregiver's environment. These people included neighbors, and friends made through a church, a work setting, and senior centers. The remaining 18 people providing support had medical expertise or experience as a caregiver. All 40 people were known by the caregivers prior to their involvement in caring for an Alzheimer's patient and were physically accessible within the caregiver's environment.

Table 8

Informal Social Support Networks of Caregivers

		Type of Support			
Relation to Caregiver	N	Information[a]	Emotional[b]	Decision[c]	Practical[d]
Immediate family					
Wife	2	1	2	1	2
Husband	9	4	9	6	9
Mother	2	2	2	2	2
Father	1	-	1	1	1
Daughter	10	6	9	6	7
Son	11	7	11	6	8
Brother	10	3	3	7	3
Sister	20	13	20	16	16
Extended family					
Aunt	2	1	1	1	2
Uncle	1	-	1	1	1

Table 8 (continued)

Informal Social Support Networks of Caregivers

		Type of Support			
Relation to Caregiver	N	Information[a]	Emotional[b]	Decision[c]	Practical[d]
Niece	3	1	2	1	3
Mother-in-law	1	1	1	1	1
Father-in-law	1	1	1	1	1
Brother-in-law	3	-	3	1	3
Sister-in-law	2	1	2	-	2
Cousin	2	-	1	-	2
Friends					
Neighbors	8	-	8	-	7
Through church	9	4	9	1	4
From work setting	2	1	2	-	-
Senior center	3	1	2	-	2

Table 8 (continued)

Informal Social Support Networks of Caregivers

		Type of Support			
Relation to Caregiver	N	Information[a]	Emotional[b]	Decision[c]	Practical[d]
With professional expertise	4	4	1	2	-
Alzheimer's caregiver	13	13	13	2	1
Experienced loss of a parent	1	1	1	-	-
Total	120	65	105	56	77

[a] Sharing information by providing resources and discussion. [b] Providing emotional support by giving love, showing empathy, and listening. [c] Decision-making support includes providing resources and suggestions. [d] Practical support involves day-to-day help with feeding, doing chores, bathing and so forth.

Immediate family, extended family, and friends provided support to caregivers (see Table 9). In comparing the percentage of the types of support given by each group, friends showed a higher involvement in sharing information (30.4%) and giving emotional support (45.6%). These friends were accessible to caregivers. For some of the caregivers, immediate family members did not live in the area. Contact was by phone or for short visits. In decision-making support, the immediate family showed a higher percentage of involvement. Only 6.5% of the friends and 15.8% of the extended family helped with making decisions. The extended family showed a higher percentage (39.5%) in providing practical support. They provided practical help to both the caregiver and the Alzheimer's patient. Many in this group were older and had available time to help.

The immediate family provided 186 (61.4%) of the 303 informal support activities to the 30 caregivers. Twenty-three caregivers chose a close family member as the person who was most significant to them in their role as a caregiver. The remaining seven caregivers felt that a friend or neighbor was most significant.

The amount of time caregivers received and the number of people involved in their informal support system differed for the 30 caregivers. Sixteen caregivers had an extensive system of four or more people involved and daily contact

Table 9

Informal Supports of Immediate Family, Extended Family and Friends

	Immediate[a]		Extended[b]		Friends[c]	
Type of Support	N	%	N	%	N	%
Information[d]	36	19.4	5	13.2	24	30.4
Emotional[e]	57	30.6	12	31.6	36	45.6
Decision-making[f]	45	24.2	6	15.8	5	6.3
Practical[g]	48	25.8	15	39.5	14	17.7
Total	186	100.0	38	100.1	79	100.0

Note. Not equal to 100% due to rounding. [a] Immediate family included parents, spouses, siblings, and adult children. [b] Extended family included aunts, uncles nieces, cousins, and in-laws. [c] Friends included neighbors, people through church, work or senior center, and people with medical expertise or similar experience. [d] Sharing information by providing resources and discussion. [e] Providing emotional support by giving love, showing empathy, and listening. [f] Decision-making support includes providing resources and suggestions. [g] Practical support involves day-to-day help with feeding, doing chores, bathing, and so forth.

with one or more of these people. Fourteen caregivers had a limited system with less than four people involved and less than daily contact. A comparison of the amount of informal support with caregiver support group activity showed that of the 16 people with an extensive informal support system, 11 (68.8%) were not members of a support group (see Table 10). Caregivers with an extensive informal support system might have less need of an organized or formal system of support. In contrast, five of the seven most active support group members had limited informal social support systems. All caregivers had knowledge of local support group activity. Seven (50.0%) caregivers with a limited informal support chose not to become support group members.

Reasons for Seeking Medical Help

The specific reasons for seeking medical help were preceded by noticeable changes in the patient. All 30 caregivers were aware of behavior changes in the patient prior to a diagnosis of Alzheimer's disease. The behavior changes were ongoing and caused significant concern for caregivers. Four different behavior changes were identified by caregivers. The four were (a) difficulty with day-to-day, (b) forgetfulness and repeating, (c) disorientation, hallucinations, and unfounded jealousy, and (d) wandering or becoming lost.

Table 10

Support Group Activity and Amount of Informal Support

	Amount of informal support					
	Extensive[a]		Limited[b]		Combined	
Support Group Activity	N	%	N	%	N	%
Active[c]	2	12.5	5	35.8	7	23.3
Moderate[d]	2	12.5	2	14.3	4	13.3
Inactive[e]	1	6.3	-	-	1	3.3
Not a member	11	68.8	7	50.0	18	60.0
Total	16	100.1	14	100.1	30	99.9

Note. Not equal to 100% due to rounding. [a]Four or more people involved and daily contact. [b]Less than four people involved and not always daily contact. [c]Attend all meetings and share in planning of activities. [d]Attend special meetings thought to be helpful. [e]Remained on mailing list and attended few meetings.

Difficulty with day to day chores was the one behavior change which all caregivers mentioned. The most frequent example for male patients was the inability to handle finances. "My husband couldn't keep a checkbook and couldn't add, subtract, or write." Not being able to cook was the example used for female patients. "My mother was not able to fix her own meals. Once we found pickles in the coffee pot."

Forgetfulness and repeating was the second most noted behavior change. "Mother was always hunting for something she put up and couldn't find it." Other caregiving children noted that "Mother would buy the same grocery items over and over," "my mother would hide money, forget where she put it, and accuse others of stealing it," and "he (father-in-law) had trouble with names for common objects." One husband mentioned that his wife "constantly wrote notes to remind herself of things to do."

Half of the caregivers noted disorientation, hallucinations, or unfounded jealousy as changes. "My husband was seeing other people in the house, or that men were breaking in and had guns." A daughter noted that her father's "stories seemed plausible unless you knew the characters." Although it was many years after her father had died, one caregiver's mother "kept seeing Daddy and wanted to cover him because he was so cold." Another daughter described her father's "night terror." "My father would fall out of bed. This continued for two to three years. We had large sponge rubber around the bed to protect him." Unfounded jealousy was mentioned by male and female caregiving spouses. "My husband was convinced that I had a boyfriend." Another wife mentioned that her husband would often see "a young boyfriend" standing beside her. A caregiving son remembered his mother being unusually jealous of his father's friends.

Becoming lost while driving or wandering out of the house was noted by twelve caregivers. One wife said she had to constantly give her husband directions while driving with him in the car. The most common example was having neighbors or friends call to alert the family of a wandering person.

As changes in behavior continued, the patient became more dependent on the caregiver. Specific events caused caregivers to seek medical help. The reasons for seeking medical help fell into three separate categories. They were (a) a crisis type situation, (b) another medical concern requiring a physician's care, and (c) recognition of symptoms of Alzheimer's by the caregiver or patient.

The first category included nineteen caregivers who sought medical help due to a crisis type of situation. For spouses who are caregivers, the crisis was an incident which built upon many smaller incidents. One wife said that her husband "ran a red light and had his driver's license removed." Another wife watched as her husband drove the car "through the garage door." For those two caregivers and others, the situation could not be ignored or overlooked any longer.

In general, the adult children were not as aware of minor incidents as were the spouses until the time of the first parent's death. One daughter remarked that she was able to "brush the little things aside" until her father died and her mother could not live alone. Another caregiving son mentioned that his mother could not do any housekeeping chores after the death of his father. He felt that his father might have compensated for his mother's inability and kept it from the children. One additional example was that of a caregiver's stepfather who said, "Something is wrong with your mother, she can't take care of herself." He was dying of cancer and could no longer care for his wife.

One reason for adult children not being aware of minor incidents was that they lived in different area. A daughter became concerned when her mother's car caught on fire and was totally destroyed. The mother had let the insurance lapse. Another daughter explained her situation. "She (mother) slipped and fell on a Friday and was not found until Tuesday. She had broken her hip and was very disoriented." The daughter waited for her mother's "reasoning to come back" but it did not. While caring for her mother in a nursing home, the caregiver sought information about her mother's condition from staff members and located reading materials. She became aware that Alzheimer's disease might be a possibility. The mother was diagnosed with Alzheimer's disease after her daughter moved her to Tennessee to care for her.

In the following two cases the adult children became caregivers because the spouses would not accept the role. "She (father-in-law's second wife) told me one Sunday while doing dishes that 'you're going to have to help your Daddy.' She had already divorced him and was gone the next day." In another situation an adult daughter accepted the care for a father who had little to do with her own upbringing. "My father's fourth wife brought him to Tennessee and left him with me. She had divorced him and took much of his money."

The second category of the reasons for caregivers to seek medical help included six patients who had another medical concern which required a physician's care or hospitalization. Three of the Alzheimer's patients had fallen and broken a hip. Following the surgery was a period of disorientation which resulted in further testing. Two caregivers mentioned Parkinson's type symptoms as the reason for seeking help. One man was hospitalized for an infection.

In the third category the patient, the caregiver, or the patient and caregiver together came to recognize the symptoms of Alzheimer's and were able to relate them to their own experience. One of five caregivers in this category went with a friend to an Alzheimer's support group meeting and realized that her sister's behavior was similar to that described by a husband whose wife had Alzheimer's. Another caregiving son said his mother called to tell him she could "no longer handle her own affairs" and needed his help. A daughter said her mother had identified her own memory loss and read as much as she could find on the subject in local libraries. She sought medical help on her own with the support of her family. A fourth caregiver said that his wife was able to hide some of her memory loss, and that he was not willing to acknowledge any change in her behavior. It was their son who came home for visits, became aware of the changes, and gently forced his father to seek medical help for his mother. A fifth man, after seeing the television program starring Joanne Woodward, Do You Remember Love?, turned to his wife and said, "That's what I have." He was diagnosed with Alzheimer's shortly after.

Learning at Time of Diagnosis

Caregivers received verbal information and material resources at the time of diagnosis. All 30 caregivers were given verbal information. Three categories of information were remembered by caregivers as being provided to them by physicians, and in one case, a hospital social worker. The categories were (a) key phrases, (b) cause and stages of disease, and (c) cause, stages, and tests used to diagnose the disease. Six of the caregivers were also provided with material resources (see Table 11).

Verbal information given by physicians to caregivers at the time of the diagnosis of Alzheimer's disease varied from physician to physician. The diagnosis can be emotional for many caregivers. One caregiver felt that "whatever information was given at that time did not sink in." Sixteen of the caregivers identified key phrases which they remembered from the time when their family member was diagnosed. Statements regarding the cause of the disease included: "not know the cause;" "brain deteriorating;" and "something in the brain." Statements related to the progression of the disease included: "get not to remember;" "gradually loose all faculties;" "never get better;" "going to get worse each day;" "not know how long it will take;" and "let's hope it slows down." Phrases describing what can be done include: "protect her;" "keep her stimulated;" "handle problems as they come up;" and "nothing science can do."

Table 11

Learning at Time of Diagnosis

	Material resources			
Human resources[a]	36-hour[b]	Other[c]	None[d]	Total
Key phrases[e]	1	-	15	16
Cause and stages of disease[f]	2	-	9	11
Cause, stages, and tests used[g]	2	1	-	3
Total	5	1	24	30

[a] All human resources were physicians except for one hospital social worker. [b] The 36-Hour Day by Nancy L. Mace and Peter V. Rabins (1981) is a guide for families caring for an Alzheimer's patient. [c] References to books, journal articles, and the Alzheimer's Disease and related disorders Association, Inc. [d] No material resources given. [e] Caregivers only remembered short phrases from their physicians' description of the disease. One caregiver received information about support groups. [f] Six caregivers received information about support groups. [g] All three received information about support group.

The material resource received by this group was The 36-Hour Day (Rabins & Mace, 1981), a guide for families caring for an Alzheimer's patient. Only one person received the reference for this book. Local support-group activity information was given to one person. Of the total sample, 53.3% of the caregivers interviewed received limited information at the time of diagnosis.

In the second category, caregivers stated that their physicians described the disease and the stages involved as the disease progressed. Only one caregiver in this group had no memory of a physician at the time of diagnosis. Rather, this caregiver was spoken to by a social worker connected with the hospital where her husband was a patient. The social worker described the disease and handled all the financial arrangements in placing the woman's spouse in a long-term care setting.

Of the 11 caregivers in this category, nine (81.8%) received no written resources while two (18.2%) were given the reference to The 36-Hour Day. Overall, this group was provided with an understanding of the disease and six of the caregivers received information about local support group activity.

In the third category, three physicians provided additional information as to the disease description and progression. They included an explanation of the tests involved in a diagnosis of Alzheimer's, acknowledged caregiver stress, and offered their help to patient and family. One caregiver felt that her physician treated her as "having some comprehension to understand" and told her that he couldn't "do anything for the patient but can help the family." Another caregiver mentioned that the physician shared her personal experiences in caring for a parent with Alzheimer's.

The material resources provided to the three caregivers included The 36-Hour Day. In addition, one caregiver received a list of references with related journal articles and the address of the Alzheimer's Disease and Related Disorders Association, Inc. All received information about local support group activity. Compared to the other 27 caregivers, these caregivers received an extensive amount of information and resources. However, they were only 10.0% of the total number of caregivers.

Learning Activities

According to the definition of this study, a learning activity consists of the content and the process the caregiver identifies and describes as learning in his or her role as caregiver. The 30 caregivers described 185 learning activities under five major content areas. The content areas were (a) general knowledge of the disease, (b) day-to-day caregiving, (c) decision-making for those with

Alzheimer's, (d) effects of the caregiver's role, and (e) facilitating learning and understanding for others (see Table 12).

Content Areas

General Knowledge of the Disease

General knowledge of the disease included the cause and progression of Alzheimer's. Many of the caregivers had "never heard of the disease." However, they already were aware of behavior changes which led to the diagnosis of Alzheimer's. All caregivers expressed a need to "understand the disease." There was a desire to know "what was going to happen" or "what to expect."

At the time of diagnosis the majority of patients were in the early stages of the disease. This allowed caregivers the time and relative freedom to engage in learning.

The thirty caregivers described 57 learning activities related to the general knowledge of the disease. The degree to which caregivers felt the need to obtain information differed. The three groups identified were (a) active, (b) moderate, and (c) passive (see Table 13).

The active group consisted of 16 caregivers who were avid readers, sought and attended conferences, training sessions, and workshops, used support groups and other knowledgeable people to obtain additional information, and were continuous in their effort to increase their knowledge

Table 12

Content Areas Identified by Caregivers

Content Area	N	%
General knowledge of disease	57	30.8
Day-to-day caregiving	53	28.6
Decision-making	44	23.8
Effects of the caregiver's role	21	11.4
Facilitating learning for others	10	5.4
Total	185	100.0

Table 13

Need to Obtain Information about Alzheimer's Disease and Formal Education Level

Caregivers	Need for information Active[a] N=16	 Moderate[b] N=10	 Passive[c] N=4
Learning activities[d]	32	18	7
College degree	9	3	-
Post secondary	3	3	-
Secondary diploma or less	4	4	4

[a] Avid readers, sought and attended conferences, training, sessions, and workshops, used support groups and other knowledgeable people to obtain additional information. [b] Read the basic information including The 36-Hour Day and sought information within their own setting. [c] Little reading if any. None had read The 36-Hour Day. [d] Total of 57 learning activities.

base. One caregiver noted that she did "not learn anything new from recent support group meeting." Another mentioned having "gotten to a point where nothing was really new."

There were 10 caregivers in the moderate group. These caregivers had read the basic information including The 36-Hour Day. They sought information available in their own setting. Many in this group were limited by other roles and responsibilities.

In the passive group of four caregivers none had read The 36-Hour Day. One caregiver mentioned an article on Alzheimer's in "Good Housekeeping." The general feeling was that one had to "accept that little can be done" and to "take each day as it comes."

There existed a relationship between a higher level of formal education and the intensity of learning about the disease. Within the active group, 12 of the 16 had completed college level study. In the moderate group 6 of 10 caregivers received above a high school education. The four in the passive group included two with a high school degree and two completing the eighth grade. Two of the four requested that a third party read the Informed Consent form before they would sign.

The learner's environment for increasing one's knowledge about the disease was at a time when there existed relative freedom and time to seek out resources and to learn. Only one exception existed. A caregiver's parent was taking an excessive amount of drugs which resulted in the patient exhibiting characteristics usually seen much later in Alzheimer's patients. There was not time for learning. The patient was placed in a long-term care setting and the drugs slowly withdrawn. At this point, the caregiver read The 36-Hour Day, joined a support group, and began to understand more about the disease.

The learner's need to understand about the disease varied from active, moderate, and passive. There also existed a relationship between a higher level of formal education and the intensity involved in learning about the disease.

Day-to-Day Caregiving

The patients with Alzheimer's exhibited a greater dependency on caregivers as the disease progressed. They were not able to care for themselves. Caregiver activity ranged from providing food and a protective environment to a totally bedridden condition. The content area of day-to-day caregiving included caring for the Alzheimer's patient at home and caregiving in a long-term care facility.

There were 53 learning activities in this content area with 41 learning activities in caring for the Alzheimer's patient at home and 12 in caregiving in a long-term care facility. The area of caring for the Alzheimer's patient at home was further divided into seven areas. The seven areas were (a) bathing and dressing, (b) weight loss and nutrition, (c) use and control of medications, (d) increasing home nursing skills, (e) communicating with the patient, (f) behavior and moods of the patient, and (g) stimulation and patient activity (see Table 14).

Caregivers identified eight learning activities in bathing and dressing. They mentioned that their patients could not dress and bathe themselves. One caregiver said that her mother disliked bathing so much that she would go "kicking and screaming to the tub."

Caregivers described three learning activities in weight loss and nutrition. Caregivers noted a lack of desire to eat and increased weight loss. Caregivers identified four learning activities in the use and control of medications. Two mentioned their patients having drug-related hallucinations. One caregiver said she wanted to decrease her mother's use of sleeping pills, and another said that her mother carried a "bag of pills with her at all times."

As the disease progressed, increased home nursing skills were necessary. Caregivers described 10 learning activities which included lifting and bathing a bedridden patient, maintaining mobility or flexibility, and incontinence.

Table 14

Day-to-Day Caregiving

Content area	N	%
Caring at home		
Bathing and dressing	8	15.1
Weight loss and nutrition	3	5.7
Use of medications	4	7.5
Increasing home nursing skills	10	18.9
Communicating with patient	7	13.2
Behavior of patient	4	7.5
Stimulation and patient activity	5	9.4
Caring outside the home		
In long-term care setting	12	22.7
Total	53	100.0

Seven learning activities involved caregivers communicating with patients. As the patient's use of language was hindered by the disease progression, caregivers wanted to understand the language changes in order to provide better care and to help maintain the best quality of interaction with their patient. Three caregivers considered communicating as a means to provide happiness to the patient. One caregiver controlled the communication to prevent hurtful things from being said.

The behavior and moods of patients included wandering, inappropriate sexual behavior, and uncooperative behavior. There were four learning activities identified in this area. Caregivers described five learning activities related to stimulation and patient activity. Caregivers desired "to keep the patient active as long as possible," "to keep Mother laughing," and to continue making her "husband feel productive."

Day-to-day caregiving in a long-term care setting included interacting with staff, monitoring the quality of care, and providing additional care for the patient. There were 15 caregivers having patients in a long-term setting and 12 identified a learning activity related to day-to-day caring.

The learner's environment for the content area of day-to-day caregiving was one of constant change. Immediate responses were required for many situations. For those caregivers with patients in a long-term care setting a new and different caregiving role was required. Support group activity, staff, and other resources were available to caregivers. Caregivers had the option to do very little or a great deal in terms of learning to care in a new setting. Three of the 15 caregivers with patients in a long-term care facility did not identify learning activities.

Decision-Making

As Alzheimer's disease progresses patients lose their ability to make certain decisions regarding their life. Caregivers described 44 learning activities in the content area of decision-making for those with Alzheimer's. The content included legal and financial, controlling life and death choices, and long-term care placement (see Table 15).

Legal and financial decisions accounted for 22 learning activities. Caregivers obtained a power of attorney, a conservatorship, or a guardianship to maintain the finances and to perform other necessary legal activities. The inability of the patient to handle his or her own finances concerned 11 caregivers. One daughter "found a $2,000.00 error in mother's checkbook." The inability to finance care disturbed six caregivers. One caregiver saw her father being "wiped out financially." Another caregiver's father

Table 15

Decision-making for Caregivers of Alzheimer's Patients

Content area	N	%
Legal and financial	22	50.0
Controlling life and death choices	3	6.8
Long-term care placement	10	43.2
Total	44	100.0

had "too much money for medicaid and too little to remain in the Alzheimer's disease unit." In three cases the patients wanted to financially protect their families and therefore placed all their assets in their spouse's or children's names. One caregiver wanted to understand an existing conservatorship set up in a parent's trust. Another caregiver desired to change an existing conservatorship to a guardianship.

Caregivers described three learning activities in controlling life and death choices. One caregiver, after understanding both processes, chose a stomach feeding tube over a nose tube. Two caregivers made decisions regarding an autopsy program and eventual burial.

The decision to place a patient in a long-term care setting included 19 learning activities. Many of the older caregivers did not have the physical ability to care for a increasingly ill patient. Caregivers working full-time found it difficult to provide care. Abusive behavior of the patient caused three caregivers to explore long-term care.

The learners' environment for the content area of decision-making for those with Alzheimer's involved making decisions based on some previous information. Caregivers experienced the ongoing change in their patients and realized that decisions need to be made in the future. Interaction with other caregivers and previous reading provided additional background. The motivation to learn more came when a decision was required.

Effects of the Caregiver's Role

The effects of the caregiver's role included recognizing and learning to manage isolation, learning to handle guilt, and fear of Alzheimer's and aging. Each caregiver reacted differently to the stresses and demands of caregiving. Caregivers described 21 learning activities in this content area (see Table 16).

Four caregivers recognized their isolation and the effect on their caregiving and made changes. One caregiver could not drive. A younger, single caregiver recognized that she socially isolated herself by caring for her parent at home. Two recognized depression resulting from isolation. While other caregivers also felt depression, they did not recognize the cause and identify a plan to change as did the two caregivers included in this content area.

While guilt was very evident among caregivers, only five caregivers described learning activities. Guilt involving a parent and child relationship concerned four adult children caring for parents. Lack of ability to care for a spouse and subsequent placement in long-term care triggered learning on the part of an older caregiver.

Table 16

<u>Effects of the Caregiver's Role</u>

Content area	N	%
Recognizing and learning to manage isolation	4	19.0
Learning to handle guilt	5	23.8
Fear of Alzheimer's and aging	12	57.1
Total	21	99.9

<u>Note</u>. Not equal to 100% due to rounding.

Fear of Alzheimer's and aging accounted for 12 learning activities conducted by adult children caring for their parents. While nine caregivers expressed a positive view of aging and many said they had good role models, they were very afraid of "inheriting Alzheimer's." Two caregivers expressed a desire to control their "own end" and "to be free of pain." Both took action to insure their goals. One caregiver, a daughter-in-law caring for her spouse's father, questioned who would provide care for her as she aged. She identified ways to provide care for her future if necessary.

The effects of the caregiver's role as a content area recognized the stressful environment which caregivers faced daily. Caregivers chose learning activities after they identified a situation created by their environment. These caregivers showed reflection and action in their learning activities.

Facilitating Learning and Understanding for Others

Ten learning activities involved helping others learn. Five caregivers took the responsibility of planning individual support group meetings or training sessions at a local senior center. A local church asked two caregivers to develop a workshop for its members in order for the church to better care for its older members. A physician with the local medical school asked a caregiver and patient to share in a seminar for medical students. Another caregiver taught other caregivers how to use his video equipment so that he and other working caregivers could view a conference on Alzheimer's in the evening. Writing stories and poetry enabled one caregiver to help others understand while exploring his own changing feelings.

The content area of facilitating learning and understanding for others included caregivers who can use their experience to help others. The 10 caregivers represent a higher average of years as a caregiver (4.6 years) compared to the overall average of the 30 caregivers (3.7 years). Six of the 10 caregivers continued to care for their patient at home and also help other caregivers. As shown in Table 17, six of the caregivers completed college work or degrees and had been caregivers from one to six years. The four remaining caregivers had a secondary diploma or less and had been caregivers from four to 10 years. While the years of experience differed slightly between the two groups, all 10 caregivers facilitated learning and understanding for others. The experience gained in years of caring and the willingness to interact with others were shared by this group of caregivers.

The content areas were reflective of the stages of Alzheimer's disease. The learning about the cause and progression of the disease occurred shortly after diagnosis. Only the active learners continued to learn about the

Table 17

Years as a Caregiver and Educational Level in Facilitating Learning for Others

		Years as a caregiver		
Educational level	N	1-3	4-6	7-10
Graduate degree	1	-	1	-
College work or degree[a]	5	3	2	-
Secondary diploma	2	-	1	1
Less than secondary	2	-	1	1
Total	10	3	5	2

[a] One caregiver completed two years of college, one received an undergraduate degree, and three completed hours beyond the undergraduate degree.

disease beyond the early stage. As caregivers learned more about the debilitating effects of the disease, many began to seek information regarding legal and financial matters. All patients in this sample were mobile at the time of diagnosis and had the ability to perform some daily functions with limited help from a caregiver.

As the disease progressed into the middle stage, patients were less able to care for their personal needs independently. They could not be left alone and required help in dressing, eating, and using the toilet. Problems with language and memory loss worsened. Many patients were still physically active and wandering was common. Some patients showed angry outbursts, sudden shifts of mood, suspicion, fearfulness, or violence. Caregivers were involved in learning related to communicating with the patient, handling moods and behavior changes of the patient, keeping the patient productively active and stimulated, keeping the patient clean and adequately fed, and controlling the use of medications. At this time many caregivers sought information regarding placement in long-term care facilities. Caregivers were becoming more isolated due to the increasing dependency of the patient. This increased dependency created a stressful environment for the caregiver. Some caregivers recognized this environment and used learning to change it.

In the final stage, the Alzheimer's patient became withdrawn and exhibited involuntary emotional expression. Most were incontinent and unable to walk. Some refused to eat. Caregivers were involved in life and death choices. Knowledge of increased nursing skills including use of catheters, a hoist to move the patient, and care of bedsores became necessary. With increasing experience, caregivers showed the ability to reach out to help others to learn about the disease.

The content for each caregiver was dependent on how the disease progressed in their patient and the caregiver's choice of patient's living arrangement. Caregivers with an incontinent patient at home needed to learn about catheters or other means to control the problem. Caregivers with an incontinent patient in a long-term care facility learned how to monitor staff and charts to provide the best care. While caregivers reacted differently in their choice of how to care for the incontinent patient, the content area is similar and resulted from the patient's condition.

Process of Learning

The process of learning as defined in this study included the steps involved and the human and material resources used. Learning involved change and altered behavior. Change was identified in this study in terms of a newly developed skill to better care for the Alzheimer's patient, an increase in the understanding of the disease, and caregivers' ability to reflect and reinterpret their current and past behaviors from a new perspective.

An analysis of the steps and resources showed similarities and differences in how caregivers learned about the content areas. Six different learning processes were identified. Each was compared to the possible types of learning as described in the literature. Labels were given to the six processes based on caregivers' choice of words and the research of the literature. The six were (a) professionally guided, (b) informal conversation, (c) observation, (d) solving problems, (e) reading, and (f) change in perspective (see Table 18).

A learning activity consists of both the content and the learning process (see Table 19). In order to further explain the relationship between content and process, the following components are described for each of the six learning processes: (a) the common elements of the learning process, including steps taken and the material and human resources; (b) the learning process as used within separate content areas; and (c) a case example to further illustrate a learning activity using a specific process in a content area.

Table 18

Processes of Learning in Learning Activities

Process of learning	N	%
Professionally guided	65	35.1
Informal conversation	47	25.4
Reading	32	17.3
Solving problems	23	12.4
Change in perspective	10	5.4
Observation	8	4.3
Total	185	99.9

Note. Not equal to 100% due to rounding.

Table 19

Relationship Between Content and Process

	Process													
	PG[a]		IC[b]		OB[c]		SP[d]		R[e]		PER[f]		Total	
Content	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Knowledge of Disease	13	20.0	19	40.4	-	-	-	-	25	78.1	-	-	57	30.8
Day-to-day caregiving	16	24.6	2	4.3	8	100.0	21	91.3	5	15.6	1	10.0	53	28.6
Decision-making	28	43.1	16	34.0	-	-	-	-	-	-	-	-	44	23.8
Effects of care-giving role	4	6.2	6	12.8	-	-	2	8.7	2	6.3	7	70.0	21	11.4
Facilitating learning	4	6.2	4	8.5	-	-	-	-	-	-	2	20.0	10	5.4
Total	65	100.1	47	100.0	8	100.0	23	100.0	32	100.0	10	100.0	185	100.0

Note. Not equal to 100% due to rounding. [a]Professionally guided. [b]Informal conversation. [c]Observation. [d]Solving problems. [e]Reading. [f]Change in perspective.

Professionally Guided

The learning process of professionally guided activities included an authority figure and usually organizational support. The authority figure defined the objectives of the learning and structures the time and place of an activity. Any materials were referred to or provided by the authority figure.

Organized programs identified in professionally guided activities included support groups, workshops or conferences, and training sessions sponsored by the Area Agency on Aging. Human resources were health professionals related to an agency, physicians, nurses, and attorneys. The most common material resource noted was The 36 Hour Day. Copies of articles from professional journals were also given to caregivers. Each of the five content areas included professionally guided activities.

In General Knowledge of the Disease. Thirteen caregivers had the ability to identify and use an established system to obtain information. Support group participation and related conferences or workshops contributed to the learning for 10 caregivers. These caregivers chose support groups because their physician recommended they do so or they had a previous successful experience in a support group type of activity. The ten caregivers used the support group to provide information and additional resources. Two other caregivers mentioned that attending a caregiver training program sponsored by the Area Agency on Aging greatly increased their knowledge of the disease. Both initially called their local senior center and were referred to the training sessions which helped to answer their questions and provide additional resources. A social worker at a hospital where her spouse was diagnosed explained and answered questions about the disease for one caregiver. A sister of another caregiver worked professionally in the field of aging out of state. This sister sent many articles and sought answers to question concerning the disease. The common material resource for this group was The 36-Hour Day.

Case Example

Prior to the diagnosis of Alzheimer's disease, the patient was an active member of a local senior citizens center. Staff reported unusual behavior to the caregiver, a 58 year old daughter. Medical advice was sought and the diagnosis of Alzheimer's was confirmed. The caregiver sought help from the director of the senior center who recommended attending a current training program for caregivers sponsored by the area Agency on Aging. The caregiver attended all six sessions. She made copies of the written materials she obtained and shared with other family members and friends. She organized and filed the materials as well as the names of contact people for future use. As a result of the training the caregiver chose to become a member of a local support group which she attends when able.

In Day-to-Day Caregiving. Sixteen caregivers used professionally guided activities. Physicians provided information and medical advice to five caregivers. These caregivers required help in weight loss, drug use, and mood changes which involved the use of prescribed medications. Professional health aids already employed by four caregivers answered questions regarding daily care. Staff members in a long-term care facility helped three caregivers provide better care. Local agencies answered questions for two caregivers. One caregiver used her support group to help with suggestions. Another caregiver took a local workshop on nutrition. Six of the above caregivers mentioned the use of The 36-Hour Day as a reference.

Case Example

The caregiver's mother carried a "bag of pills" with her everywhere. The patient was very abusive to the daughter, beating her with a cane on one occasion. The caregiver went to every pharmacy in the local area obtaining a list of drugs prescribed for her mother. The patient had been seen by three or more physicians each prescribing medications. The caregiver went to one physician with this information to learn about the effect of these drugs on her mother. Together they developed a plan to monitor and reduce the prescribed drugs.

In Decision-Making. Twenty-eight learning activities were professionally guided. The ability to handle financial and legal matters, controlling life and death choices, and the placement of the patient in a long-term care facility were the major decisions necessary for caregivers. In choosing the best legal instrument, a power of attorney, guardianship or conservatorship, 18 caregivers sought advice from an attorney. All caregivers mentioned that they already knew the attorney. Two caregivers sought information from a trust officer at a bank. One caregiver was referred to legal services. All these caregivers discussed options presented by an authority figure, compared, and chose what was best in their situation.

In making life and death choices, one caregiver decided to have a stomach tube surgically inserted rather than have a nose tube. The attending physician explained both procedures but allowed the caregiver to choose. Physicians played a major role in the decision to place patients in a long-term care facility and also in recommending specific sites. In many cases family members visited long-term care facilities to observe and ask questions of staff. Two caregivers mentioned reading over again the section in The 36-Hour Day on long-term care placement.

Case Example

The patient's physician described two long term settings each with an Alzheimer's unit. The caregiver visited both places. She spoke with administrative staff, nursing staff, patients, and other caregivers. It was important to the caregiver that her mother would be allowed to wander and not be medicated or restrained. The caregiver took her mother for a weekend trial to see how she would adjust. Based on her mother's visit, the caregiver's observations and questioning, and that her mother's physician would make medical visits to this Alzheimer's unit, the caregiver was able to choose one of the initially recommended long term care settings.

In Effects of the Caregiver's Role. Four learning activities were professionally guided. Inheriting Alzheimer's or lingering in an incompetent state concerned three caregivers. Physicians and attorneys explained recent medical and legal information. Attorneys provided copies of living wills for caregiver use. A caregiver with extreme guilt over placement of her parent in a long-term care setting sought help from the nursing director of the facility. She received articles dealing directly with guilt and placement, individual support from the director, and became an active member of the support group at the facility.

Case Example

The caregiver was extremely concerned about inheriting Alzheimer's. Not only did his mother have the disease, but his father's sister was also diagnosed with Alzheimer's. He sought medical information from his mother's physician. Both he and his spouse went to their attorney to obtain information in order to understand a living will. Both signed the document in the attorney's office. A copy of the document was placed in their medical files. The couple discussed their intentions with close relatives. They were concerned that the living will "would not be honored."

In Facilitating Learning and Understanding for Others. Four learning activities were professionally guided. All involved teaching others about caring based on their own caregiving experience. A caregiver who worked during the day taught other caregivers how to use his video equipment in order to view training sessions later with other caregivers who also worked. The development and presentation of a program to other caregivers was conducted by two caregivers. A caregiver and her mother were interviewed by medical students under the supervision of a physician.

Case Example

A 76 year old woman cared for her spouse of 51 years at home for two years prior to his placement in a long-term care facility. She assumed an active caregiver role at the facility and with its support group activity. After attending a conference on Alzheimer's held in another state where her daughter lived, the caregiver used the materials and resources to present a program to her own support group.

Informal Conversation

In the learning process of informal conversation, the caregiver determined the needed information. The caregiver identified people with the necessary knowledge or special skill. The human resources used were available in the caregiver's environment. They included relatives, friends, and neighbors. Specific questions were asked. Discussions included possible solutions or additional resources. The caregiver applied the new information in his or her own setting.

In General Knowledge of the Disease. There were 19 learning activities using informal conversation to learn about the disease. The most significant human resource for six caregivers was another person with caregiving experience. The other caregivers were friends, neighbors, work associates, or church members. Of the seven family members used as resources, three had medical backgrounds. Professional staff at a long-term care facility, a social worker at a hospital, and a home health care nurse provided information about the disease. Friends in the medical field responded to questions from two caregivers. A support group was the significant resource for one caregiver. All human resources already existed in the caregivers' environment prior to the need to learn more about the disease. The only exception is the one caregiver using a local support group as a resource.

Case Example

A 45 year old daughter was responsible for the daily care of her father with Alzheimer's disease. Her sister who lived in another state is a professional in the field of aging and was very knowledgeable of the stages and symptoms of the disease. The caregiver described their father's activities and her sister helped to explain the process of the disease and suggested possible solutions to daily concerns. The sister sent professional journal articles to the caregiver.

In Day-to-Day Caregiving. There were two learning activities using informal conversation. The learning activities were identified in two different long-term care facilities. Each caregiver used another caregiver in the same facility as the human resource. The similarities of caring for an Alzheimer's patient in the same facility created a bond among caregivers. There existed common concerns in dealing with staff and handling daily activities. In the two cases, another caregiver provided understanding and support.

Case Example

A 71 year old woman was caring for her 76 year old husband. It was difficult to place her spouse of 52 years in a long-term care facility but she could no longer physically care for him at home. She spent most of her day with him. She has developed a close friendship with another caregiver her age. The two caregivers provided each other with a dependable resource to handle day-to-day caring. When the caregiver was unable to get a staff member to help her get her husband back into bed, the other caregiver taught her how one person could lift a patient. She was teaching the caregiver a skill she learned from a staff member. The two caregivers shared information daily.

In Decision-Making. There were 16 learning activities using informal conversation in the decision-making content area. The decision for 14 caregivers regarding possible long-term care placement involved relatives and friends. The decision-making process did not involve a physician. Caregivers sought information from people with previous experience. The people chosen were from the immediate environment of the caregiver. After obtaining information from others and visiting long-term care facilities, the caregiver and close family members shared information in order to make a feasible decision. In a discussion with a close friend concerning options to provide legal and financial care for his wife, a caregiver learned that he could go to the local courthouse, and without the help of an attorney, file his own papers to establish a conservatorship. Another caregiver became interested in donating her father's body to medical science. She discussed her desire with a friend who was a nurse. This friend obtained and gave to the caregiver verbal and written information about an autopsy program.

Case Example

A 57 year old caregiver could no longer care for her 86 year old mother at home. The caregiver sought information from friends she knew with parents living in a long-term care facility. Using this information to create a checklist, the caregiver visited and compared several nursing homes. This information enabled her to choose a long-term facility for her mother.

In Effects of the Caregiver's Role. There were six learning activities using informal conversation. The three caregivers who recognized their guilt in the caregiver role sought information to limit possible harmful effects of the guilt. Other caregivers within the study group expressed having guilt but did nothing beyond accepting that guilt existed. Two of the caregivers sought information from friends in the medical field. The other caregiver received help from a friend whose mother had died with Alzheimer's. Each of the three caregivers developed a plan to reduce the cause of the guilt. The fear of having Alzheimer's and being dependent on someone else for care concerned two caregivers. Both discussed their feelings with close family members and their physicians. They became aware of the concept of a living will and were seeking additional information. The sixth caregiver in this group realized how depressed she was becoming in her role as caregiver. She questioned a close friend if she noticed changes in her behavior. Together they recognized a need for paid part-time care to allow time for the caregiver to become involved in other activities. They also identified and listed requirements they thought to be necessary in a part-time care person. After several interviews, a person was hired.

Case Example

The caregiver was a 50 year old son responsible for the care of his 76 year old mother. The mother lived in a long-term care facility and was visited often by her son. No matter what the son said or did, the mother's response was, "you're not a good son." He spoke often to a male friend in the medical field who was also caring for his own mother. The caregiver acquired additional information about the disease, specifically about communication and language changes. While his mother's comments did not change much, the caregiver felt less guilty about putting his mother in the long-term care facility and, at times, could better communicate with his mother.

In Facilitating Learning and Understanding for Others. The four caregivers in this group shared information and resources on a one-to-one basis. Three caregivers described an active role in their support in their support group activity. They interact with new members, share personal books and articles, and are willing to maintain this support outside of the formal support group organization. One other caregiver provided help to a neighbor whose husband was diagnosed with Alzheimer's.

Case Example

The caregiver was a 75 year old woman. Her husband lived in a long-term care facility and she lived alone. Her neighbor's husband has recently been diagnosed with Alzheimer's. Having spent five years caring for her own husband at home, the caregiver was able to share her experience with her neighbor. The caregiver spent part of each day helping the neighbor care and teaching new skills in the process.

Observation

Observation as a learning process involved a skilled person as a model. This person was a trained health care provider or a more skilled caregiver. The desire for the caregiver to learn a new skill or technique was usually after the caregiver had observed someone else caring for the patient. After watching, questions were asked of the more skilled person. In the cases identified, the caregiver performed the new technique while the skilled person watched. For most, there were additional questions and comments.

In Day-to-Day Caregiving. Eight caregivers provided examples of observation as a learning process. Four caregivers observed techniques used by long-term care staff. Professionals in the health care field who came to three caregivers' homes showed how to care for a patient with a catheter, how to prevent decubitus ulcers, and how to use medical equipment. One caregiver helped and received help from a neighbor also caring for an Alzheimer's patient. As a more skilled caregiver, the neighbor provided the less-experienced caregiver with new skills. It was not an intentional activity in the beginning. The less-experienced caregiver observed the more-experienced one and adapted the techniques to her own situation.

Case Example

A 50 year old caregiving daughter could no longer lift her mother out of bed and into a wheel chair. She called a medical equipment company who sent out personnel with a Hoyer Hoist. The man demonstrated the use of the hoist. The caregiver with the help of the man used the hoist to pick up her mother. Next, the caregiver lifted her mother out of bed and into the wheelchair on her own. It was necessary for the caregiver to teach the LPN who came daily to help. To quote the caregiver, she "learned by listening, observing, and doing."

Solving Problems

The steps in solving problems included understanding the problem, developing ways to solve the problem, choosing what appears to be the best one, choosing resources, applying the solution, reflecting on the outcome, and beginning the process again if necessary. In developing ways to solve the problem, caregivers might use other learning processes. The process often involved reading, professional guidance, and informal conversation. The common element in the 23 learning activities identified as solving problems was the "trial and error" approach to solutions. In all cases the first solution was not satisfactory. What evolved was a spiral of different processes in order to solve the initial problems. Each learning activity contained a variety of material and human resources. Twelve caregivers described the 23 learning activities identified as solving problems. Five of these caregivers described two or more activities. They showed the ability to approach new problems with greater ease and creativity. Also, they were able to use humor to reduce tension which enabled them to identify additional solutions.

In Day-to-Day Caregiving. Of the 23 learning activities, 21 were in day-to-day caregiving. Ongoing problems existed in bathing and grooming, eating, sleeping, keeping the patient active, and changes in communicating. All of these situations changed and created new problems as the disease progressed. While other caregivers were able to identify individual learning activities in these areas, only the 12 mentioned were able to describe an ongoing or cycle of learning in solving a problem which changed over time.

There were seven learning activities describing ongoing problems with bathing and grooming the patient. Six learning activities involved changes in language and communication. Two caregivers in this group kept written accounts of activities and sayings of the patients. Solutions to specific problems and suggestions to try in the future were also kept. There were five learning activities related to keeping the patient active. As the disease progressed, activities once enjoyed were modified to the patient's level of activity. Two learning activities involved getting the patient to eat. One learning activity involved the use of music and television to relax and encourage sleep in the patient.

Each caregiver learned what worked best for their patient. One caregiver promised her mother a "gold star" if she would eat. This worked for several months and then the caregiver needed to find another solution. One caregiver discovered that her mother responded to some words but not others. When using the word "turn," her mother would not move. When she used the word "pivot" her mother moved. As the disease progressed, the caregiver was able to communicate with the patient for a longer period of time. In solving problems, caregivers learned from their patients and experience. They had the ability to look at a series of problems related to bathing, eating, and so forth as one ongoing problem. Most of these caregivers accepted change and anticipated new concerns and solutions.

Case Example

Getting her 77 year old mother to eat was difficult for an adult daughter. It was discouraging to cook a favorite meal for her mother and not have her eat. The daughter sought help from a fellow caregiver who suggested that she keep a daily record of what her mother ate and drank. The other caregiver also suggested developing a routine or schedule for eating times. Advice was sought from her mother's physician. He recommended "five good meals a week and not to feel guilty." The caregiver tried using TV dinners once or twice a week. She "found this avoided having hurt feelings after spending time cooking a favorite meal." The caregiver discovered that her mother would drink, or not drink a liquid based on the color. She experimented with different color liquids and glasses. The caregiver used role playing as a method to put her mother in a good mood and therefore encourage eating. If her mother was not eating, the caregiver would take the food away, brush her hair or change her blouse, reheat the meal and go back to her mother. Many times her mother would eat.

In Effects of the Caregiver's Role. Two learning activities were used as a process of solving problems. The most significant resources were self reflection and time.

Case Example

The caregiver, an adult daughter, made a conscious choice to care for her mother and never to place her in a long-term care facility. As her mother's disease progressed, the daughter realized that she had only "one level of thought." Caring for her mother dominated her life. She developed a "self-help program" for herself. The caregiver set aside time each day to work on a crossword puzzle. She also read political literature to challenge her mind. She enjoyed reading mysteries. Setting aside time for these activities, the caregiver obtained a respite from her caregiving chores.

Reading.

Reading as a learning process was used by 32 caregivers. The process varied according to the degree to which caregivers felt a need to know. For the active group, the learning outcome was identified. They searched for sources, read relevant materials, organized materials, and applied information when able. For the moderate group, the learning outcome was sometimes directed by another person. Reading was limited to the basic literature and only that which was available within their own setting. Application was limited. The passive group, which accepted that little can be done, reads very little. Only lay magazines found at food stores or given by a friend were read. This group was unaware of The 36-Hour Day. Over half of the caregivers mentioned seeing "Do You Remember Love," a television program dealing with Alzheimer's.

In General Knowledge of the Disease. Reading was the learning process for 25 learning activities. Eleven caregivers received materials from other people. The most common resource given was The 36-Hour Day. Five caregivers purchased "Newsweek," or a "lady's magazine" at a food or discount store. One caregiver read information about the disease from a home health book she already had in her home. Eight caregivers intentionally sought materials at libraries and foodstores. Of the eight, four used local libraries, two used bookstores, and two used both libraries and bookstores. Only one in this group used interlibrary loan to obtain additional materials. Six of the eight caregivers received information from the Alzheimer's Disease and Related Disorders Association (ADRDA) and two were members of the American Association for Retired Persons (AARP). Many of the eight caregivers shared their information with others and received new information.

Case Example

His wife of many years was diagnosed with Alzheimer's, when the disease was in an early stage. Both he and his wife read about the disease. They sought information at local libraries, purchased books and articles, and became members of ADRDA. They discussed the disease with each other, but the wife denied that she had Alzheimer's. She became violent if the word was mentioned. At this point the caregiver chose not to obtain any additional information about the disease.

In Day-to-Day Caregiving. Five caregivers used reading as a learning process to obtain new information for application. Three caregivers reread parts of The 36-Hour Day and directly applied what they had read. A patient in the early stages of the disease forgot to take her medicine. Her caregiver daughter read about the use of labels in The 36-Hour Day, made the labels with instructions for her mother, and taped them to the bathroom mirror. The idea worked. One caregiving son became interested in his mother's changing use of language. A friend in the medical field obtained specific articles from professional journals for him to read and increase his understanding. One daughter planned a physical therapy program for her mother based on her readings.

Case Example

The patient was becoming bedridden due to the progression of Alzheimer's. The caregiving daughter wanted to provide physical activities in an attempt to slow the deterioration. She sought information at the local library. She found what she wanted in a nursing manual written for LPNs. Based on this material, the caregiver planned a range of motion activities to do with her mother.

In Effects of the Caregiver's Role. Two caregivers used reading as a learning process. One caregiver needed to identify reasons why her spouse said "hurtful things." She reread The 36-Hour Day which dealt with this concern. The reading led to acceptance that the patient "can't help the things he says." The other caregiver recognized her isolation through her readings on caregiver stress.

Case Example

A 72 year old caregiving wife and her husband had been married 50 years. She did not drive a car but was able to walk to a grocery store. She basically cared for her husband by herself. The wife had materials about caregiver stress and isolation. As her husband's disease progressed, she again read the articles on isolation. She realized a need for reliable transportation and a new support system. She and her husband moved to a retirement community.

Change in Perspective

Change in perspective as a learning process included an evident and strong cause for change. The trigger-producing event resulted in a new or different point of view or comprehension. An obvious outward change was not always apparent. The most significant resource was the process of self reflection. Eight caregivers described 10 learning activities.

In Day-to-Day Caregiving. One caregiver related a change in perspective learning process.

Case Example

A caregiving daughter, 36, assumed responsibility for her 67 year old father. He was living in a long-term care facility. The daughter saw her father daily. Her father lost 58 pounds in 14 months and had not been seen by a physician for six months. The caregiver, a registered nurse, saw neglect and lack of caring on the part of the staff. The caregiver felt strongly that Alzheimer's patients should be "treated emotionally and physically." She left her position at a local hospital to work in an Alzheimer's unit in another long-term care facility. Her father was moved to the same unit.

In Effects of the Caregiver's Role. Seven caregivers described a change of perspective. Five caregivers identified a fear of inheriting Alzheimer's. All desired to have control over their own end. These caregivers did not want to have their family care for them in the same way they were currently doing. Two of these caregivers discussed their concern with their physicians and explored a living will. Of the five, three caregivers mentioned suicide as a viable option. The change in perspective for the other two caregivers was different. One caregiver was the youngest sister. She had always received from others in the family. As caregiver for her mother she gave more of her time, energy, and love to someone else. She felt that what should be done is so strong, and that the experience of caregiving will allow her to have "more control of her own life later." In another situation, the caregiver was a daughter-in-law assuming the care for her husband's father. Having severe rheumatoid arthritis, she wondered if her husband would treat her in the same way as he does his own father.

Case Example

A 40 year old daughter was caring for her 69 year old mother. While the daughter had positive feelings about aging and good role models in her family, she had developed a real fear of developing Alzheimer's. She had explored the means of suicide if she was ever diagnosed with Alzheimer's.

<u>In Facilitating Learning and Understanding for Others</u>. Two caregivers described learning activities. One caregiver wrote about her experience. It was the first time she wrote about her own family. She felt that the experience of

caring "changed her outlook towards writing." The other caregiver felt an obligation to educate the members of her church about Alzheimer's.

Case Example

A 49 year old daughter caring for her mother realized the need for the members of her church to become more involved in helping other members care for Alzheimer's patients. The caregiver, with a 10th grade formal education, coordinated and planned training sessions. She was committed to providing a means of support to other families through increasing their understanding. She did not have previous experience in organizing or helping others learn.

Summary

In summary, six learning processes were used to learn about the five major content areas. The content areas identified by caregivers were reflective of the patient's progression of Alzheimer's disease and the caregiver's choice of patient's living arrangements. The case studies used to illustrate the learning processes also described the special environment in which caregivers learned. Caregivers used a variety of learning processes to learn about the content areas.

Patterns of Learning

The three patterns of learning identified from the data were (a) influence of previous related caregiving experience, (b) learner's choice of learning processes, and (c) content as an influence in choice of learning processes.

Nine caregivers identified previous caregiving experience as an influence on their present role as caregivers. Three mentioned a supportive role each played to another family member. The other caregiving person became a role model. Self expectations were based on this model. Six caregivers noted caregiving experience in which each was the primary caregiver.

The nine caregivers with experience appeared to be more organized. They identified available resources earlier and used them more frequently. Six of the nine were members of a local support group. The average number of learning activities in professionally guided learning was 2.67 for the nine caregivers and 1.92 for the remaining 21 caregivers. Five of the nine used a solving-problems process of learning. All six learning processes were used in various combinations by this group.

Caregivers showed a preference for combinations of learning processes (see Table 20). Five subgroups of two or more caregivers chose like combinations of learning processes. Six caregivers each having a different pattern

Table 20

Learner's Choice of Learning Processes

	A		B		C		D		E		Others	
	N=10		N=7		N=3		N=2		N=2		N=6	
Learning process	N	%	N	%	N	%	N	%	N	%	N	%
Professionally guided	24	42.9	20	37.0	8	44.4	5	22.7	2	20.0	6	24.0
Informal conversation	20	35.7	15	27.8	3	16.7	-	-	2	20.0	7	28.0
Reading	12	21.4	9	16.7	3	16.7	3	13.6	2	20.0	4	16.0
Change in perspective	-	-	-	-	4	22.2	2	9.1	-	-	4	16.0
Solving problems	-	-	10	18.5	-	-	9	40.9	2	20.0	2	8.0
Observation	-	-	-	-	-	-	3	13.6	2	20.0	2	8.0
Total	56	100.0	54	100.0	18	100.0	22	99.9	10	100.0	25	100.0

Note. Not equal to 100% due to rounding.

from each other and the other groups were placed together under the heading of "Others."

The subgroup A consisted of 10 caregivers or 33.3% of the total sample. Of the 185 total learning activities they identified 56 (30.0%) learning activities. This subgroup chose the three learning processes of professionally guided (42.9%), informal conversation (35.7%), and reading (21.4%). Subgroup A included spouses and adult children caregivers who had a wide range of ages, educational levels, other roles, and initial information given at diagnosis. Five had an extensive informal support system. Three of the 10 had previous experience. The subgroup was more dependent on formal supports with 8 of 10 using formal supports. Five of the 10 were support group members with three being active and two being moderate. Significant to this group were the living arrangements and the time caregivers cared for patients prior to long-term care placement. Three patients continued to live with family, two lived alone, and five were in long-term care facilities. Prior to placement caregivers took care of their patients less than six months from diagnosis to placement. Subgroup A showed a more limited caregiving role than other groups due to less time spent caring in the home and the earlier stage of the disease for two patients living alone.

The subgroup B included seven caregivers, or 23.3% of the sample. Of the 185 total learning activities they identified 54 (29.2%) learning activities. This subgroup chose the four learning processes of professionally guided (37.0%), informal conversation (27.8%), solving problems (18.5%), and reading (16.7%). This subgroup had a wide range of caregiver age and various other roles. Both adult children and spouses were caregivers. Initial information varied from key phrases to more detailed explanation. The average number of years patients had Alzheimer's was 2.9. Four caregivers had an extensive informal support system. This subgroup had a higher level of formal education with one high school diploma, four with college work or degrees, and two with graduate degrees. Another significant factor was that four of seven had previous caregiving experience. All seven used formal supports and three were support group members. While four of the seven had patients in long-term care, the average time caregivers provided care prior to placement was two years and two months. Three continued to care for patients in their homes. The higher number of caregivers having previous experience could explain a greater use of formal supports and provide a partial explanation for the use of solving problems as a learning process. In addition, the slightly over two years that caregivers gave care prior to long-term care placement provided caregivers with the opportunity for them to become involved in a greater number of activities and a more varied caregiving role.

The subgroup C included three caregivers, or 10.0% of the sample. Of the 185 learning activities they identified 18 (9.7%) learning activities. This subgroup chose the four learning processes of professionally guided (44.4%), change in perspective (22.2%), reading (16.7%), and informal conversation (16.7%). Subgroup C showed many similarities. All were women, worked full-time, had two to four years of college, used formal supports, had limited informal support systems, and were caregivers to patients in a long-term care setting. Their average age was 47.7 years. Initial information varied and one had previous caregiving experience. The care provided prior to long-term placement was 2.3 months and the average years the patients survived with Alzheimer's was 3.0. Significant to this subgroup was the identification of a change in perspective by all three. Comparing the three caregivers in this subgroup with the other caregivers in subgroups D and Others who also identified a change in perspective showed that all were women with an average age of 47.2 years and all but one had completed some college work or obtained degrees. It is possible that the ability to identify and the willingness to describe a change in perspective was related to the sex, age, and educational level of the caregiver.

The subgroup D included two caregivers, or 6.7% of the sample. Of the 185 learning activities they identified 22 (11.9%) learning activities. This subgroup chose the five learning processes of solving problems (40.9%), professionally guided (22.7%), observation (13.6%), reading (13.6%), and change in perspective (9.1%). Both caregivers were daughters, obtained college degrees, averaged 46.5 years old, and had received good information and ongoing support from their physicians. While they had limited informal support systems and no previous experience, they both were active support group members and used formal supports. The two daughters had cared for their mothers for 1.5 years. The one difference was that one was a full-time caregiver and the other worked full-time. The two caregivers used all learning processes except informal conversation. With a limited informal support system both were dependent on support groups and formal supports coming into the home. The use of a solving problem process could be related to support group activity and the use of observation to the almost daily use of formal in-home supports. This subgroup showed the highest number of learning activities, averaging 11 per caregiver. In both cases the patients had limited mobility, required help with feeding, and were incontinent. This later stage of the disease required a greater degree of caring by the caregivers.

The subgroup E included two caregivers, or 6.7% of the sample. Of the 185 learning activities they identified 10 (5.0%) learning activities. This subgroup chose the five learning processes of professionally guided (20.0%), informal conversation (20.0%), reading (20.0%), solving problems (20.0%), and observation (20.0%). The two caregivers were wives caring for husbands at home. Both were 78 years old with one having an eighth grade education and the other a high school diploma. They remembered only key phrases from their physician about the disease. They used formal supports but were not members of support groups. Both did have an extensive informal support system. The two wives identified all learning processes except change in perspective. To discuss a perspective change such as suicide might be uncomfortable or thought to be unacceptable for this age group. Both couples had been married over 50 years. One wife had cared for her husband at home for over six years. He was now bedridden, incontinent, and totally dependent on her. The other wife cared for her spouse for over four years. He had limited mobility, needed to be fed, and was incontinent. The longer time of caring and the disease progression into a later or final stage resulted in new content areas for the caregivers.

The last subgroup, Others, included six caregivers having a pattern unlike anyone else in the sample. The six represented 20.0% of the sample. Of the 185 learning activities they identified 25 (14.5%) learning activities. This subgroup identified all six learning processes. The six caregivers included four daughters and two wives. They ranged in age from 40 to 75 years. Initial information varied from key phrases to more detailed description. Formal educational level also varied with two having less than high school, two with high school diploma, one with an undergraduate degree, and one with a graduate degree. Five of the six had an extensive informal support system and none belonged to a support group. Three patients lived with their caregivers and three were in long-term care. Prior to long-term care placement the three caregivers provided an average of one year and seven months care. The average time since the patient was diagnosed with Alzheimer's was 4.8 years.

Comparing the data using the learner's preference presented limited implications. Referring back to Table 20, all subgroups used professionally guided and reading as learning processes. Informal conversation was used by all except subgroup D where two caregivers had a limited informal support system and were dependent on formal supports and support group activity. Change in perspective was identified in subgroups C, D, and Others. All were women, averaged 47.2 years old, and had a higher level of formal education. Solving problems was found in subgroups B, D, E, and Others. While B and D showed a greater use (82.6%) of the process, had a higher level of formal education and support group activity, subgroups E and Others also used the process and had six of eight with a high school or less education with none being members of a support group. All using a solving problem process were caring for patients with limited mobility to a bedridden condition. Observation was used by subgroups D, E, and Others. Of the 10 caregivers in these subgroups, seven cared for patients at home with the additional support of a professional health care worker. All had access to observe someone with medical skills and knowledge. This additional help was required due to the limited mobility or bedridden condition of the patient.

Content as an influence in the choice of learning processes was explored (see Table 21). A different combination of processes was used for each content area.

Caregivers described 57 learning activities in the content area of general knowledge of the disease. This represents 30.8% of the total 185 learning activities. The

Table 21

Content as an Influence in Choice of Learning Processes

	Know[a]		Day[b]		Dec[c]		Effects[d]		Facil[e]	
Learning process	N	%	N	%	N	%	N	%	N	%
Professionally guided	13	22.8	16	30.2	28	63.6	4	19.0	4	40.0
Informal conversation	19	33.3	2	3.8	16	36.4	6	28.6	4	40.0
Reading	25	43.9	5	9.4	-	-	2	9.5	-	-
Change in perspective	-	-	1	1.9	-	-	7	33.3	2	20.0
Solving problems	-	-	21	39.6	-	-	2	9.5	-	-
Observation	-	-	8	15.1	-	-	-	-	-	-
Total	57	100.0	53	100.0	44	100.0	21	99.9	10	100.0

Note. Not equal to 100% due to rounding. [a]Knowledge of disease. [b]Day-to-day caregiving. [c]Decision-making. [d]Effects of caregiver's. [e]Facilitating learning for others.

nature of the content area was to provide an initial understanding of the disease. The need for caregivers to know more about the disease was usually at the time shortly after diagnosis. Patient demands were limited and the caregiver had time to seek information. While learning was intentional, caregivers were not able to identify specific goals other than a desire to "know more about the disease." The learning processes used to understand more about the disease were reading (43.9%), informal conversation (33.3%), and professionally guided (22.8%).

Caregivers described 53 learning activities in the content area of day-to-day caregiving. This represented 28.7% of the total 185 learning activities. The nature of the content area was problem oriented. Continuous learning was necessary. In most cases, an immediate solution was required. Caregivers built on past experiences and there existed evident growth on the caregiver's part to find new creative solutions.

The learning processes used to solve day-to-day caregiving problems included all six processes. Of the 53 total learning processes in this content area, 21 (39.6%) were solving problems, 16 (30.2%) were professionally guided, 8 (9.4%) were observation, 5 (9.4%) were reading, 2 (3.8%) were informal conversation, and 1 (1.9%) was change in perspective.

Caregivers described 44 learning activities in the content area of decision-making. This represents 23.8% of the total 185 learning activities. The nature of the content area was specific and goal directed. There existed an obvious authority figure. Learning outcomes could be identified.

The learning processes used in decision-making were professionally guided and informal conversation. Of the 44 total learning processed, 28 (63.6%) were professionally guided, and 16 (36.4%) were informal conversation.

Caregivers described 21 learning activities in the content area of effects of the caregiver's role. The nature of the content area was reflective. There existed a recognition of change over a period of time. It was not goal directed or intentional.

The learning processes used in effects of the caregiver's role were change in perspective, informal conversation, professionally guided, solving problems, and reading. Of the 21 total learning processes, 7 (70.0%) were change in perspective, 6 (28.6%) were informal conversation, 4 (19.1%) were professionally guided, 2 (9.5%) were solving problems, and 2 (9.5%) were reading.

Caregivers described 10 learning activities of facilitating learning and understanding for others. The nature of the content area was to help others understand about the disease and caregiving. It involved the understanding of one's own caregiving experience.

The learning processes identified in facilitating learning and understanding for others were professionally guided, informal conversation, and change in perspective. Of the 10 total learning processes, 4 (40.0%) were professionally guided, 4 (40.0%) were informal conversation, and 2 (20.0%) were change in perspective.

The learning processes used by the total group to learn about each content area was compared to the processes used by each of the subgroups in the same content areas (see Table 22). In the content area of knowledge of the disease the same processes were used by the total sample as subgroups A, B, and C. No one in the sample used solving problems, observation, or change in perspective. In the content area of decision-making, only the processes of professionally guided and informal conversation were used by the total group and also subgroups A, B, C, and Others. No one used any other learning process. One implication could be that the content areas influenced the choice of learning processes. The most used way to learn about the disease was reading. In decision-making, the most used way to learn about living wills and legal matters was to seek the acknowledged authority, a lawyer or banker.

Table 22

Comparison of the Total Group's Preference of Learning Processes in the Content Areas with Subgroups

	Total N=30		A N=10		B N=7		C N=3		D N=2		E N=2		Others N=6	
Process	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Knowledge of disease														
Reading	25	43.9	9	39.1	6	40.0	3	50.0	2	50.0	2	50.0	3	60.0
Informal conversation	19	33.3	8	34.8	5	33.3	2	33.3	-	-	2	50.0	2	40.0
Professionally guided	13	22.8	6	26.1	4	26.7	1	16.7	2	50.0	-	-	-	-
Total	57	100.0	23	100.0	15	100.0	6	100.0	4	100.0	4	100.0	5	100.0
Decision-making														
Professionally guided	28	63.6	11	68.8	8	57.1	5	83.3	1	100.0	1	100.0	2	33.3
Informal conversation	16	36.4	5	31.3	6	42.9	1	16.7	-	-	-	-	4	66.7
Total	44	100.0	16	100.1	14	100.0	6	100.0	1	100.1	1	100.0	6	100.0

Table 22 (Continued)

Comparison of the Total Group's Preference of Learning Processes in the Content Areas with Subgroups

	Total		A		B		C		D		E		Others	
	N=30		N=10		N=7		N=3		N=2		N=2		N=6	
Process	N	%	N	%	N	%	N	%	N	%	N	%	N	%
							Day-to-day caregiving							
Solving problems	21	39.6	-	-	10	66.7	-	-	7	53.8	2	50.0	2	25.0
Professionally guided	16	30.2	6	54.5	4	26.7	1	50.0	1	7.7	-	-	4	50.0
Observation	8	15.1	-	-	-	-	-	-	4	30.8	2	50.0	2	25.0
Reading	5	9.4	3	27.3	1	6.7	-	-	1	7.7	-	-	-	-
Informal conversation	2	3.8	2	18.2	-	-	-	-	-	-	-	-	-	-
Change in perspective	1	1.9	-	-	-	-	1	50.0	-	-	-	-	-	-
Total	53	100.0	11	100.0	15	100.1	2	100.0	13	100.0	4	100.0	8	100.0
							Effects of the caregiver's role							
Professionally guided	7	33.3	-	-	-	-	2	66.7	2	50.0	-	-	3	100.0
Informal conversation	6	28.6	3	75.0	3	42.9	-	-	-	-	-	-	-	-
Professionally guided	4	19.0	1	25.0	2	28.6	1	33.3	-	-	-	-	-	-
Solving problems	2	9.5	-	-	-	-	-	-	2	50.0	-	-	-	-
Total	44	100.0	16	100.1	14	100.0	6	100.0	1	100.1	1	100.0	6	100.0

Table 22 (Continued)

Comparison of the Total Group's Preference of Learning Processes in the Content Areas with Subgroups

	Total N=30		A N=10		B N=7		C N=3		D N=2		E N=2		Others N=6	
Process	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Reading	2	9.5	-	-	2	28.6	-	-	-	-	-	-	-	-
	21	99.9	4	100.0	7	100.1	3	100.0	4	100.0	-	-	3	100.0
Facilitating learning for others														
Professionally guided	4	40.0	-	-	2	66.7	-	-	1	100.0	1	100.0	-	-
Informal conversation	4	40.0	2	100.0	1	33.3	-	-	-	-	-	-	1	50.0
Change in perspertive	2	20.0	-	-	-	-	1	100.0	-	-	-	-	1	50.0
Total	10	100.0	2	100.0	3	100.0	1	100.0	1	100.0	1	100.0	2	100.0

Note. Not equal to 100% due to rounding

In the content area of day-to-day caregiving, all six learning processes were used by the total group. However, there were major differences when compared to the subgroups. None of the subgroups used six learning processes. Some reasons were presented earlier which could account for the diversity of this content area. Patients in the earlier stages of the disease required less care; therefore, caregivers were not confronted with the problems of caring for a patient with limited mobility or in a bedridden condition. A solving problem process accounted for 39.6% of the learning activities. A related caregiving experience showed an increase in the caregiver's use of the solving problem process of learning. Day-to-day caregiving included 21 learning activities using the process of solving problems. The only identification of learning activities using observation was in this content area. All caregivers using observation had access to in-home health care providers or professional staff in a long-term care facility. The identified factors causing a diversity in the day-to-day content areas were the nature of the content with the wide range of disease stages, related caregiving experience, and access to professional health care providers.

In the content area of effects of the caregiver's role, the five learning processes of change in perspective, informal conversation, professionally guided, solving problems, and reading were used by caregivers. None of the subgroups used all five processes. The most significant learning process was a change in perspective with 33.3% of the total number of learning activities. Also, seven of the 10 identified changes in perspective were in this content area. The content reflects the stress of caregiving and a recognition by the caregiver of a change in attitude or belief over a period of time. As previously presented, the ability to identify or the willingness to discuss a change in perspective was limited to women with an average age of 47.2 years and having obtained a higher level of formal education.

In the last content area of facilitating learning for others, the learning processes of professionally guided, informal conversation and change in perspective were described by the total group. None of the subgroups used all three learning processes. Ten learning activities were identified by caregivers. These caregivers represented a higher average of years as a caregiver (4.6 years) compared to an overall average of the 30 caregivers (3.7 years).

In summary, caring for a patient with Alzheimer's disease created a special environment in which caregivers learned. Because there are recognized stages in the progression of the disease, they were difficult to define other than in general terms; therefore, the response of each patient to the disease was different. However, the progression in each patient's disease produced a number of areas which caregivers identified as necessary learning in order to care for the patient. The stage or mobility level of the patient determined the variety of learning activities described by the sample. While learning continued for caregivers in a long-term setting, more diversity of learning activities was identified by those caregivers who cared for a patient in a home setting for a longer period of time.

The content area showed the greatest influence on caregiver's choice of learning processes. Caregivers were efficient and direct in their choice of learning processes and resources. Caregivers chose observation when they had access to a health care provider who could demonstrate caregiving skills. Reading was the significant choice to learn more about the disease. A professional authority figure was used most in decision-making. Change in perspective was most obvious in the content area of effects of the caregiver's role which reflected the stress involved in caregiving.

The time spent caring was the major influence for caregivers to become involved in facilitating learning for others. The progression of the disease influenced the diversity of learning processes in day-to-day caregiving. Some evidence of learner's preference could be identified in day-to-day caregiving. However, the influence of time caring at home was also a strong influence.

CHAPTER 5

Summary, Findings, Conclusions, and Recommendations

Summary

The purpose of this study was to identify and describe the learning activities of adults caring for patients diagnosed as having Alzheimer's disease. Five research questions were identified to accomplish this purpose:

1. What is the caregiver's support system (e.g., formal supports, used, informal supports of family and friends, support group affiliation)?

2. What specific situation(s) resulted in the caregiver seeking medical help?

3. What initial information was given to the caregiver at the time of diagnosis?

4. What are the learning activities after diagnosis that a caregiver can identify in his/her caregiving role?

    a. What triggers or causes a learning activity to occur?

    b. What is the process of the learning activity (e.g., steps involved, material and human resources, how and why they were chosen)?

5. What patterns of learning activities evolve among the caregivers sampled?

A nonrandom sample of 30 caregivers was interviewed. Participants from eight Northeast Tennessee Counties were identified through the programs of the First Tennessee Development District Area Agency on Aging and with the help of senior center staff. Subjects were asked to volunteer.

An instrument was not available for use; therefore, an instrument, a focused interview guide, was developed. The guide was developed through a review of the literature, consultation with several spouses or adult children caring for an Alzheimer's patient, and professionals in the health care field.

The major analysis procedure for the study was the grounded theory approach as described by Glaser and Strauss (1967). The constant comparative method is an inductive method which employs systematic coding and analysis to generate a theory which is integrated, consistent, close to the data, and in form clear enough to be operationalized for testing, using other methods.

Findings

The following findings are the results of the 30 in depth interviews with caregivers of Alzheimer's patients:

Research Question 1

What is the caregiver's support system (e.g., formal supports used, informal supports of family and friends, support group affiliation)?

Caregivers were aware of an existing formal support system. Twenty-three caregivers used in-home care services, three used day care, and five participated in the ACCESS program. All caregivers were aware of support group activity. Of the 12 who were members, five were active, four were moderate, and three were inactive.

The four main types of informal support identified were information sharing, emotional support, decision making support, and practical support. Eighty-two family members and 40 friends provided support for the 30 caregivers. The most important informal support for 23 caregivers was a close family member. For seven caregivers, a friend or neighbor was most important. In decision making 62.0% of family members and 12.5% of friends provided support. In practical support 70.27% of family members and 35.0% of friends shared in practical support. Both groups were involved in giving emotional support with 86.59% of the families and 90.0% of the friends. Most significant to this study was the sharing of information. Sixty percent of the friends shared articles, helped locate resources, and discussed this information with caregivers. Fifty percent of the families shared information with the caregiver. An informal support system existed for all 30 caregivers. Sixteen caregivers had an extensive system of four or more people involved and daily contact. Fourteen caregivers had a limited system with less than four people involved and less than daily contact.

Research Question 2

What specific situation(s) resulted in the caregiver seeking medical help?

The one behavior change mentioned by all caregivers was the patient's difficulty with day-to-day chores. Forgetfulness and repeating was the second most noted behavior change. Half of the caregivers mentioned disorientation. Twelve caregivers noted wandering or getting lost. Adult children were not as aware of behavior changes as were spouses.

Three specific reasons were identified for seeking medical help. First, the patient had another medical concern which required a physician's care or hospitalization. Second, the patient, the caregiver, or the patient and the caregiver together came to recognize the symptoms of Alzheimer's and were able to relate them to their own experience. Third, medical help was sought due to a type of crisis situation.

Research Question 3

What initial information was given to the caregiver at the time of diagnosis?

Sixteen caregivers remembered key phrases about the disease from their physicians. Ten caregivers noted that their physicians described the disease and the stages involved as the disease progressed. Three caregivers received information regarding tests in addition to the disease description and progression. One caregiver received no information from a physician but through a hospital social worker.

Twenty-four of the caregivers received no written information. Five caregivers were given a copy of The 36-Hour Day (Mace & Rabins, 1981). Only one caregiver was given additional references and the 36-Hour day. Ten caregivers were given information about local Alzheimer's support groups.

Research Question 4

What are the learning activities after diagnosis that a caregiver can identify in his/her caregiving role?

a. What "triggers" or causes a learning activity to occur?

b. What is the process of the learning activity (e.g., steps involved, material and human resources, how and why they were chosen)?

Learning activities consisted of content area and learning processes. The 30 caregivers interviewed described 185 learning activities in five major content areas. Of the 185 learning activities, 57 (30.81%) were in general knowledge of the disease, 53 (28.65%) in day-to-day caregiving, 44 (23.78%) in decision-making, 21 (11.35%) in effects of the caregiver's role, and 10 (5.41%) in facilitating learning and understanding for others.

Six learning processes were identified as professionally guided, informal conversation, observation, solving problems, reading, and change in perspective. Of the 65 (35.14%) learning activities using a professionally guided process, 13 (20.00%) were in knowledge of the disease, 16 (24.62%) were in day-to-day caregiving, 28 (43.08%) were in decision-making, 4 (6.15%) were in effects of the caregiver's role, and 4 (6.15%) were in facilitating learning and understanding for others.

Of the 47 (25.40%) learning activities using an informal conversation process, 19 (40.43%) were in knowledge of the disease, 2 (4.26%) were in day-to-day caregiving, 16 (34.04%) were in decision-making, 6 (12.76%) were in effects of the caregiver's role, and 4 (8.51%) were in facilitating learning and understanding for others.

Of the 8 (4.32%) learning activities using an observation process, 8 (100.00%) were in day-to-day caregiving.

Of the 12 (12.43%) learning activities using a solving problems process, 21 (91.30%) were in day-to-day caregiving and 2 (8.70%) were in effects of the caregiver's role.

Of the 32 (17.30%) learning activities using reading as a process, 25 (78.13%) were in knowledge of the disease, 5 (15.62%), and 2 (6.25%) were in effects of the caregiver's role.

Of the 10 (5.41%) learning activities involving a change in perspective, 1 (10.00%) was in day-to-day caregiving, 7 (70.00%) in effects of the caregiver's role, and 2 (20.00%) were in facilitating learning and understanding for others.

Research Question 5

What patterns of learning activities evolve among the caregivers sampled?

The three patterns of learning identified from the data were (a) influence of previous related caregiving experience, (b) learner's choice of learning processes, and (c) content as an influence in choice of learning processes. Based on the review of these patterns, the following implications were made:

1. Previous caregiving experience leads to a greater use of the learning processes of professionally guided and solving problems.

2. The more limited the mobility of the patient, which implied an advanced stage of the disease, the greater the amount of learning opportunities for caregivers.

3. The longer the period of time a caregiver cares for an Alzheimer's patient in a home setting, the greater the

use of the learning processes of solving problems and observation.

4. A change in perspective was described only by women with an average age of 47.2 years and with a higher level of formal education.

5. The content areas of knowledge of the disease and decision-making showed a specific combination of learning processes for all caregivers implying that the content was a factor in determining process.

6. The content area of effects of the caregiver's role which reflects the stress of the caregiving environment showed the highest percentage of the learning process of change in perspective.

7. Initial information provided by medical professionals to the caregiver showed no effect on type of process and number of learning activities. The two caregivers receiving the greatest amount of information and support had previous caregiving experience. They might have had the skills to solicit more information from the medical source.

8. The caregivers involved in the content area of facilitating learning for others showed a higher average of years as a caregiver (4.6) compared to the average of the total group (3.3).

Conclusions

This research is consistent with previous research related to Alzheimer's disease and caregivers. The demographic data obtained had many similarities to research using larger sample populations from wider geographical areas. While the sample of this study was limited to 30 caregivers, the following comparison of data with previous research shows the sample to be adequate.

Mortimer and Schuman (1981) stated that by the age of 80 the incidence of the disease for this population is 15% to 20%. Of the 30 patients in this study diagnosed with Alzheimer's, 6 (10%) ranged in age from 80 to 86 years.

Several studies demonstrated that most long-term care of older persons was provided by families (Brody et al., 1968, Carrilio & Eisenberg, 1983) and that a significant role was played by the immediate family (Shanas, 1979a, 1979b). All patients in this study were being cared for by immediate family members including two daughters-in-law who accepted responsibility for their spouses' parents.

The majority of caregivers were women (Brody, 1981; U.S. Congress, Office of Technology Assessment, 1987). In this research 26 (86.7%) of the caregivers were female. Studies showed that when a disabled person was married, the caregiver will most often be the spouse (one-third to one-half) usually women (OTA, 1987). In this sample, the caregiving spouses included eight (26.7%) wives and two (6.7%) husbands for a total of 33.4% of the sample caring for Alzheimer's patients. When there was no available spouse, adult children assumed the role of caregiver. The OTA report (1987) cited one-third adult children as caregivers. This study had a higher percentage with 14 (46.7%) daughters and two (6.7%) sons for a total of 53.4% of the sample.

The research by Brody (1981) noted the increasing number of middle-aged women in the work place with many having multiple family responsibilities. This study included 13 (43.3%) women who were working. Ten (33.3%) held full-time positions and 3 (10.0%) held part-time positions. The average age for the total number of adult children working full or part-time jobs was 46.2 years.

The OTA report noted a variety of reasons for long-term care and also the characteristics of the caregivers. More adult children placed parents in a long-term care facility than did spouses. In this study, the 15 caregivers with patients in long-term care consisted of 11 (73.3%) adult children and 4 (26.7%) spouses.

A nation wide study by Chenoweth and Spencer (1986) of 289 caregivers showed a number of similarities. Forty-five percent of their sample were caregivers caring at home and 55% were caring in a long-term setting. In this study, half of the patients were in a home setting and half in a long-term care facility. Chenoweth and Spencer's sample had a high level of formal education with 63% having some college or graduate school. In this research, 59.9% of the sample had some college or graduate school. The authors also recognized that the sample was more educated than the general population. In the research by Chenoweth and Spencer, initial explanations given to families about Alzheimer's included "'Nothing can be done, hopeless,'" (54%), adequate explanation about disease (28%), and no information (20%). In the present study, 53.3% remembered "key phrases," 36.7% received information about cause and stages of the disease, and 10.0% received additional information, material resources and ongoing support to the caregiver. All 30 caregivers in this study received some information at the time of diagnosis.

This study generally supported the findings of other research and assumptions on adult learning. Knox (1977) stated that adults learn continually and informally as they adjust to role changes which occur throughout their life span and that a life crisis was a significant cause and motive for learning. Brookfield supported a similar view that life changes necessitated the development of new competencies. The life crisis of caring for a loved one with Alzheimer's did produce a role change for these caring and created a need for caregivers to learn new competencies.

A problem-solving perspective and immediacy of application toward most of their learning as defended by Cross (1981) and Knowles (1980) as reasons for adult learning were noted in this study. Within the caregiving environment Gilleard (1984) and Sanford (1975) identified patterns of evolving problems, adaptations, then additional problems requiring new adjustments. This study supported the patterns of problems and also Gilleard's further assumption that the significance of problems may fluctuate according to the situation of the caregiver and the development of the dementia. In the area of day-to-day caregiving, where there was the greatest use of a solving problem process, a relationship to the stage of the disease was apparent.

The study supports the previous work of Tough (1971), 1982), Brookfield (1984b), and others, that learning is a natural part of adulthood and is carried out in informal and independent ways. This study, with 185 identified learning activities, shows that caregivers as adult learners had a capacity for self-directed learning.

Penland (1975) found that environmental factors such as lack of formal opportunity or negative views of formal opportunities as a means of learning were often associated with self-initiated learning projects. The one formal learning opportunity for caregivers was support group activity. While all caregivers were aware, not all joined or participated with the same degree of activity. This study supports and also contradicts Penland's view. First, some caregivers were not able to travel the distance to meetings so they could not attend. Two or more caregivers mentioned a negative experience at the first meeting and chose not to return. One man mentioned feeling uncomfortable with a predominantly female group and chose not to return. Other caregivers more active in support groups mentioned that they no longer learned from the group and that activities became repetitive. Some caregivers were extremely selective in what they attended. This study shows that the level of information being provided to caregivers did not meet the needs of these caregivers desiring more in-depth information. The interesting fact was that two of these caregivers continued to attend programs where they felt they knew as much as the presenters. These two caregivers had a limited informal support system. For them, the need for social and emotional support might be more significant than the need for informational support.

The existence of preplanning in self-directed learning activities was noted by Tough (1971), Heimstra (1975), and Penland (1979). In this study the evidence of preplanning is identified more clearly in three instances. First, when more time was available and the patient was in an earlier stage of the disease, caregivers were more systematic in their approach to learning about the disease. Second, the

10 caregivers with previous caregiving experience showed greater preplanning. Shortly after diagnosis, one caregiver established files which included the obtainment and use of medical equipment even though her mother was still living on her own with limited help. The caregiver had analyzed what she might need in the future based on her early reading about the progression of the disease. Third, preplanning was noted by those caregivers with more years of experience and the willingness to help others learn. Organization was necessary in order to present material to others.

Spear and Mocker (1984) in their study of self-directed learners with less than high school completion found that while their subjects did not do detailed preplanning, their efforts could not be characterized as random or non-rational. The authors derived the concept of the "Organizing Circumstance" which states that learners tended to select a course from limited alternatives which occur fortuitously within their environment and which structures their learning projects. The learning process of observation is similar to the "Organizing Circumstance" in that the process depended upon a health professional being in the caregiver's environment. Another supporting example would be the caregivers' use of a neighbor or friend with medical or legal expertise. Also, the four caregivers categorized as passive in their need to obtain information about Alzheimer's disease mentioned reading magazines they found primarily in food stores while shopping. All four had a secondary diploma or less. However, of the remaining eight who had a high school diploma or less, four were moderate and four were active. A lower educational level did not appear to be a significant factor in how these caregivers chose to learn about the disease.

Adult education literature documented the use of personal experience as a learning resource (Boyde & Fales, 1983; Simpson, 1980). In this study past caregiving experience is applied to the present role. The effect of current experience was noted in facilitating learning for others where the caregivers involved showed a greater number of years as caregivers. In solving problems, caregivers had the ability to describe a process which could be applied to each new or different situation. The caregivers using a solving problem process were caring for patients requiring constant care. These caregivers did appear to adjust to the constant change brought about by the progression of the disease. Caregivers recognized an ongoing trial and error approach. The caregivers were not repeating the identified experience over and over by a variation of earlier experience. Getting an Alzheimer's patient to eat varies from the patient forgetting to eat in the earlier stages to tube feeding near the end of the disease. Age and educational level of these caregivers were not significant. Initial information ranged from key phrases to a good description by physicians. The only significant factors were the extensive informal support system and the absence of support group involvement of all but two of these caregivers. The two with a limited informal support system were both active support group members. A problem solving process was discussed in their meetings. Sharing their experiences within an extensive informal support or within a support group meeting appeared to be significant factors in caregivers learning to solve problems over a period of time. One additional factor mentioned by a number of these caregivers was the use of humor both with the patient and themselves as caregivers.

A "perspective transformation" (Mezirow, 1981) was described by eight caregivers. The causes for change varied. Poor care her father received at a long-term care facility resulted in a caregiver who was a registered nurse to change the emphasis of her career and work with Alzheimer's patients. Fear of Alzheimer's and having their families care for them caused two caregivers to establish a living will, while three mentioned suicide as a possibility. One caregiver, a writer, discovered that her "outlook toward writing" changed.

Hooyman (1983), Shanas (1979b & 1979b), Treas (1977), Wentowski (1981), and others have documented the importance of the informal social support system in caring for an older person. This study adds to the information on informal support systems by looking at caregivers of Alzheimer's patients as a group. Luikart (1977) noted the relationships between individuals in a social network. He found that the amount, source, and type of assistance was related to the size, density, and composition of the group providing assistance. This study showed that 53.5% had an extensive informal support network of four or more people involved and daily contact. The immediate family provided 61.4% of the total number of supporting activities identified by caregivers. Friends provided 26.1% and the extended family 12.5%. Four different types of supports were provided by these groups (see Table 10). Friends played the most significant role in providing information and emotional support to caregivers. The immediate family was involved most in decision-making support. The extended family showed a higher involvement in providing practical help.

Family and friends play a significant role as "lay consultants," a term used by Furstenberg (1985) in her research. She defined lay consultants as "the way people talk about and look for information from nonprofessionals about health problems they are experiencing" (p. 108). Caregivers identified 65 activities in using family and friends to obtain information related to Alzheimer's and 56 activities in decision making. Furstenberg also found that the use of lay consultation carried more weight and was sought actively when people felt ill-informed by their physician. Although caregivers generally received limited information at the time of diagnosis and did have significant informal networks, this study did not show definite support for this assumption.

From a methological perspective, this study had some limitations. The sample was based toward a slightly more formal educated and white population. Although caregivers were sought in all areas of the eight counties through local senior centers, it was difficult to get caregivers in the extreme rural areas to agree to an interview. Many of the experiences discussed in the research depended on caregivers' descriptions of past events. The passage of time is likely to affect caregivers perceptions of experience.

The strength of the study was the selection of a sample population which did not use lists from local or national Alzheimer's support groups which presents an initial biased group. The majority of research to date has chosen samples in this manner.

Recommendations

Based on the findings of this study, the following recommendations are suggested:

1. Additional research should be conducted on how caregivers use a problem solving process. This study shows greater use of the process by caregivers with a previous

related caregiving experience, those with a longer time as a caregiver, and those with an extensive informal support system. What specific role does experience play in the problem solving process? How do caregivers identify and learn to apply a problem solving process? What role do other people play in the process? The investigations of questions such as these may provide some explanations as to why some caregivers were able to identify and use a problem solving process and others could not.

2. Caregivers and learning styles should be examined further. There was some evidence to suggest that caregivers had a preference for some learning processes over others. How does stress affect learning styles? Does the environment of caring force the use of uncomfortable learning styles on caregivers? Questions such as these may provide some explanation as to why some caregivers were better able to adjust to the constant change brought about by the progression of the disease.

3. A study should be conducted on the learning activities of a family group who care for an Alzheimer's patient. This research documents the significance of the family in providing information to caregivers. A comparison of what different family members feel is important to learn and how they learn would show the strengths and weaknesses of the family as a learning network.

4. Further research should be conducted on the friends, neighbors, and acquaintances of caregivers. This study noted that 60.6% of this group provided information, resources, and discussion to caregivers. How are these people chosen? Do they volunteer information? The investigations of questions such as these may provide some explanation as to why some caregivers had an extensive informal support system and others did not.

5. Longitudinal studies should be conducted on the learning of caregivers as the disease progresses in the patient. One weakness of this study was the reliance on caregivers' ability to recall past events.

6. Continued attempts should be made to do research on caregivers with levels of formal education representative of the population. Having a higher level of formal education, this group did not adequately represent all possible caregivers in the East Tennessee area.

7. Research should be conducted on learning in a support group. This study showed positive and negative aspects of the influence on learning by support groups. Additional research is necessary to determine the impact of such groups.

8. Research should be conducted on caregivers showing a change in perspective regarding the fear of having Alzheimer's disease to determine if their views toward suicide change after the decease of the Alzheimer's patient.

REFERENCES

Aronson, M. K., & Lipkowitz, R. (1981). Senile dementia, Alzheimer's type: The family and the health care delivery system. *Journal of the American Geriatrics Society*, *29* (12), 568-571.

Bailey, K. D. (1978). *Methods of social research*. New York: The Free Press.

Barnes, R. F., Raskind, M. A., Scott, M., & Murphy, C. (1981). Problems of families caring for Alzheimer patients: Use of a support group. *Journal of the American Geriatrics Society*, *29* (2) 80-85.

Boyde, E. M., & Fales, A. W. (1983). Reflective learning: Key to learning from experience. *Journal of Humanistic Psychology*, *23* (2), 99-117.

Breen, A. R., & Reifler, B. V. (1983). Helping the family of the patient with dementia. *Geriatric Medicine Today*, *2* (11), 46-57.

Brody, E. M. (1981). Women in the middle and family help to older people. *The Gerontologist*, *21* (5), 471-480.

Brody, E. M., Poulshock, S., & Masciocci, C. (1978). The family caring unit: A major consideration in the long-term support system. *The Gerontologist*, *18* 556,561.

Brookfield, S. (1984a). *Adult learners, adult education and the community*. New York: Teachers College Press.

Brookfield, S. (1984b). Self-directed adult learning: A critical paradigm. *Adult Education Quarterly*, *35* (2), 59-71.

Brookfield, S. (1986). *Understanding and facilitating adult learning*. San Francisco: Jossey-Bass.

Bureau of the Census (Issued August, 1983). *General social and economic characteristics, Tennessee in 1980 census of population*. PC 80-I C44, Tables 171 and 188.

Carrilio, T. E., & Eisenberg, D. M. (1983). Informal resources for the elderly: Panacea or empty promises. *Journal of Gerontological Social Work*, *6* (1), 37-47.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. *The Gerontologist*, *26* (3), 267-272.

Cohen, D., Kennedy, G., & Eisdorfer, C. (1984). Phases of change in the patient with Alzheimer's dementia: A conceptual dimension for defining health care management. Journal of the American Geriatrics Society, 32 (1), 11-15.

Cohen, G. (1979). Fact sheet: Senile dementia (Alzheimer's disease). WIMH.

Cross, P. K. (1981). Adults as Learners. San Francisco: Jossey-Bass.

Furstenberg, A. (1985). Lay consultation and its implications for health professionals. In E. Brody (Ed.), Mental and Physical Health Practices of Older People (pp. 107-121). New York: Springer Publishing Company.

Gilhooley, M. L. M. (1984). The impact of care-giving on care-givers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. British Journal of Medicine Psychology, 57, 35-44.

Gilleard, C. J. (1984). Living with dementia: Community care of the elderly. Philadelphia: Charles Press.

Glaser, B. G. (1978). Theoretical sensitivity. Mill Valley, CA: The Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory. Chicago: Aldine.

Gwyther, L. P. (1985). Care of Alzheimer's patients: A manual for nursing home staff. American Health Care Association and Alzheimer's Disease and Related Disorders Association.

Hiemstra, R. (1975). The older adult and learning. Lincoln: University of Nebraska.

Hiemstra, R. (1981). The implication of lifelong learning. In Z. Collins (Ed.), Museums, adults and the humanities (pp. 120-130).

Hirschfeld, M. (1983). Homecare versus institutionalization: Family caregiving and senile brain disease. International Journal of Nursing Studies, 20 (1), 23-32.

Hooyman, N. (1983). Social support networks in service to the elderly. In J. K. W. Haher, J. Garbarino & Associates (Eds.), Social support network: Informal helping in the human services (pp. 133-164), New York: Aldine Publishing Company.

Horowitz, A., & Shindelman, L. W. (1983). Reciprocity and affection: Past influences on current caregiving. Journal of Gerontological Social Work, 5 (3), 5-20.

Howell, M. (1984). Caretakers' views on responsibilities for the care of the demented elderly. Journal of American Geriatric Society, 32, 655-658.

Katzman, R. (1976). The prevalance and malignancy of Alzheimer disease: A killer (editorial). Archives of Neurology, 33, 217-218.

Knowles, M. (1975). Self-directed learning. Chicago: Association Press.

Knowles, M. (1980). The modern practice of adult education: From pedagogy to androgogy. Chicago: Association Press.

Knox, A. B. (1977). Adult development and learning. San Francisco: Jossey-Bass Publishers.

Lazarus, R. S., & DeLongis, A. (1982). Psychological stress and coping in aging. American Psychologist, 380, 245-254.

Luikart, C. (1977). Social networks and self-planned adult learning. University of North Carolina Extension Bulletin. 61, (2).

Mace, N. L., & Rabins, P. V. (1981). The 36-hour day. Baltimore: Johns Hopkins University Press.

Merton, R. K., Fiske, M. D., & Kendall, P. L. (1956). The focused interview. New York: The Free Press.

Mezirow, J. D. (1978). Perspective transformation. Adult Education, 28 (2), 100-110.

Mezirow, J. (1981). A critical theory of adult learning and education. Adult Education, 32 (1), 3-24.

Middleton, L. (1984). Alzheimer's family support groups: A manual for group facilitators. Tampa: Suncoast Gerontology Center.

Mortimer, J. A., Schuman, L. M., & French, L. R. (1981). Epidemiology of dementing illness. In J. A. Mortimer & L. M. Schuman (Eds.), The Epidemiology of Dementia (pp. 3-23). New York: Oxford University Press.

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior, 19, 2-21.

Peck, A., Wollock, L., Rodstein, M. (1973). Mortality of the aged with chronic brain syndrome. Journal of the American Geriatrics Society, 21, 264-270.

Penland, P. (1979). Self-initiated learning. Adult Education, 29, 170-179.

Postma, P. D., Hastings, D. W., & Jacobsen, J. C. (1984). Changes in Tennessee: What the 1980 census data show. Nashville: The Tennessee State Planning Office.

Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39 (2), 230-239.

Reece, D., Waltz, T., & Hageboeck, H. (1983). Intergenerational care providers of non-institutionalized frail elderly: Characteristics and consequences. Journal of Gerontological Social Work, 5 (3), 21-34.

Reifler, B. V., & Wu, S. (1982). Managing families of the demented elderly. The Journal of Family Practice, 14 (6), 1051-1056.

Reisberg, B. (1986). Dementia: A systematic approach to identifying reversible causes. Geriatrics, 41 (4), 30-46.

Robinson, B. C. (1983). Validation of a caregiver strain index. Journal of Gerontology, 38 (3), 344-348.

Rockhill, K. (1982). Researching participation in adult education: The potential of the qualitative perspective. Adult Education, 33 (1), 3-19.

Sanford, J. P. A. (1975). Tolerance of debility in elderly dependents by supporters at home: Its significance for hospital practice. British Medical Journal, 3, 471-475.

Schatzman, L., & Strauss, A. L. (1973). Field Strategies for a Natural Sociology. Englewood Cliffs, New Jersey. Prentice-Hall.

Schneck, M. K., Reisberg, B., & Ferris, S. H. (1982). An overview of current concepts of Alzheimer's disease. American Journal of Psychiatry, 139 (2), 165-173.

Shanas, E. (1979a). The family as social support system in old age. The Gerontologist, 19 (2), 169-174).

Shanas, E. (1979b). Social myth as hypothesis: The case of the family relations of old people. The Gerontologist, 19 (1), 3-9.

Simpson, E. L. (1980). Adult learning theory: A state of the art. In H. Lasher, J. Moore, & E. L. Simpson (Eds.), Adult Development and approaches to learning. Washington, D.C.: National Institute of Education.

Spear, G., & Mocker, D. (1984). The organizing circumstance: Environmental determinants in self-directed learning. Adult Education, 35 (1), 1-10.

Steinberg, G. (1983). Long-term continues support for family members of Alzheimer's patients. In B. Reisberg (Ed.), Alzheimer's disease (pp. 23-28). New York: Free Press.

Strub, R. L., & Black, F. W. (1981). Organic brain syndromes: An introduction to neurobehavioral disorders. Philadelphia: F. A. David Company.

Teusink, J. P., & Mahler, S. (1984). Helping families cope with Alzheimer's disease. Hospital and Community Psychiatry, 35 (2), 152-155.

Tough, A. (1967). Learning without a teacher: A study of tasks and assistance during adult self-teaching projects. (Educational Research series No. 3). Toronto: Ontario Institute for Studies in Education.

Tough, A. (1971). The adult's learning projects. Ontario: Ontario Institute for Studies in Education.

Tough, A. (1982). Intentional changes: A fresh approach to helping people change. Chicago: Follett Publishing Company.

Treas, J. (1977). Family support systems for the area: Some social and demographic considerations. The Gerontologist, 17 (6), 486-491.

U. S. Congress, Office of Technology Assessment, Losing a million minds: Confronting the tragedy of Alzheimer's disease and other dementias, OTA-BA-323 (Washington, D.C.: U.S. Government Printing Office, April 1987).

Wentowski, G. (1981). Reciprocity and the coping strategies of older people: Cultural dimensions of network building. The Gerontologist, 21 (6), 600-609.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feeling of burden. The Gerontologist, 20 (6), 649-655.

Zarit, S., Orr, N., & Zarit, J. (1983). Working with families of dementia victims: A treatment manual. Los angeles, CA: Andrus Older Adult Center.

APPENDICES

Appendix A

INTERVIEW GUIDE

Interview Code #______

I. DEMOGRAPHICS

A. Person with diagnosis of Alzheimer's disease

Age ______ Sex ______

Other chronic illness(es) ______________
____
____

Living arrangements

Living alone ______________
With family caregiver ______________
With paid caregiver ______________
Long-term care ______________
Other (specify) ______________

B. Primary caregiver

Relation to Alzheimer's patient

Spouse ____
Adult Child ____
Other ____

Age ______ Sex ______

Formal educational level ______

Other family role(s) - (check all which apply)

Spouse ______
Parent ______
Provider ______

Adult Child ______
Grandparent ______
Other ______

II. CAREGIVER SUPPORT SYSTEM

A. Formal Supports

	Ever used?	Use now? Hours/week
Home health care and services	________	________
Adult day care	________	________
Hospital and/or nursing home respite care	________	________
Homebound services (including meals on wheels, physical therapy)	________	________
Legal services, (including ombudsman)	________	________
Public housing	________	________
Other (specify)	________	________

Participate in Project ACCESS ____

B. Support Group Affiliation

Member ________ When join? ______________
month year

Active (try to attend all activities) ________

Moderate (select topics or meetings of personal interest) ________

Inactive (joined but attend very few activities ________

C. Informal Supports (family and friends)

Relationship	Type of Support	Hours/Week
________	________	________
________	________	________
________	________	________
________	________	________

III. PRIOR TO DIAGNOSIS OF ALZHEIMER'S DISEASE

What specific situation(s) caused you to become concerned about your ________________ and seek medical help?

What was the date of diagnosis?

IV. LEARNING AT THE TIME OF DIAGNOSIS

What initial information was given to you about the disease at the time your ______________ was diagnosed as having Alzheimer's?

Who provided this information?

Any written material provided? What?

Resources to obtain additional information?

V. LEARNING AFTER DIAGNOSIS

What have you learned or needed to learn in caring for you ____________?

What caused this learning?

What were the steps involved in learning? (Include significant people, resources and other sources used.) How and why they were chosen?

Who or what was the <u>most significant source of help</u>?

Time spend in learning?

VI. SKETCH OR CAREGIVER'S MOST RECENT DAY WITH ALZHEIMER'S PATIENT.

Date and Place of interview:________________________________

Appendix B

INFORMAL SOCIAL SUPPORT NETWORKS OF CAREGIVERS

INFORMAL SOCIAL SUPPORT NETWORKS OF CAREGIVERS

Alz. pat. ____________

Caregiver ____________

	INFORMATION SUPPORT	EMOTIONAL SUPPORT	DECISION MAKING	PRACTICAL SUPPORT
Relation				
Activities				
How Often				
Other				
Relation				
Activities				
How often				
Other				
Relation				
Activities				
How often				
Other				
Relation				
Activities				
How often				
Other				

Appendix C

INFORMED CONSENT FORM

INFORMED CONSENT

PRINCIPAL INVESTIGATOR: Jeannette G. McLaughlin

TITLE OF PROJECT: A Study of Learning Activities of Selected Caregivers of Alzheimer's Patients in East Tennessee

A caregiver of someone who has been diagnoised with Alzheimer's disease is confronted with new and changing situations as the disease progresses. The purpose of this interview is to explore and describe the learning activities that occur while caring for a person with this disease. Your participation as a respondent in this research project has the possibility of helping other individual caregivers through Alzheimer's support groups, and to the medical community in their desire to provide support to families caring for an Alzheimer's patient.

As a respondent, I understand that the caregiving role can be stressful and an interview on this subject might be upsetting. My participation in this interview is voluntary and I may end the interview at any time. I understand that information acquired during this interview will be treated confidentially. General descriptions may be included in the interviewer's report. Specific identify will not be reported.

I understand that I can call Jeannette McLaughlin at (615) 753-8429 for answers to pertinent questions about the research and research subjects's rights, and Dr. Robert D. Fox at (615) 929-6275 in the event of a research-related injury.

I also understand that while East Tennessee State University does not provide compensation for medical treatment other than emergency first aid, for any physical injury which may occur as a result of my participation as a subject in this study, claims arising against ETSU or any of its agents or employees may be submitted to the Tennessee Claims Commission for disposition to the extent allowable as provided under TCA Section 9-8-307. Additional information concerning this may be obtained from the chairman of the Institutional Review Board.

I also understand that while my rights and privacy will be maintained, the Secretary of the Department of Health and Human Services and the ETSU Institutional Review Board does have free access to any information obtained in this study should it become necessary and I freely and voluntarily choose to participate. I understand that I may withdraw at any time without prejudice to me. Refusal to participate will involve no penalty or loss of benefits to which I am otherwise entitled, and I may discontinue participation at any time without penalty or loss of benefits to which I am otherwise entitled.

Having read the above statements and agreeing to the interview, please sign below as the Respondent.

Date Interviewer	Date Respondent

Appendix D

VITA

VITA

JEANETTE GOSS McLAUGHLIN

Education:	University of Maryland, College Park, Maryland. Certificate in Rural Aging Administration, 1987
	George Washington University, Washington, District of Columbia. MAT-Museum Education, 1980
	Syracuse University, Syracuse, New York. M.S. Elementary Education, 1973
	University of North Carolina at Charlotte, Charlotte, North Carolina. B.A. History, 1970
Professional Experience:	Student Teaching Coordinator, East Tennessee State University, Johnson City, Tennessee, 1987-1988
	Administrative Intern, First Tennessee Development District Area Agency on Aging, Johnson City, Tennessee, 1986-1987
	Doctoral Research Assistant, Center for Geriatrics and Gerontology, East Tennessee State University, Johnson City, Tennessee, 1984-1986.
	Research Assistant, Archives of Appalachia, East Tennessee State University, Johnson City, Tennessee, 1982-1984
	Education Program Coordinator, Sully Plantation, Fairfax County Park Authority, Fairfax, Virginia, 1979
	Assistant Education Curator, Jefferson County Historical Society, Watertown, New York, 1974-1978
	Kindergarten Teacher, Heman Street School, East Syracuse, New York, 1973-1974.