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# LIFE HISTORY OF MEN WITH ALZHEIMER'S DISEASE AND THEIR SPOUSAL CAREGIVERS: RELEVANCE FOR GROUNDED THEORY OF FAMILY CARE

By

Margaret Mary Flatt

A DISSERTATION

Submitted to
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Department of Family and Child Ecology

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# ABSTRACT

# LIFE HISTORY OF MEN WITH ALZHEIMER'S DISEASE AND THEIR SPOUSAL CAREGIVERS: RELEVANCE FOR GROUNDED THEORY OF FAMILY CARE

By

Margaret Mary Flatt

Qualitative methodology was used to analyze the relevance of life history to family care of a member with Alzheimer's disease. Life history methodology proved effective for generating a large amount of data describing family patterns over multiple generations. Historical data from genograms and interviews were compared with data from interviews and observations related to current functions of providers and recipients of care.

The main themes that emerged from the data were commitment and coping with progressive loss. Findings were related to continuity theory, the science of unitary human beings, and family ecological theory as well as to concepts of hardiness and energy use in systems.

Grounded theory on care and the dynamics of family care evolved from the data. Care was defined and the capacity to provide care was described. The capacity of a family to provide care was seen as dependent upon learned commitment to family and community as well as learned interdependence between social systems. Commitment to care was hypothesized to depend upon perceived comfort and safety of family members, energy requirements and resources, and cohort socialization. The concept of zones of care within which families function

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was introduced. The boundaries of safe family care were described as they relate to knowledge and skill.

Implications of this study were discussed relative to individuals with senile dementia, family care, and family research and theory. The study identifies the need for more research using people with Alzheimer's disease as participants, focusing on the dynamics of family care, and clarifying the relationship between hardiness and family care. The roles of educators, professional caregivers, family scientists, and policymakers were discussed as they relate to empowering caregiving families.

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# DEDICATION

The dissertation is dedicated to Lydia Anderson and Margherita Valgoi, my mother and maternal grandmother, who introduced me to family care. My mother was an excellent role model, providing home care for my disabled grandmother. She recommended I spend some time asking my grandmother about her youth and her journey from Italy to the United States. By carrying out my mother's recommendations I not only had a rich intergenerational experience but also learned to appreciate the wealth of family history data that could be retrieved from aging family members.

The dissertation is also dedicated to Edmund Flatt, my father-in-law, who reawakened my interest in family care. As I pursued doctoral education his health deteriorated, and I observed and participated in family caregiving activities. Coming at that time in my life, the experience enhanced my understanding of the complexity of issues related to provision of care for aging family members.

Finally, this dissertation is dedicated to all of the families providing home care to dependent family members. Their service to society is largely unrecognized and unrewarded.

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# ACKNOWLEDGEMENTS

The contributions of many led to the successful completion of this dissertation and other requirements for the doctoral degree. Their assistance throughout the process has been greatly appreciated.

I am grateful to my original committee members, Dr. Barbara Ames, Dr. Margaret Bubolz, Dr. Linda Nelson, and Dr. Katherine White who have each played an important role in guiding my doctoral education. Dr. Bubolz and Dr. Nelson, co-directors of my research, have provided valuable insights into theory and methodology. Thanks are also in order for Dr. Alice Whiren, who contributed to the final review of the dissertation.

This research would not have been possible without the families who welcomed me into their homes and shared information on their life experiences. They taught me a great deal, for which I am grateful.

Special thanks go to my husband Ralph and my sons Joel and Kevin for the support provided throughout my doctoral studies. They appreciate the time and effort that has been expended in pursuit of a doctoral degree. Each contributed in his own way to the attainment of the degree and the maintenance of the family.

# TABLE OF CONTENTS

Con

Chapter

Esta

Rela

Litera

# LIST OF TABLES

Figure

# LIST OF FIGURES

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# CHAPTER I. INTRODUCTION

## Statement of the Problem

Alzheimer's disease is the most common cause of dementia, affecting about 2.5 million people in the United States or approximately 50% of those diagnosed with senile dementia (Merrill, 1988). The prevalence of dementia rises with age, affecting approximately 2% of the 60-70 age group and 20% of individuals over 80 years of age. Demographic trends indicate the greatest population growth is occurring in the 80 and over group, those most likely to be afflicted with senile dementia (Bronte, 1987). Most victims of senile dementia are cared for by family members (Shanas, 1979).

Wilson (1989a) described eight stages experienced by family caregivers dealing with a member with Alzheimer's disease. The first two stages involve noticing changes, but then discounting them as part of normal aging. During stage three and four families begin to suspect there is something wrong, and start searching for explanations. Once a diagnosis of Alzheimer's disease is made stage five is reached and the changes noted in the first four stages are recast in light of the diagnosis. Stage six requires a decision either to take on the role of caregiver or relinquish it to others. Going through that role is stage seven. When family members are no longer able to deal with the demented individual in the home, stage eight occurs, and the primary responsibility for care is turned over to an institution such as a nursing home. Families going through the experience of providing care for a member with Alzheimer's disease encounter many problems.

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Included are misunderstandings with regard to the illness, breakdown of shared meanings, and changing patterns of personal care and household maintenance (Wilson, 1989b). Blieszner and Shifflett (1990) found that within six months of receiving a diagnosis of Alzheimer's disease family caregivers experience patience with and understanding of the changes in their relationships with the demented individual. By the time six more months had passed, the same caregivers reported their relationship with the demented individual had been redefined, but there were communication problems that limited their ability to share positive feelings related to the old relationship and to explain their commitment to the new relationship.

As the physical and mental health of the elderly deteriorate, reciprocal interaction within the dyad is replaced by a one-way flow of aid to the recipient of care (Archibald, 1980). Deteriorating mental conditions are not well understood by caregivers, leading to ambivalent or negative feelings (Archibald, 1980; Robinson & Thurston, 1979; Worchester & Quayhagen, 1983). The likelihood of institutionalization of the elderly increases as the caregiver's energy is expended, satisfaction with caregiving is diminished, and as the sense of burden and strain increase.

## Need for Research

Good care is individualized, based on knowledge of the individual's wishes, abilities, history, and family (Mace, 1987). With Alzheimer's disease there is progressive loss of functioning, but the relationship between wishes, abilities, history, family, and functioning has not been well explored.

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Despite estimates that a high percentage of persons in nursing homes and acute care facilities suffer from premature loss of functioning, research is lacking on its prevalence among persons with dementia, and on response to treatment (Cook-Deegan, Mace, Baily, Chavkin, & Hawes, 1988). Studies done to this point have occurred in institutional settings, leaving the family caregiving system without data on prevention, assessment, and elimination of premature loss of functioning in the home setting. More research is needed on assessment and use of social abilities in the care of patients with Alzheimer's disease, especially as they relate to reversing or preventing premature loss of functioning (Dawson, Kline, Crinklaw-Wiancko, & Wells, 1986).

Research is needed on coping strategies of families providing home care for individuals with senile dementia, and their effect on caregiving (Cook-Deegan et al., 1988). Studies are needed that simultaneously focus on the characteristics of family caregivers and on the patient's functioning as it relates to dependence (Silliman & Sternberg, 1988). There is insufficient research on the experience and needs of families of Alzheimer's victims, and on possible contributions of family reactions to manifestations of the disease in the patient (National Institute on Aging, 1984). If such research could enhance family caregiving capabilities and reduce the incidence of premature loss of functioning, the cost of care, in economic and social terms, could be reduced for both the family and society.

From a practice perspective it is imperative that health and human services professionals learn as much as possible about Alzheimer's disease and prevention of premature loss of functioning.

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> We are only beginning to understand that there are ways in which we can help persons with Alzheimer's disease and other forms of dementia. It is important that we continue to examine and test new approaches and programs in efforts to find methods to improve the quality of life for persons who are experiencing such a devastating illness (Coons, Sommers, & Vincent, 1986, p. 195).

Oral history has been acknowledged as a rich source of research data in anthropology, history, nursing, and social science (Hoopes, 1979; Leininger, 1985b; Watson & Watson-Franke, 1985). While there is agreement that life histories are important, there has been little agreement on how to use life histories, with the focus usually being on the individual or the culture (Leininger, 1985b; Watson et al., 1985).

Leininger (1985b) indicated health professionals have rarely used longitudinal life histories for research purposes, despite the fact that they regularly gather historical data from clients. She suggested life histories are extremely valuable for understanding factors affecting the health of individuals and the development of care behaviors, especially of the elderly. This research project represents an attempt to fill that gap, to determine the relevance of life history data to family care of a member with Alzheimer's disease.

## Historical Interest of the Researcher

As part of a doctoral course in ethnographic methods the investigator had the opportunity to consider how life history methods and analysis could be adapted for use with a caregiving spouse and her husband with a diagnosis of Alzheimer's disease. Data were gathered through observation, planned activities, and interviews. Life history data from the person with Alzheimer's disease and his caregivi

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caregiving spouse resulted in findings with potential relevance for facilitating family caregiving (Flatt, 1988; Flatt, 1989b).

Care Receiver

Data gathered during visits with the family revealed that historical interests of the victim of Alzheimer's disease persisted over time, but participation in activities related to those interests was dependent upon the family's ability to adapt to current changing functional ability of the member with Alzheimer's disease. The primary caregiver, and other family members, responded in one of four ways to changing functional ability.

1. Some activities were recognized as still within the capability of the person with Alzheimer's disease if supervised or facilitated by other family members (e.g.: outdoor work such as gardening).
2. Some activities were considered to be within the capability of the person with Alzheimer's disease despite observable behavioral evidence that his cognitive ability would not reasonably accommodate those activities (e.g.: reading a newspaper).
3. Some activities were recognized as outside of the current capabilities of the person with Alzheimer's disease (e.g.: hunting).
4. Some activities were considered to be outside of the capability of the victim of Alzheimer's disease despite the fact that adaptation of the activity to current functional ability levels was possible (e.g.: participating in social games).

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Comments made by the primary caregiver about various activities suggested that the first response resulted in a sense of control and satisfaction for both caregiver and care receiver, the second resulted in frustration for both, the third required protective behavior on the part of the caregiver, and the fourth resulted in premature loss of functioning.

### Care Provider

In this situation the care provider's expectations and feelings were, at least in part, affected by prior life events. More specifically, the primary caregiver described her current feelings and expectations of self and others in relation to prior experiences observing and participating in care of the aged and care of a family member with Alzheimer's disease. The perceived acceptability of caregiving resources within the community was dependent in part on prior experiences with similar services.

## Objectives

The main objective of this study was to analyze the relevance of life history to family care of a member with Alzheimer's Disease. Qualitative methodology was used to determine how life history data relate to current activities of the husband with Alzheimer's disease and his caregiving spouse. Data were collected through use of genograms, oral history and behavioral observations for purposes of developing grounded theory on family care.

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## Research Questions

The questions which this study was designed to answer are:

1. What type of personal historical data can be obtained from men with Alzheimer's disease, and their caregiving wives?
2. How do historical behavior patterns and experiences of these people relate to current behavior patterns and experiences with home care?

## Definitions

Due to the qualitative nature of the study, concepts initially identified were limited to those necessary for understanding the objective and research questions. Those concepts include family, caregiving, life history, behavioral observations, behavior patterns, experiences, and premature loss of functioning. Concepts were defined as follows, with further discussion of the concepts being provided in the next chapter with the review of the literature.

Family: the husband-wife dyad, living together.

Caregiving: actions taken to meet the physical, intellectual, emotional, and social needs of another.

Life history: oral summary of personal experiences throughout one's lifetime.

Behavioral observations: objective actions apparent to others.

Behavioral patterns: rhythmic routines occurring over time.

Experiences: life events of significance to the individual.

Premature loss of functioning: elimination of an activity from one's behavior pattern, despite the fact that one is still capable of performing that activity.

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## Research and Theoretical Perspectives

The review of the literature found in the next chapter summarizes research and theoretical perspectives initially considered pertinent to this study. Additional literature was reviewed as the study progressed, with much of it discussed in Chapter V.

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# CHAPTER II. REVIEW OF THE LITERATURE

What follows is information obtained in a preliminary literature review related to Alzheimer's disease as well as major concepts and theories which were initially perceived to have potential relevance to the study. With qualitative studies the actual relevance of literature to the findings can only be determined during data analysis. The information presented provides background data with which the emerging theory was compared. Information from literature reviewed after themes became apparent can be found in Chapter V through VII where it is integrated with the emerging theory, a process recommended by Glaser (1978).

## Alzheimer's Disease

As described by Merrill (1988) Alzheimer's disease is a neurological disorder characterized by deterioration of cognitive functions. It is a progressive and irreversible condition affecting a large number of middle-aged and elderly persons. A definitive diagnosis of Alzheimer's disease is only possible through examination of brain tissue during an autopsy. Therefore the diagnosis of living victims is dependent upon symptomatology and exclusion of other conditions which would result in dementia.

Memory loss is the earliest and most obvious symptom of Alzheimer's disease (Gruetzner, 1988). Recent memory is affected early, making it difficult for people with Alzheimer's disease to learn new activities. Remote memory, where personal history is recorded, remains intact much longer. Maintenance of daily routines

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routines provides organization and security for people with impairment in recent memory.

The comprehensive report of the Office of Technology Assessment (U.S. Congress, 1987) described four overlapping categories of symptoms found in persons with Alzheimer's disease: cognitive/neurological, functional, behavioral, and excess disabilities. Cognitive/neurological problems include memory loss, language problems (aphasia), motor disturbances (apraxia), disorders of perception (agnosia), impaired learning, and disorientation. Functional problems relate to impairment of ability to carry out activities of daily living. Behavioral problems include mood alterations as well as symptoms compatible with mental illness. Excess disability relates to the presence of other illnesses, delirium, sensory impairment, external stressors, and the premature loss of functioning incorrectly attributed to the debilitation of dementia.

## Concepts

### Family

The family has been defined in a variety of ways, based on the conceptual framework of interest to the person or persons providing the definition. Some examples follow.

> A bonded unit of interacting and interdependent persons who have some common goals and resources, and for part of the life cycle, at least, share living space (Andrews, Bubolz, & Paolucci, 1980, p. 32).
>
> Family: two or more persons related by marriage, blood, birth, or adoption. Structurally a family is a set of positions each of which is composed of roles, which in turn are composed of norms; dynamically a family is a system of role complexes played sequentially to form a set of related careers (Duvall & Miller, 1985, p. 406).

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> Family: a semi-closed, mutually interacting system of individuals characterized by long-term, intimate, reciprocal relationships, usually by blood, marriage, or adoption (Melson, 1980, p. 212).

Based on critical elements of these definitions this investigator prefers to define the family as a group of interacting and interdependent persons related by birth or choice, whose central purpose is to create and maintain a common culture which promotes the physical, intellectual, emotional, and social development of each of its members (Flatt, 1989a).

This definition is broad in scope, applicable to a wide variety of groups who consider themselves families. It has structural and functional components. Structurally there is a need for more than one individual. Functionally it requires interaction, interdependence, and purposefulness. The common culture of the family is reflected in norms, roles, and other factors that bind the group together into a whole. Using this definition, at least two members are required for a family to exist. Likewise, a group that does not carry out the functions listed in the definition would not be considered a family.

### Family Care

Care is a term that is often used, but difficult to define. Based on her research related to care, Leininger (1984) defined it as "those assistive, supportive, or facilitative acts toward or for another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway" (p. 4). Greensburg-Edelstein (1986) suggested nurturance is made up of caring and helping, that nurturance is fundamental to human relationships and groups. She suggeste

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suggested any interactions that build unity and support can be considered nurturant.

Within a family unit care is provided and received, with the care provider being referred to in the literature as the caregiver and the care receiver being referred to as the recipient of care. Research on family care of the frail elderly indicates that the givers and receivers of care form dyads, which are essential to maintenance of the infirm elderly within the family unit. The majority of caregivers are women (72%), with adult daughters accounting for 29% and wives 23% (Stone, Cafferata, and Sangl, 1987). When the disabled individual is married the caregiver is usually the spouse, most often the wife (U.S. Congress, 1987).

Behavioral problems such as wandering, agitation, and angry outbursts are often more burdensome to family caregivers than memory and intellectual difficulties (Cook-Deegan & Whitehouse, 1987). Such behaviors may incorrectly be attributed to irreversible cognitive impairment when they are actually due to reversible conditions, such as pressing physiologic need or inadequate social or sensory stimulation (Dawson, et al., 1986).

Family caregivers inaccurately attributing behavior change to irreversible cognitive impairment may promote "excess disability", defined as impairments in functioning that exceed disability attributable to the underlying condition (Brody, Kleban, Lawton, & Silverman, 1971). When the family is no longer able to provide care and seeks institutional care, improvement in functioning can occur. The documented "improvement" among demented nursing home residents may be more accurately described as elimination of excess disability (U.S. Congress, 1987).

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Toseland, Derico, and Owen (1984) provided some indication of why families might promote premature loss of functioning. They noted that as a demented person's functional level declines, caregivers can find it easier to take on tasks rather than help the demented individual to do as much as possible. Family caregivers may not be able to assess accurately the actual functional limitations of the demented person. They may not know how to organize and assist with activities rather than eliminating the activity from the demented person's skill repertoire.

Families providing care for victims of Alzheimer's disease find that the burdens of care change over time, with some families reporting it is easier to care for a bedfast patient in the late stages of Alzheimer's disease than to care for one who is agitated and wanders (Cook-Deegan et al., 1988). If limitation of idle time can diminish the wandering, the burden on families can be lessened.

### Excess Disability

The concept of excess disability was introduced by Kahn in 1965. Brody et al. (1971) studied excess disabilities in institutionalized elderly who were mentally impaired. The found that apathy, isolation, and regressed behavior could be reduced and social relationships enhanced with intervention. Improvements in functional abilities and quality of life occurred despite general declines in health status. This was accomplished through the development and use of treatment plans focusing on the individual's unique traits, personality, history, and current potential strengths.

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Dawson et al. (1986) studied nursing interventions that promote self care and socialization in nursing home residents, thereby preventing and reversing excess disability. They found that excess disabilities could be reduced and a sense of competency enhanced by focusing on the dominant stimuli of familiar activities.

The most current information on the concept of excess disability of victims of Alzheimer's disease and related disorders is summarized in the work of the Office of Technology Assessment of the United States Congress (U.S. Congress, 1987; Cook-Deegan et al., 1988). Findings of research performed in residential and day treatment facilities provided the basis for information on excess disability. This research indicated most successful residential and day treatment programs are based upon common goals that include: prevention of excess disability, enhanced functioning, minimal idleness, activities that enhance self-worth, and individualized approaches. Data from programs specifically designed to provide care for persons with Alzheimer's disease and related disorders suggested that behavior improved as excess disabilities were addressed. Data from all specialized programs indicated that activities that are meaningful and individualized are a key to success. Such activities result in decreased wandering, agitation, inappropriate behavior, depression, hallucinations, and incontinence as well as minimal use of psychotropic drugs and improved orientation, weight gain, sleep, humor, relaxation, and socialization.

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## Continuity Theory

The Duke Longitudinal Studies of Normal Aging and the Baltimore Longitudinal Study of Aging (Busse & Maddox, 1985; Shock, Greulich, Andres, Arenberg, Costa, Lakatta, & Tobin, 1984) provide strong support for continuity theory which indicates that personality tends to be stable over time. Continuity theory provides the framework which explains stability of habits, behaviors, and preferences throughout the lifespan (Burbank, 1986). It indicates that lifelong experiences predispose people to behave in an individualized, but predictable, fashion. This predisposition evolves from interactions among personal preferences, biological and psychological capacity, situations opportunities, and experiences (Atchley, 1972). It provides a stabilizing force that can help the individual maintain a sense of security even while adapting to change.

Continuity is manifested in internal and external forms (Atchley, 1989). Internal continuity is based on a person's understanding that the current sense of self is connected to the individual's past. External continuity is based on interaction with familiar physical or social environments, including participation in familiar activities. Internal continuity provides the psychic structure and external continuity provides the environmental structure that support stability in times of change. Discontinuity in either realm can lead to mental health problems if knowledge or skill essential to the core of one's identity is lost.

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## Ecological Theory

Bronfenbrenner (1977) suggested that an ecosystems approach to human studies is needed if we are to understand the relationship between humans and the environment. He conceived of the ecological environment as a nested arrangement of structures, each contained within the next. The four levels he identified are the microsystem, mesosystem, exosystem, and macrosystem.

The microsystem within which the human interacts is made up of those persons, places, and activities immediately surrounding the individual. The mesosystem is composed of the linkages between the microsystems with which the individual regularly interacts. The exosystem, an extension of the mesosystem, is composed of the major structures of society which influence behavior and development of individuals, often through indirect means. The macrosystem refers to the overarching patterns of values and institutions upon which society is based.

The micro and mesosystems are the environments in which care of individuals is provided, and families are the primary caregiving system for people with Alzheimer's disease. The family ecosystem thus becomes the system of interest in studies of family care. The environment of interest in such studies is the near environment, defined by Bubolz, Eicher, and Sontag (1979) as "that part of the environment closest physically, psychologically, and socially to human beings." (p. 31).

Bubolz, Eicher, and Sontag (1979) further differentiated the environment into natural, human constructed, and human behavioral components. Each of those components of the environment relates to family systems. The natural

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phenomena of time, space and energy were identified by Kantor and Lehr (1975) as dimensions through which families gain access to affect, power, and meaning. The human constructed phenomenon of sociocultural patterns can be studied in relation to family care. Human behavioral phenomena can be related to functional abilities and activities of those who give and receive care.

In their study of four types of families McCubbin, Thompson, Pirner, and McCubbin (1988) found that family time and routines were highly valued throughout the life cycle. Family routines were seen as stabilizing factors that evolved over time, providing families with a sense of predictability and control in their daily life. Routines were identified as playing a vital role in family development and in strengthening family life. Families in the empty nest and retirement stages of life placed high value on their routines. Findings from this study indicated family time and routines were less influenced by prior experiences and practices than by immediate and current demands. The researchers suggested family time and routines may well be the most viable strategy families have to maintain a sense of continuity and structure when faced with change.

One of the family system typologies described by McCubbin et al. (1988) is the rhythmic model of the family. Within that model are four family types, with rhythmic families being those who foster development of predictable activities and routines which provide family members with a sense of meaning and purpose. Olson, Sprenkle, and Russell (1979) suggested the most viable family systems are those that maintain a balance between stability and change.

## Rogers' Science of Unitary Human Beings

Rogers wrote An Introduction to the Theoretical Basis of Nursing in 1970. She has been refining her framework since that time, and by 1983 identified her framework as a paradigm equally applicable to families as to individual human beings (Rogers, 1983). Unitary human beings are seen as irreducible wholes. Human beings and the environment in which they live are seen as two distinct, unbounded, and irreducible energy fields. These energy fields are described as open systems experiencing a constant interchange of energy. Each energy field is identified by a dynamic, negentropic, changing pattern. Change is seen as continuous and innovative, occurring in rhythmic waves. The human field is described as existing in an abstract four-dimensional "relative present" which transcends the spatial and temporal domain of the real world (Rogers, 1983, p. 222).

Rogers (1983) described a family as an energy field distinct from that of its members, identified by rhythmically changing patterns occurring in the relative present. Individuals within the family are recognized as part of the environment of other family members. Whall (1981) suggested that human development is characterized by rhythmic patterning and repatterning. Influenced to some extent by previous experience. She indicated there are times the pattern of one family member may not be in synchrony with those of others, leading to intense energy expenditure within the family unit. Fawcett (1975) suggested the family system is identified by the visible portion of its pattern and organization.

Rogers (1970) indicated professional nursing practice should promote synchrony between man and environment, strengthen the human field, and assist with patterning and repatterning of the human and environmental fields to optimize health potential. She recognized man as the "expression of the totality of events present at that point in time", indicating the relevance of past to present (Rogers, 1970, p. 57). She suggested the rhythmicity of activities of daily living provides opportunities for consistency and repatterning. She indicated health is promoted by assisting people in developing patterns of living consistent with their individual characteristics and with their changing environment (Rogers, 1970).

## Research Structure

The literature described in this chapter provided a structure within which subsequent data analysis was organized. That analysis can be found in the last three chapters of this dissertation. The research methodology and data collection techniques described in the next chapter provided structure for the data gathering process.

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# CHAPTER III. RESEARCH METHODOLOGY

Within the last decade qualitative methodology has gained recognition as a valid scientific approach to use if human experiences are to be studied from a holistic perspective (Tinkle & Beaton, 1983). Erikson (1982) suggested that human existence is best studied using a qualitative psychosocial approach that focuses on developmental and historical relativity. He suggested that such research could enhance understanding of how the changing environment affects basic human strengths and weaknesses. Qualitative research has proven useful in the field of gerontology. It has produced descriptive data that refute stereotypes related to aging and contribute to our understanding of meaning, values, intentions, and behavior patterns evident in life experiences (Rowles & Reinharz, 1988). Qualitative methodology was therefore considered appropriate to use in this study, which was designed to determine the relevance of life history to family care of a member with Alzheimer's disease.

A combination of ethnographic data collection methods was used to gather data on historical, current, and projected future experiences and activities of husbands with Alzheimer's disease and their caregiving wives. Such a combination of qualitative approaches has been used effectively by others (Hutchinson & Webb, 1989). This chapter provides an explanation of life history as a research methodology followed by information on how informants were obtained and the combination of data gathering approaches used.

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## Life History

A life history is the retrospective account of all or some of the life events of an individual. Life histories can be autobiographical or biographical in nature, focusing on oneself or others (Leininger, 1985b). The informant is asked to discuss life events using a chronological format (Agar, 1980). Participation in the process of providing life histories can have a therapeutic effect for the informant as some recollections bring pain, but others bring joy (Leininger, 1985b).

Merriam (1989) found that reminiscenses commonly include four stages: selection, immersion, withdrawal, and closure. When promoted by a stimulus such as an interview question, the reminiscer sorts through multiple memories and selects a particularly emotional experience to relate. Once selection has occurred, reminiscers immerse themselves in the past, providing graphic descriptions. As the person withdraws from the memory, details become less vivid and reflection on its relationship to the present may occur. Closure involves a summing up, in which the reminiscer shares a general truth or bit of wisdom related to the memory.

Life history methodology is an appropriate technique to use in studies investigating the ways in which individuals account for their actions (Jones, 1983). Analysis of life histories helps identify longitudinal patterns of living related to care and health (Leininger, 1985a). There is no uniform approach recommended for analysis of data obtained through life history, other than a simple edited presentation of the narrative (Agar, 1980). Spradley (1979) suggested the words,

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phrases, and sentences of the informant must be analyzed so individualized concepts and meanings can be described as closely as possible.

## Obtaining Informants

Informants for this study were obtained through the mid-Michigan chapter of the Alzheimer's Disease and Related Disorders Association, Inc. The president of the chapter placed a notice of the need for research participants in the chapter newsletter. She also provided names of support group leaders throughout the region. Each of these individuals was contacted. A few indicated they had no members who met the criteria required for participants in this study, so their groups were not visited. Six support groups were visited, with a total of ten families being obtained from those groups.

Three of the support groups met in urban areas, and three in rural areas. Two urban groups had social workers as leaders, and the other urban group had a nurse who attended meetings regularly. All rural groups were led by nonprofessional leaders who had personal experience dealing with Alzheimer's disease. Participants for this study were obtained from five of these groups, with none coming from one urban group.

Ten families participated in the study. Five families lived in a city or town of the size indicated in Table 1 (McNally, 1990). The remaining five families lived in rural settings.

Table 1: Location of Families

| Community of Residence | Number of Families |
|---|---|
| City of 73,000 | 3 |
| Town of 2,700 | 1 |
| Town of 1,025 | 1 |
| Rural | 5 |

Five of the wives who became informants and one husband were present at support group meetings attended by the researcher, and agreed to participate in the study at that time. Four additional families were obtained after group leaders provided the researcher with phone numbers of absent group members who met the research criteria. Information on an additional family, the only one with no contact with a support group, was provided by a niece who was at the third group meeting attended by the researcher. Families not present at support group meetings attended by the researcher were contacted by phone by the researcher or the support group leader to determine their willingness to participate in the study.

Families were screened to assure they met the following criteria established for the study. Dyads studied were composed of a husband with a diagnosis of Alzheimer's disease, and a wife who was the primary person caring for him. Each diagnosis was made at least six months prior to participation in the research project, and each marriage existed for at least ten years prior to the diagnosis. Each dyad lived together. Husbands were at least sixty years of age, and were capable of verbal conversation with strangers. Selection of families which met these criteria resulted in a theoretical sample (Glaser, 1978; Glaser & Strauss, 1967; Morse, 1989).

All but one family met the criteria that there be no other family member living with them as a permanent resident. That family had a grown son who had moved back with his parents following a divorce. Since he worked long hours, his availability to the caregiver was comparable to that of a daughter whose family lived next door to another dyad in the study. Data from the family with a son in residence were similar to those obtained from other families, so they were included in the study.

The number of families to be included in the study was to be determined when theoretical saturation occurred. Theoretical saturation exists when patterns of data are repeatedly found, and additional data gathering would not add anything new to the findings (Glaser, 1978; Glaser & Strauss, 1967). Due to the small number of families agreeing to participate in the study, data were gathered on all of them in spite of the fact that patterns began emerging long before ten families were studied.

## Data Collection Techniques

As soon as contact was made with informants, data collection began. Visits to support groups occurred from May 12 to June 12, 1990. Home visits began on May 16 and continued through November 27, 1990. Information obtained with the consent to participate in research included names, ages, birth dates, date of marriage, time of diagnosis of Alzheimer's disease, husband's medications (See Appendix A). When appointments were made to visit families, they also were asked if the husband knew of his diagnosis, if the family spoke about his condition in his presence, and how he dealt with such openness. That information was used to guide communications occurring with the husband present. During the home visit, data were gathered through construction of a genogram, interviews designed from a life history perspective, and participant observation. Verbal interactions in the home were recorded on audio tape which was later transcribed into field notes.

### Genogram

Holman (1983) and Hartman (1979), whose books include instructions on how to construct and use genograms, agree that the genogram is a useful assessment tool for gathering and organizing family history. A genogram is a diagram of a family's relationship system, based on the concept of a family tree. It typically contains information describing how three or more generations of a family are related.

At the beginning of the session with each family a genogram was constructed to provide the investigator with a framework for understanding the family system. Explanations provided for families are found in Appendix B. The form used, with a simulated genogram provided as an example, is in Appendix C. With both informants present, data were gathered on their families or origin and family of procreation. Occupational data provided baseline information on interests and talents (Hartman, 1979). Family members with Alzheimer's disease and family members currently or previously involved in caregiving were identified; unless these data were supplied willingly in the joint session, questions related to this were held until the wife was being interviewed. Later, during interviews with wives, lessons learned from these people and their impact on the current caregiving situation were explored.

### Interviews

Following genogram construction, ethnographic interviews were conducted with husbands and then with wives. Since the content of answers may be changed if the spouse is present, and the spouse may interrupt answers, attempts were made to conduct interviews with the spouse absent. Husbands were interviewed first, with wives absent. Caregivers were asked to help determine how their part of the interview could be conducted with the demented person absent or otherwise occupied. In most cases this occurred, but three felt it did not matter as their husband would not remember or relate to what was being said. Men present during the wife's interview did not exhibit signs of distress due to this arrangement. One dozed as his wife was interviewed beside him.

Three types of ethnographic questions have been identified by Spradley (1979); they are descriptive, structural, and contrast questions. Questions of each of these types were included in the interviews. Descriptive questions were used to gain personal descriptions of historic and current experiences, in the words of the informants. Structural questions were used to gather data within domains such as activities and experiences. Contrast questions were used to explore meaning, as in comparing historic activities and experiences with their current counterpart.

Examples of such questions follow. The interview guide can be found with other communication guides in Appendix B.

Descriptive: How would you describe yourself at this point in time?

Structural: How did you spend most of your time as a young adult?

Contrast: What was the happiest day of your life? What was the saddest day of your life?

### Participant-Observation

While in the home setting the investigator functioned as a participant observer. Family artifacts such as pictures, awards, crafts, and family trees were discussed. Observations were made related to functioning of the recipient of care and interaction patterns between the giver and receiver of care. The investigator did not rely solely on the interview guide, but interacted with informants in related conversations and activities.

## Data Analysis and Synthesis

Data were analyzed for cultural themes as described by Spradley (1979). He suggested cultural themes can be tacit or explicit, recurring in a number of domains and providing a meaning framework within which subthemes can be understood. Initially all themes must be identified. The culture examined in this study was that of families providing home care. The constant comparative method of Glaser & Strauss (1967) was used to help identify themes. The method involves four activities which are engaged in until the analysis is terminated. Incidents are compared and placed into categories. Relationships between incidents in a category and between categories themselves are explored. As the theory begins to emerge, both categories and potential theoretical frameworks are reduced and a cohesive framework emerges related to specific theory. While writing begins at the first level, the final writing of the theory is dependent upon successful completion of each of the subsequent stages.

Following sessions with informants, data were transcribed from audio tapes as soon as possible. Analysis began as soon as data were obtained, a practice common to ethnographic and grounded theory methods (Brink, 1989). Information on genograms was confirmed or clarified through comparison with information provided on tapes. As interviews were being transcribed, the genograms proved useful in helping clarify who the speaker was talking about when a family member was mentioned by name. The transcription process resulted in 185 pages of single spaced data and proved to be quite time consuming. Data were then resorted so comparisons could be made within and between families using initial categories identified from genograms and main questions.

Relationships between incidents in a category and between categories were identified as genogram data and data on each interview question were pulled out of transcripts, resulting in further compression. The categories into which data were initially placed were consistent with questions asked in the interview process. Initially the data were compressed to 69 single spaced pages. Those pages did not include all of the data on the current life events of these families, as described by wives. Information on that topic was so extensive that original transcriptions were marked to assist in identifying relationships. Further reduction of all of the data resulted in 54 pages of research findings related to categories.

As themes began to emerge, the literature was reexamined in an effort to clarify what was being found and its relation to existing theory. The analysis of the data in relation to theory continued well beyond the time required for data gathering and transcription. Continued reexamination of theory in relation to the findings eventually resulted in identification of main and supporting themes which form the framework for the grounded theory suggested by this study.

## Validity and Reliability

Validity and reliability are measured differently in qualitative research than they are in its quantitative counterpart. Qualitative validity is present when the data are sufficient to provide knowledge and understanding of the phenomena under study (Leininger, 1985a). In qualitative research content validity is dependent upon the ability of the investigator to find congruency, meanings, and relationships in the data; predictive validity is dependent upon the ability of the investigator to identify abstract and empirical data that predict human behavior (Leininger, 1985a).

The variety of methods designed to obtain data in this study provided the investigator with the opportunity to use triangulation for purposes of validation. Triangulation involves the verification of findings through comparison of those from one method, or one source, with those from other methods or sources (Brink, 1989). Data obtained during construction of the genogram were compared with that obtained during interviews. The accuracy of factual data obtained from informants with Alzheimer's disease was often validated or invalidated by the primary caregiver. Objective data gained through observations of interactions and activities were compared with subjective data obtained from informants. Tape recordings of conversations were used to assure accuracy of documentation of content of conversations. All data from the caregiver and opinions from the individual with Alzheimer's disease were considered valid current individual perceptions.

In qualitative research, reliability is present when patterns or themes can be documented with the data (Leininger, 1985a). Reliability was enhanced when informants were asked to rephrase or elaborate on what they had said. Multiple examples of the same data in one family, and comparable findings in additional families, established the reliability of findings.

Prior to family contact the investigator developed research guides, including one for communications occurring with informants, which can be found in Appendices A, B, and C. Each of the guides, used by the sole investigator, provided as much consistency in the data gathering processes as is appropriate for a qualitative study. Questions included in the guide for ethnographic interviews were either used in a previous study (Flatt, 1988), or were designed to provide additional data suggested as needed when results of that study were analyzed (Flatt, 1989b).

When field notes were transcribed, activities of the investigator were noted and objective quotes were differentiated from subjective data in an effort to minimize bias. Results have been reported in the same manner to facilitate verification of findings.

## Protection of Human Subjects

The investigator in a qualitative research project is the major instrument affecting data collection, and must have a good understanding of "use of self" (Lipson, 1989). Lipson suggests psychiatric nursing skills which depend upon "therapeutic use of self" can provide excellent preparation for ethnography, where investigators must understand how their own behavior affects data gathering and analysis. Specific skills common to both nurses and ethnographers include establishment of trusting relationships, interviewing, listening, observing, and interpreting on several levels simultaneously (Lipson, 1989). Nurses value the worth and dignity of others, respecting their rights, which include the right of self-determination (American Association of Colleges of Nursing, 1986). The investigator for this study was a registered nurse with over 23 years of experience in the field, and with a master's degree in psychiatric nursing. The background proved to be sufficient to provide the interpersonal skills needed to conduct the study without causing harm to the informants.

Since half of the informants in this study were people with Alzheimer's disease, special precautions were taken to protect human subjects. Caregivers were required to sign a form indicating their willingness to participate with their spouse in the research project. The consent form explained the need for audio tapes and explained how data would be handled and disseminated. Due to the dementia present in half of the informants, they were not asked to sign the consent form, although one requested and was granted the opportunity to do so. Instead they were informed verbally of the intent of the investigator, and their participation in the interview process was regarded as implied consent to participate in the research project. Procedures used in this study were approved at Michigan State University by the University Committee on Research Involving Human Subjects (UCRIHS) on April 2, 1990.

Fatigue, anxiety, or emotional reactions can alter the data (Deatrick & Faux, 1989), so attempts were made to minimize these responses. Data collection plans were altered when anxiety was noted. For example, when one wife cried some questions were omitted and she was asked if she wanted to continue, which she did.

The demented person's knowledge of the diagnosis of Alzheimer's disease, the openness of family communications about the condition, and the response of the demented person to such communications were determined prior to the initial contact with the person with Alzheimer's disease. This information was used by the interviewer to determine the type of data to be collected in the presence or absence of the demented individual. Protective communication patterns developed by caregivers were not violated.

At the beginning of the research project informants were advised that the role of the investigator was that of researcher. If data had been obtained that suggested health care intervention was needed by the family, recommendations of that nature would have been given after the life history data were collected. Leininger (1985b) indicates it is appropriate to handle such situations in that way "since in qualitative nursing research, the researcher is not expected to remain totally detached and nonresponsive to the people being studied" (p. 130).

Confidentiality was maintained through the following means. The names and addresses of informants were kept on file by the investigator for the duration of the research and were not shared with others. All field notes, memos, and tapes were identified using initials of informants. Data were stored in the investigator's office when not being used for research or educational purposes. Any publication or presentation of data from this study will not include information that could be used to identify informants.

## Risk/Benefit Analysis

There are inherent risks in any research project, but this study did not pose any greater risk to the families being studied than would interactions with other human service professionals. The data gathering techniques had been utilized with a family of the type to be studied, with positive effects (Flatt, 1988). The procedures used in this study were not invasive and were flexible enough to allow for adaptation to respect the rights of informants.

Leininger (1985b) indicates informants often experience marked therapeutic effects in the process of describing their life histories. While it cannot be stated that this definitely occurred, most women in this study were eager to share information with the researcher. Some began providing information before research questions could be posed, and others continued to provide data long after all research questions had been answered.

In addition to individual benefits which informants may have experienced, society may benefit from this study. Data were obtained that can help human services professionals and policy makers understand factors affecting home care of Alzheimer's disease, factors that may contribute to a family's ability to provide home care and delay institutionalization. This study also provides data on the potential value of life history data to human services professionals working with the elderly.

## Limitations of the Study

This study was designed to produce qualitative data on the relevance of life history to family care of a member with Alzheimer's disease. Data on past and current experiences of individuals with Alzheimer's disease and their caregiving spouses were obtained. Data on people with other conditions or on other categories of caregivers were not obtained, but those populations could be the focus of future comparative studies.

In spite of the fact that a supportive agency was used as a source for informants, several participants had not been able to take advantage of support group activities and one was obtained who had no connection with the support group. Because of this sampling method informants were more diverse than had been expected, representing not only those who are actively seeking assistance from a support group but also those who have not yet determined that assistance is needed and those whose caregiving responsibilities prevent them from attending group meetings.

## Presentation of Research Findings

In succeeding chapters research data are utilized to describe the family dyads studied, the environment in which they lived, and the process by which grounded theory was developed. Initial data analysis led to identification of major themes which were then synthesized into grounded theory.

## CHAPTER IV. DESCRIPTION OF FAMILIES IN ENVIRONMENT

Descriptive data on the informants as a group are followed by a brief introduction of each family and the environment in which it lives. The families who participated in the study will be referred to as families 1 through 10 with numbers reflecting the numerical order in which they were visited. Information from husbands and wives will be identified with use of an H or W. Where clarification of material is needed to understand direct quotes, information provided by the researcher will be placed in parentheses.

### Descriptive Data on Families

Genograms and questions asked when permission was granted to participate in this research provided descriptive information on research participants. As noted on Table 2 informants ranged from 61 to 89 years of age, with women consistently younger than their husbands.

Table 2: Informant Age by Gender

| Gender | Range | Mean |
|---|---|---|
| Men | 67-89 | 78 |
| Women | 61-81 | 73 |

Years married ranged from 21 to 58 years, averaging 44 years. This was a second marriage for husband 5 and wife 7, but their marriages to the present spouse were still lengthy at 32 and 21 years respectively.

Table 3 provides data on families of origin and families of procreation. Informants generally came from families of origin that were larger than their families of procreation. Two of the families were childless. Seven couples had grandchildren and three had great grandchildren. Most informants had experienced the death of at least one sibling.

Table 3: Patterns of Family Size

| Family of Origin | Range | Mean | Mean Living Sibs |
|---|---|---|---|
| Men | 2-14 | 6 | 1 |
| Women | 3-12 | 7 | 3 |
| **Family of Procreation** | | | |
| Children (n=8) | 1-8 | 4 | |
| Grandchildren (n=7) | 4-25 | 11 | |
| Great Grandchildren (n=3) | 1-31.5 | 13 | |

## Families in Environment

A brief description follows of each family and the environment in which it was found, as well as a description of individual patterns of response to the research process. These data provide a backdrop from which these families can be better understood.

### Family #1

The first family lives in a ranch home in the city, a home they have lived in for 23 years. When the researcher arrived they were watching a soap opera in a bedroom used as a TV room. After a brief greeting the tape recorder was set up at the kitchen table where most data were collected. The kitchen had a sliding glass door covered with sun catchers that the husband had made in his younger years. Another room with a TV had a wall covered with golf trophies and other awards. This is the room to which the husband went as his wife was interviewed.

Most of the husband's answers were very quiet, almost in a whisper. The volume rose and his voice broke once, when he spoke of his experience in World War II. He spoke in complete sentences, stuck to the topic, and was easy to understand but memories of some facts had faded. He needed prodding to remember names of his mother and brother, but did remember his father. He willingly followed his wife's suggestion to go watch TV while she was interviewed.

At the time of the interview the wife was receiving rehabilitative treatment for a heart ailment that had resulted in her hospitalization. She cried often during the interview, regardless of the questions asked. The researcher skipped some questions, and asked if others were troubling her. She said, "I just get these spells..." and continued providing information, even after questioning had stopped. She brought out pictures of her husband and herself on camping trips they used to take in the western states.

This couple maintains regular contacts with a niece and their only daughter. "She calls every day or else stops in, or we go there. She only lives two miles down the road." (W) About neighbors the wife said, "Of course the neighbors all offer to help, but I just never ask them."

### Family #2

The second family lives in a small ranch style home in the same city as family #1. The women from these two families had attended school together in their youth, growing up in this community. After retirement this couple moved to the Upper Peninsula for 12 years. They have lived in their current home for only 2 years. Their daughter and her family now live in their prior home in this city. Pictures of family members hang on the living room wall.

The husband was napping in a living room chair in front of the television as the researcher entered. He willingly moved to the kitchen table where interviews occurred. He could not remember names or ages of family members, but spoke repeatedly about the railroad on which he worked for 37 years. Both his father and son were railroad workers.

When interviewed alone this husband kept asking where his wife went, but he did not leave the table at which we sat until he was told the interview was over and was asked where his wife might have gone. About half way through his interview he expressed some confusion or concern about "what you're trying to figure out."

Before leaving her husband in the living room to watch TV during her interview, the wife made sure her husband had his cigarettes and knew the location of his ashtray. She said the doctor felt that since he would never before give up cigarettes there was no point in trying to break the habit now, even though it was causing her husband to have some circulatory problems.

During the wife's interview her husband came into the kitchen four times. On his first trip in she suspected he had a physical need.

W: You want to go to the bathroom?

H: Yeah, where is it?

W: Right down the hall. (She had to get up and point out the way to the bathroom.)

On his second trip in she asked how the ball game was going and sent him back to watch it in the living room. The third time she determined he was looking for his lighter since he was holding an almost empty cigarette pack. She reminded him the lighter must be in the living room. His last trip into the kitchen occurred as the interview was ending.

The wife willingly shared a great deal of information with the researcher. She seemed to enjoy the opportunity to talk, and even asked if the researcher would be coming to support group meetings in the future.

She indicated she sees one of her sisters weekly and regularly sees her children. Their oldest daughter "lives a mile away, and she stops in every other day or so." (W) The middle son "works on the railroad, so we don't see him quite as often, but his wife comes every week or calls a couple, three times a week." (W) The youngest son moved in with this couple 7 months ago, following a divorce. He "stays here with us since I needed help." (W)

## Family #3

The third family lives in a small ranch style home in the country with a 30 acre lot and a large garden plot. The wife indicated the plot used to be much bigger when her husband was able to help with it. The house was built by the husband and a few other men as a retirement home, which the couple moved into 13 years ago. At that time the couple moved from the Detroit area to their current location, a few miles from the home where the husband had grown up.

When the researcher arrived the wife was watching her husband rake fallen branches in the yard. While outside the wife pointed out a burned spot on the lawn. She indicated her husband had set a fire that morning. He had a hearing aid and needed to be asked repeatedly to come into the house. She indicated he might not have the hearing aid turned up.

Once inside the house, everybody sat at the kitchen table. The husband fell asleep in his chair as genogram information was gathered. His memory for factual data was not good, even with prodding. He did not remember how he earned a living, or anything about his fourteen siblings. He did remember his parents' names, but incorrectly indicated they were still living. His wife remembered each of her 12 siblings, but was only able to supply information on his six living siblings, "I don't know too much about his family." (W)

During the husband's interview the wife left the room. When time came for her interview she was asked if there was a safe place for her husband to be left alone. She replied, "Doesn't matter really. He wouldn't remember anything anyway." He remained at the table, dozing through most of her interview, eventually getting up to go outside. This wife seemed guarded, answering questions without embellishment until she spoke of petty feuding that occurs among his relatives who live in the area.

This is a childless couple with limited family support. Speaking of his relatives, the wife indicated, "They live up around here, but they aren't much to visit or anything like that. The only way we see them is when we go up there to see 'em" or when one of the men comes to mow the lawn. They do see his sister about once a week. Her lack of closeness with relatives is a family pattern that has existed over generations. This woman experienced many family deaths in her youth including the loss of her mother at age 19, yet she never knew her father had a brother and sister until she was in her twenties and the devastation of a tornado brought the relatives together.

## Family #4

The fourth family lives in a cottage in the woods. It is found at the end of a mile long dirt road with three other cottages or trailers. Wood is stacked high in a shed behind the home. There is a small detached garage. The home was crowded with possessions. At the time of the interview a daughter was visiting with her newly adopted infant. After brief introductions, the daughter went to the bedroom area with her child while data were gathered at the kitchen table. This woman was eager to talk from the moment the researcher arrived until she left, and at the end of the session she invited the researcher to return.

The husband, while very verbose, was often hard to understand because he exhibited glossolalia, "repetition of senseless remarks not related to the subject or situation involved" (Taber, 1962). He would speak in disconnected sentences or begin a sentence that would quickly transform to gibberish that could not be understood either by the researcher or his wife. At one point he asked, "Hear that?" when he heard the hum of the tape recorder. When the researcher explained the source of the noise his humor was apparent as he said, "Good thing I didn't punch that," referring to the button on the tape recorder. When told his interview was over and his wife was needed he went to get her, and his daughter took him with her to watch TV.

Originally from Alabama, this couple had settled in southeastern Michigan, where their four children still live. "Since he's sick each one will come up one weekend a month." (W) While the children provide some support, this wife does not feel she can leave her husband with them because, "He cries when I leave and I'm not around." (W)

### Family #5

The fifth family lives in a ranch style home in the same city as families 1 and 2. The husband was outside puttering in the yard as the researcher approached. As he was about to open the door to his home he asked the researcher to guess his age. He looked ten years younger than his 81 years.

The researcher was ushered into a chair in the living room and the couple began sharing information on their educational backgrounds and how they met. After several minutes the researcher suggested a move to the kitchen table where the tape recorder could be set up. Facts provided in the living room were repeated many times during the interview process. Each earned a master's degree and worked in a human services profession. Each was anxious to share information on history and achievements, and expressed pride at being able to participate in a research project related to aging. During her individual interview the wife said, "Some day we'll know more about (Alzheimer's disease), and I will do everything in my power to do what needs to be done to find out."

This husband was able to recall most information on family members. He spoke with pride of their educational and career achievements, as well as his own. He was articulate, but repetitive in his answers. He knows that his younger sister has Alzheimer's disease, but is not aware of his own diagnosis.

This wife grew up in the Detroit area, the daughter of immigrants whose only other relatives remained in Europe. This is a childless couple. They see his sister about once a month, and one of her nieces regularly.

Family #6

The sixth family lives in a ranch style home on a country road with few other homes nearby. The couple built this home with the help of their children. One of their daughters lives next door in a similar home. There is a large garden in the space in front of and between the two houses.

The husband opened the door and invited in the researcher. A granddaughter from next door was visiting. In the living room were hand-made dolls with porcelain heads, home-made quilts, and needlework made by the wife. She said she had to keep busy with these things for her own sake.

While gathering genogram information at the kitchen table the wife brought out the family tree she had been working on to help her remember names and ages. With 6 children, 25 grandchildren, and 31.5 great grandchildren it was a lengthy family tree.

> W: I'm making a copy for each one of my kids for the simple reason that now in school they're asking for this stuff. You go to the doctor's office, they want to know everything. Just like my family. My Mom's been gone since '61. Then they start doing this. Well now I can't get anything. (W)

The husband could not remember information on his siblings or his children. He remembered his father's name, but often referred to his wife for information, such as his own age. His father died at a state mental hospital of what this wife now believes was Alzheimer's disease. A cousin, about the same age as the husband, is in a nursing home. "He is the same way. He evidently got to the point where he didn't know." (W)

According to the wife her husband has hearing aids which he will not wear. "He didn't understand enough about turning it up or turning it down." (W)

During the wife's interview the husband went next door with his granddaughter, who often engages her grandfather in activities. Her older brother, 15 years old, spend his earliest years living with this couple. His grandfather's condition "bothers him a lot." (W) It also bothers a son who lives within 4 miles of them. He does not visit often because he had some negative experiences when his own grandparents were being cared for in his home while he was growing up. "He just can't accept it I guess. All of them work. So everybody's away." (W) Neighbors also work, leaving this couple to their own resources most of the time.

### Family #7

The seventh family lives in a mobile home in a fenced yard in the country. They have been here for all of the 21 years they have been married. There are other homes on the road, but behind them is farmland occupied by cows. The researcher arrived as breakfast dishes were being cleared. A son and his wife and baby were there, but were scheduled to go out for the morning.

Interviews occurred at the kitchen table. The husband knew he had Alzheimer's disease, so people could speak about it openly with him. He could not remember his family of origin or family of procreation with accuracy, so his wife provided information he could not recall. He could remember his father's name, but not his mother's. At one point he wanted a drink of water but could not find it, so he called his wife who took some from the refrigerator for him. The wife talked freely through the session, and afterward.

This wife sees her sisters weekly because they go together to visit their oldest sister whose husband is in a nursing home. This couple frequently sees their children and nieces and nephews, although the wife said, "My grandchildren could come around a little more often."

## Family #8

For the last 22 years the eighth couple has lived in a two story white frame house in the heart of the small town in and around which they grew up. The yard was neatly trimmed. A middle aged neighbor lives next door. The husband was dressed in a shirt and tie, his wife in a dress. In spite of the fact that he has been retired for 20 years, "he always was very fussy how he dressed, and maintains it now." (W) At 89 and 81 respectively, this husband and wife were the oldest couple interviewed.

Interviews occurred at an old oak table in the living room. As the microphone was being set up the husband grabbed the red foam covering the end and said, "Oh, oh, oh!" in a voice that sounded fearful or surprised. After being told it was OK that he touched it, and what it was he said, "I'm sorry. I couldn't believe it was as soft as it was." His voice was hard to understand at times for he spoke in very deep mumbles. He had a cane and walked with a limp. He is supposed to wear a hearing aid, but he misplaced it.

The wife began talking the moment the researcher entered the home, and didn't even stop when her husband interrupted as he did when feeling the microphone. The wife expressed great pride in being chosen to participate in a research project. "I feel quite complimented to be asked. We're just plain ordinary folks."

Before the wife left her husband for his individual interview she told him, "You are in safe hands. I am going to leave you, and you are to answer the questions now, so think well." At the end of her husband's interview he was asked if he knew where his wife was and she called out, "I'm coming. I couldn't get far enough away so I couldn't hear, but I didn't have to answer, and I didn't." She indicated it wouldn't matter if he stayed during her interview session, so he remained at the table.

This couple sees one of her sisters and their children about once a month. Their children take turns phoning, with one calling each night at supper time. Neighbors also provide support.

### Family #9

The ninth family lived in a cottage that could not be seen from the gravel road in front of it. The roof was sagging and exterior paint was peeling. No one answered either the front or back door, but the back door was slightly ajar. A yell from the researcher produced a faint reply, and upon entering and yelling again a voice replied, "Come in."

The home was filled with furniture, the remnants of life in a larger home from which they had moved 5 years before. A new carpet was rolled up in front of the sofa. There were well established cobwebs on surfaces. The couple emerged from a bedroom area, neither with hair combed. He was trying to buckle his belt. She spoke of wanting to have a garage sale, but not having time or help to get one going. "We have been here since 85... and I still haven't got those dressers into the bedrooms, and I need somebody to help me with the carpet and help me with the bed. So I just leave it. I'm not going to put any strain on anybody or myself either. People can take it or leave it." (W)

When the researcher looked for an electrical outlet for the tape recorder, the wife said few of them worked, but did point out a functioning outlet. The interview started in the living room, where the researcher was offered a straight backed chair as the couple sat on the sofa with cushions that hit the floor as this thin couple sat.

The husband's responses to questions were not always coherent or related to the topic. He was able to remember his father's name, but was confused about other members of his family of origin and family of procreation. The wife said she enjoyed having a chance to talk now, indicating in prior years her husband used to dominate the conversation. She proudly shared a granddaughter's art work.

She fixed tea and cheese and crackers while her husband was interviewed. After moving to the kitchen, her interview occurred around the table, with her husband present. She said the stove had two burners that didn't work, and her electric teakettle leaked. The kitchen ceiling had falling plasterboard, walls were cracked, and the floor sank in the middle.

This couple rarely sees siblings who still live in Canada, from which this couple emigrated early in their marriage. They see any of their children no more than four times a year.

As the researcher was leaving the wife accompanied her to the car, inviting her to return if in the area. She spoke of her husband's decision to buy this place as a retirement home, and of giving in to him. She suggested he was not thinking appropriately at that time. There were huge tree trunks in the woodpile which she said she could have had cut up, but that she was too "scotch" to pay for that service. She instead planned to cut them herself, as she had before, with her arthritic hands. She spoke of fixing up a second cottage they own, adding electricity and water so they can move there, a place heated by propane rather than wood. She repeatedly stated that money was not a problem for them.

### Family #10

The last family in this study live in a ranch style home on a small peninsula of land surrounded by a bending river. The home, in which they have lived for 23 years, is on the outskirts of a small town. There are bird feeders in the yard which the squirrels often pillage. Both husband and wife met the researcher at the door.

Interviews occurred at the table in the back of the living room. The wife brought out a listing of family information to help her remember facts for the genogram. "We were just looking at our history with our daughter this weekend." (W) Both husband and wife are of Finnish extraction and grew up in the Upper Peninsula of Michigan.

This husband has been told he has Alzheimer's disease. His responses to questions are clear, although he does repeat himself at times. He was able to engage in some social conversation and showed humor. He remembered some information on siblings and parents, but did not accurately state who was living. His wife often answered for him after determining this would be acceptable to the researcher. Several times during his wife's interview he entered or left the house. Each time his wife reminded him not to lock the door because he has repeatedly locked himself and his wife out of the house. She now has keys hidden around the property.

Two years ago the wife had a cerebral hemorrhage while in Florida, where this couple lived for three winters. Since her illness the couple sees their children often. "They're real concerned about us." (W) One daughter calls every week and the children of another take turns visiting, about one per week.

## Compression of Data

Data from each of the families described in this chapter were compressed into categories from which themes began to emerge. As the data were being gathered and analyzed, the literature was again reviewed for information relevant to data obtained. Data compression and analysis persisted until grounded theory was generated. The entire process is described in subsequent chapters.

# CHAPTER V. INITIAL DATA ANALYSIS

Initial data analysis activities involved establishing and analyzing categories, then returning to the literature to explore related research and theory. Described here are activities engaged in to that end.

## Establishing and Analyzing Categories

As interviews were conducted main questions provided the framework within which the content of responses was analyzed. The process resulted in identification of the following categories: people and events considered important by informants, experiences with family care, historic and current use of time, current feelings, and projections related to the future. Data on use of time were as extensive as that from all other categories. It was far easier and faster to analyze the relationships between incidents in other categories than it was to do so with data on use of time.

### Important People and Events

When asked which people had the greatest impact on their lives the most common response was the people who raised these individuals, followed by those who influenced their early development. Most husbands had difficulty articulating what was learned from these individuals, but most wives indicated they imparted the values of living honorably and being committed to others. Living honorably was indicated by responses related to honesty, truthfulness, integrity, knowing right from wrong, and sorting out the right thing to do. Commitment was described as helping others, working hard, sticking to things, taking care of things that have to be taken care of, and living for your family.

Events identified as important were limited to the themes of work and marriage for husbands, but wives added children, death of a mother, and accepting Christ as one's savior. Six of the eight women with children included events related to their offspring. Questions about the happiest event of one's life provided validation of the significance of the marriage to both and of children to the wife. When asked to identify the saddest event of one's life the overwhelming response was the death of relatives and the surprising finding was that only one woman's reply focused on Alzheimer's disease. Questions about their greatest source of pride again showed gender differences, with husbands speaking of work, parents, or their home and all but one of the wives with children speaking of them.

## Experiences with Family Care

When women were asked about prior experiences with family care, over half indicated they learned commitment to helping others, they observed care provided by others, and they had experience with shared family care responsibility. Intergenerational transfer of values and skills related to care was described, with some women speaking of observing and learning from care provided by a grandparent.

## Historic and Current Use of Time

Responses to questions about historic use of time resulted in gender specific responses, with men tending to focus on work and women describing activities related to their own development and to experiences with their family of procreation. Husbands tended to be unclear about current activities, but wives discussed current activities at length differentiating between what they would like to do with their time and the caregiving activities that instead occupied them 24 hours per day.

Accommodations to their changing situation were described in relation to activities of daily living, role change, and their increased need for external support. Protective actions described by wives included responses to dangers related to driving, wandering, and fire. Sources of support identified by wives included their faith, education, and people.

## Current Feelings

Requests for a self-description, an explanation of the best and worst aspects of their current experience, and their hopes for their children resulted in information on current feelings. Husbands provided brief self-descriptions. The only negative response was: "It's not easy to be a has been." (H5) Self descriptions provided by wives reflected a mixture of job, satisfaction, resignation, depression, and confusion. The difficulty of their situation was clear in most responses, but so was their commitment to caring for their husbands.

Husbands providing information on the best aspect of their current life situation mentioned how good it was to be alive or in a meaningful relationship. One man identified his Alzheimer's disease as the worst aspect of his current situation and another mentioned aging, but additional comments made by them suggest they do not consider their life to be bad. Most men did not identify anything bad about their situation.

Most women were able to identify something good that they were experiencing. With some it was something to look forward to, for others it related to pride in what they were doing. In contrast to their responses to the question about the saddest event of their lives, most women spoke of their husband's condition as the worst aspect of their current situation. They expressed concern about bad days, progressive deterioration, safety, and effects of the illness upon themselves.

Men expressed pride in their children's behavior and education. Both men and women were proud of the support provided them by their children. Women were proud that children had learned values related to living honorably and caring for others.

### Future Projections

Men were not able to identify how their current situation might change in the future. Wives, on the other hand, were concerned about their finances and the inevitable declines in health of both partners. They spoke of actions planned or taken with regard to legal matters, decisions related to the caregiving environment, and the eventual death of themselves and their husbands.

## Relationship of Data to Main Objectives

To assist in analysis of the relationship between categories themselves, the contents of the interview data were summarized in relation to main objectives of the research project. The main objective of this research project was to analyze the relevance of life history to family care of a member with Alzheimer's disease. Questions which the study was designed to answer were:

1. What type of personal historical data can be obtained from men with Alzheimer's disease, and their caregiving wives?
2. How do historical behavior patterns and experiences of these people relate to current behavior patterns and experiences with home care?

The following summary of content analysis, based on data in categories, was written in relation to each of these questions.

### Husbands with Alzheimer's Disease

All men in this study were aware of the researcher's presence and were able to provide verbal responses to questions, but the quality of responses varied widely. All men had trouble remembering specific facts such as information needed for the genogram. When they could not remember such facts the men readily deferred to their wives to provide the information. The men appeared comfortable with this, probably due to decades of experience with what might be termed interdependent remembering. It was evident that they had deep and abiding trust in their wives.

Resentment, denial, and rejection of growing dependence on their wives was mainly apparent in relation to driving. Such negative responses from the men may be the reason why wives had difficulty accepting the need to limit driving, and had difficulty establishing and maintaining a non-driving policy with their husbands. This finding is consistent with Detzner's (1990) research which identified changes in driving

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Men's strongest memories were of work and family, with recollection of leisure pursuits being more limited. This is not surprising since most of their time in earlier years was spent on the job, with family being their primary social support.

While these men expressed an appreciation for and satisfaction with their current situation, they were incapable of projecting into the future. When asked about the future the two who were most articulate merely spoke of their age, and the improbability of living longer. Most spoke of memory loss as if it were a normal change occurring with aging. The one who spoke of his Alzheimer's disease was relieved that his symptoms were not due to the cancer he had suspected. Any anxiety about memory loss was not apparent in interviews, but was instead mentioned by wives. The men may have been reluctant to speak of such feelings, or they may not have remembered having them.

### Caregiving Wives

All wives realized the importance of having the husband respond to research questions, with some being quicker than others to provide data the husband did not recall. A surprising finding was that some wives had already found it helpful to compile family trees in order to facilitate their own recall of information.

For most women with children the most significant memories related to family, and their greatest pride was in their children. Early in life they learned about shared family responsibility and commitment to others. Those with a professional career spoke of growth experiences that occurred in that context. All of the women had worked outside the home at some point in their lives. This group followed the pattern common in their cohort, with most dropping out of the work force after marriage or childbirth and with mothers taking on the homemaker role while rearing children (Teachman, Polonko, & Scanzoni, 1987, p. 10). As they spoke of the challenges life had presented them, a picture emerged of women of great character and competence. Their strength of purpose was clear.

## Relating History to the Present

To the extent possible these women continue to engage in leisure activities they have enjoyed for years, but the amount of time they can devote to them is severely limited due to the responsibilities they have taken on in care of their husbands. They realize the importance of continuing these activities, such as gardening and crafts, for therapeutic purposes. They also realize the importance of providing opportunities for husbands to continue to engage in familiar activities. There was no clear evidence of these women promoting excess disability, as described in the first chapter. Instead there was much evidence that these women promoted independence and self-care to the maximum extent possible, at times to the point of possibly compromising the safety of their husbands and/or themselves.

The commitment these women have to caring for their husbands appears to be related to expectations placed on them throughout life. They have been socialized to be responsible for the care of others who are dependent, and believe in marriage as a lifelong commitment. There are two negative aspects to this.

First, their own sense of responsibility and burden from past caregiving experiences at times prevents them from asking others for assistance. Secondly, their commitment is so great that some of them are continuing to care for their husbands in spite of the fact that the husband's condition has reached the point where he is a danger to himself and/or the wife.

Over their lifetimes these women have developed skills that help them meet the challenges presented by Alzheimer's disease. They have learned to cope with personal and family adversity. They have learned to solve problems creatively. Most have learned to accept help from others, including education or advice about how to deal with new challenges. They have learned to be self-reliant, to plan for the future. All of these skills are useful now as they are adapting to the changes brought about by Alzheimer's disease.

## Literature Revisited

As data analysis began related literature was again reviewed. The literature discussed here is that which elaborates on the chosen methodology as it relates to the population under study and that which facilitates integration of theoretical constructs related to emerging concepts.

### Methodology

Use of life history methodology provided qualitative data based on reminiscence, some of which were obtained from people with a diagnosis of Alzheimer's disease. The literature discussed here clarifies the significance of reminiscence and research initiatives for this population, thus contributing to understanding of implications of the current study.

Reminiscence. Erikson (1982) suggested that the last stage of development is integrity vs. despair, with integrity requiring a sense of coherence between past and present. Reminiscence can be used to examine or promote one's sense of coherence.

Minimal training is required to successfully guide simple reminiscences (Losee, Parham, Auerbach, & Teitelman, 1988; Rybarczyk & Auerbach, 1990; Thoits, 1986). A program titled Reminiscence: Finding Meaning in Memories has been sponsored by the American Association of Retired Persons (1989). It provides training and materials designed to enhance a positive self-image in the elderly through recollection and sharing of personal experiences and their meanings.

Reminiscence has been used with elderly individuals and groups in a variety of settings for psychotherapeutic and psychosocial purposes, including stress reduction and development of coping skills (Osborn, 1989; Rattenbury & Stone, 1989; Rybarczyk et al., 1990). Due to shared life experiences coping appears to be enhanced when reminiscences are guided by someone from one's age cohort (Rybarczyak et al., 1990).

Research Initiatives. Research on Alzheimer's disease and family care is extensive, but most of it is quantitative in nature and a biomedical focus predominates (Lyman, 1989). Historically the disease process and the burden it produces in the family have been the main focus of Alzheimer's studies. The factors identified as contributing to caregiver stress or well-being include characteristics of the giver and recipient of care, the quality of the dyadic relationship, prior experiences, social resources, and the number of years spent in provision of care (Gaynor, 1990; Given, Collins, & Given, 1988; Pallett, 1990). Studies of the effectiveness of interventions that reduce the stress of family care are needed (Zarit & Toseland, 1989).

Illness oriented research must be balanced with studies designed from a health promotion perspective, focusing on family adaptation and the role of health care professionals in relation to families and health (Doherty & McCubbin, 1985). Recently researchers have begun studying meaning as it relates to coping and health. Family members providing care have indicated their own views of caregiving often differ markedly from those of health professionals, which suggests meaning must be explored by health practitioners and researchers (Hasselkus, 1988).

Meaning develops as one responds to the caregiving situation, makes personal choices about life and caregiving, and learns to value the caregiving experience (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilkens, 1991). The significance of meaning in relation to caregiving varies by gender. Women are more likely than men to seek control and meaning in their lives (Dressel & Clark, 1990; Reker, Peacock & Wong, 1987). Female caregivers have intense feelings of responsibility and a need to control the caregiving situation (Smith, Smith, & Toseland, 1991). Male caregivers operate differently, setting limits on expectations of themselves, based on the principles of justice or fairness (Pratt, Schmall, & Wright, 1987). Meaning has been shown to be more useful than duration or severity of symptoms as a predictor of stress or adaptation in female caregivers (Motenko, 1989). Women caring for husbands with Alzheimer's disease were found to adapt better to the caregiver role and feel more gratification if provision of care represented continuity of a longstanding reciprocal marital relationship than if care was perceived as a responsibility. Older women find life experiences meaningful when they are able to engage in activities perceived as needed or helpful, activities that make a difference to the individual or group for whom they are performed (Gilligan, 1983; Trice, 1990).

Caregiver impoverishment and exhaustion resulting in illness, with problematic results for family care, will persist unless society accepts responsibility to provide a service environment that supports family care (Pratt et al., 1987). The type of support needed by families dealing with Alzheimer's disease changes over time, with educational needs persisting even after institutionalization of the demented family member (Fortinski & Hathaway, 1990). Family caregivers have expressed a need for counseling which will help them improve coping skills, meet needs of all family members, gain social support, and plan for the future (Smith et al., 1991).

Since one of the most difficult challenges caregivers face is knowing when to relinquish care, spousal caregivers are likely to need assistance identifying when institutionalization of the demented spouse will benefit both members of the dyad (Pruchno, Michaels, & Potashnik, 1990). Gerontological professionals assisting those confronted with this decision must put aside any bias that may conflict with needs of the caregiver and interfere with effective counseling (Smith et al., 1991). They should also make families aware of the fact that nursing home placement may reduce the time and energy demands placed on caregivers, but emotional stress and related somatic problems may persist (Stephens, Kinney, & Ogrocki, 1991).

Researchers studying recipients of care tend to exclude the demented when designing studies or when analyzing results (Rakowski & Clark, 1985; Zweibel & Lydens, 1990). An extensive review of the literature conducted by Lyman (1989) revealed only two situations where perceptions of the demented were provided in conjunction with those of their caregivers (Cohen & Elsendorfer, 1986; Shomaker, 1987). A more recent study including perception of the demented compares marital relations of dyads free of Alzheimer's disease with dyads living with the condition (Wright, 1991).

In that study the shared developmental trajectories and shared meaning found in the control group were not found in families with Alzheimer's disease. Instead those dyads had marital relationships characterized by commitment and dependence, leading to divergent developmental trajectories and loss of shared meaning. The continued development of caregivers was evident in their adaptation to change and control of resources. Development of the demented was stalled by denial of problems and distorted interpretations of interactions with the spouse, leading to loss of shared meaning. These findings show how data from people with dementia can enhance our understanding of the dynamics of family care.

Research is needed on interventions that will improve the quality of life of those with Alzheimer's disease (Duffy, Hepburn, Christensen, & Brugge-Wiger, 1989). Hopefully such research will incorporate information from people with dementia.

## Theoretical Constructs

As the adaptive ability and endurance of caregivers emerged from this study it became apparent that a review of literature related to coping and energy use within systems would be useful. The concept of hardiness was explored after it was repeatedly found in the literature on coping with stress (Ganellen & Blaney, 1984; Holahan & Moos, 1985; Menaghan, 1983) and was identified as a characteristic indicative of strength in traditionalistic and rhythmic families (McCubbin et al., 1988).

Hardiness. Hardiness is a concept introduced by Kobasa as a result of research conducted with male executives and lawyers (Kobasa, 1979; Kobasa, Maddi, & Courington, 1981; Kobasa, Maddi, & Kahn, 1982; Kobasa & Puccetti, 1983). Results support her contention that there is a personality difference between those who are hardy and those who are passive or feel powerless. Kobasa contends the hardy person is committed to oneself and one's social context, view life changes as challenges to be faced, and maintains a sense of control over life events.

The sense of control is based on the degree of decisional control, cognitive control, and coping skill the individual is able to achieve (Kobasa, 1979). Decisional control relates to the ability to make choices; cognitive control is based on the ability to interpret information and incorporate it into one's life plan, and coping skill is based on the repertoire of learned responses to stress (Kobasa, 1979).

Kobasa's contention that the hardy person can endure more stress without becoming ill led to research on the relationship of hardiness, or its component parts, to individual health (Bigbee, 1985; Lee, 1983; Pollock, 1986; Rodin, 1986). While no studies have been found that directly address the relationship between hardiness and provisional family care, its relationship to burnout among professional caregivers has been examined (Lambert & Lambert, 1987; Langemo, 1990; McCrane, Lambert, & Lambert, 1987; Rich & Rich, 1987; Wolf, 1990).

The relationship between hardiness and social support is not clear, with findings varying with gender of the population studied. Among males, hardiness was shown to be more important than social support (Kobasa, Maddi, Puccetti, & Zola, 1985), but with females a strong correlation was found between social support and characteristics of commitment and challenge (Ganellen & Blaney, 1984). Family support was found to enhance stress resistance in females, but not in males (Holahan & Moos, 1985).

While Kobasa suggests the hardy personality is attracted to new experiences (Kobasa & Puccetti, 1983), Antonovsky (1979) suggests that the person who best resists stress and maintains health is one who has a sense of coherence, a world view that provides confidence in the predictability of life and the probability that things will work out as reasonably as can be expected.

From Antonovsky's perspective a sense of control, especially if interpreted as meaning one has to maintain personal control, is more limiting than a sense of coherence which acknowledges the fact that a balance must be maintained between personal control and legitimate control from social systems. While our culture allows us to accept control from experts, we tend to be ambivalent about turning over control to others (Antonovsky, 1979).

Antonovsky (1979) suggests a sense of coherence is developed as one has experiences that are mainly predictable and rewarding, but with some measure of frustration and punishment. The sense of coherence formed in childhood and young adulthood can be shaken by major life events over which one has no control or can gradually transform over time with changing life situations (Antonovsky). The sense of coherence provides the context within which life experiences can be understood.

The concept of hardiness has been applied to family units. McCubbin, McCubbin, and Thompson (1987) developed a Family Hardiness Index which incorporates the work of Kobasa and Antonovsky in an instrument developed to measure hardiness as a stress resistance and adaptation resource in families. The hardiness index is a multiple item instrument divided into subscales measuring co-oriented commitment, confidence, challenge, and control (McCubbin et al., 1987). Respondents indicate the degree to which they agree with statements describing their family situation.

Co-oriented commitment is said to be present when families indicate they work together to manage problems. Confidence is dependent upon their ability to plan ahead, feel appreciated for their efforts, and find meaning in life. Challenge is dependent upon a family's desire to actively pursue learning and exciting new life experiences. Control requires families to see themselves as being in control of situations rather than being the victim of circumstances (McCubbin et al., 1987).

While Kobasa suggests it is personality that influences coping, others studying aging and caregiving contend the repertoire of responses and resources one can rely upon are at least as important (Pearlin and Schooler, 1978). Studies on responses and resources tend to ignore commitment, focusing instead on responses related to control and challenge. Adjusting to loss associated with aging has been found to depend upon one's ability to meet the challenges, transform negative experiences into opportunities for personal growth, and gain perspective on what the loss means within the context of a lifetime of experiences (Wagnild & Young, 1990). Coping in caregiving situations has been found to be dependent upon one's ability to manage the stress producing situation, its meaning, and the resulting stress symptoms (Pearlin, Mullan, Semple, & Skaff, 1990). With caregivers dealing with Alzheimer's disease coping strategies that resulted in lower levels of burden were confidence in problem solving and reframing (Pratt, Schmall, Wright, & Cleland, 1985). The main moderators of stress have been identified by some as coping and social support (Pearlin et al., 1990), and by others as hardiness and social support (Ganellen & Blaney, 1984). One would expect coping to be the broader concept, but commitment has not been evaluated in coping studied outside of the framework of hardiness.

<u>Energy Use Within Systems</u>. Carrying capacity is an ecological concept developed in relation to animal life and expanded to include human life. Odum and Odum (1981) described it as the amount of animal life, human life, or

industry that can be supported with available resources. Human carrying capacity is dependent upon renewable energy resources that are available to the system from within and from the environment.

In their analysis of family systems dealing with a handicapped child, Bubolz and Whiren (1984) indicated that energy expenditure is required for maintenance of all family systems, but families with a handicapped member require more energy for maintenance. They indicated that behaviors of disabled members resulted in increased energy demands from resources within the family system and in the environment. Undue energy demands were said to result in "energy sinks" characterized by lack of ability to adapt creatively, which in turn increased family stress. As energy sinks occur, the choices available to families are to use energy more efficiently within the system, obtain more energy from the environment, or reduce or eliminate the source of stress. If sufficient energy to deal with the handicapped person is not found within the family or in the environment, disintegration of the family can occur.

Bortz (1986) suggested that when energy flow is disrupted, order is lost and entropy takes over. When energy fluctuation is too great for the system to absorb, reorganization occurs. This, in turn, increases the likelihood of additional fluctuation, instability, and reorganization. To reduce entropy within the system, disruptions of energy flow must be minimized.

## Developing Themes

As data were placed into categories and comparisons were made between categories, two main themes emerged. Commitment emerged as a characteristic valued by caregivers, and coping with progressive loss emerged as the main response pattern identified in caregivers. The significance of commitment was evident from descriptions of how it developed and was evidenced in five generations of family members. The significance of coping with progressive loss was evident from descriptions of adaptation to changes in their lives resulting from caring for a husband with Alzheimer's disease. The next chapter provides an explanation of how the data supported the main themes and related subthemes.

# CHAPTER VI. THEMES EMERGING FROM DATA

Two main themes emerged from the data. First to emerge was commitment, a characteristic found in informants of this study; second was coping with progressive loss, an activity with which informants are involved. Presented below are data which support those themes, and related subthemes. Drawn primarily from answers given to questions used in the interview process, the data used are considered representative of information provided by informants.

## Commitment

The first main theme to emerge from this study was evident from the onset. The length of time those couples have remained married provided the first evidence of commitment, but much more was to follow. The researcher was continually impressed by the depth of love and respect evident in these families as well as the strength of purpose exhibited by caregivers. When their responses were analyzed in this context, it became evident that what was being noted was a deep and abiding sense of commitment to each other. Due to the historic nature of this study, subthemes emerged which clarify how commitment developed in participants, how it relates to the ability to provide family care, how it is exhibited in their current situation, and the impact it has on future expectations.

### Development of Commitment

Commitment was a characteristic which informants were encouraged to develop in their early years as they were taught shared responsibility within the context of families and communities. Several women learned about shared family responsibility due to illness or death of a parent. Wife 3 indicated she was 19 when her mother died. At that time she and a sister had to take over care of the other children and the home. Additional examples of how commitment was learned are provided below.

> H5: My mother and father used to say 'If you start a job, finish it' regardless of what it was. That's been with me. My mother used to say 'You know there are people that need somebody else in their lives besides their relatives.'

> W1: My brother was only 15 when my father passed away, so he had to go out and get a job. When I was 15 I started working... so I could go to high school, because my mother was getting just a small pension, so everybody had to help out.

> W7: I was disappointed not being able to go to high school. We lived in the country about four miles from town. I would have went to high school, but mother was taken sick just before I graduated from the eighth grade so I had to stay home and take care of her. So my job was to do the cooking and cleaning and things like that. Like I used to bake fourteen loves of bread at a time. I remember that, cause we had family there working on the farm. But I took care of my mother. She was sick two or three years, then she got better.

> W8: (I was 21 when my mother died.) Of course being an accident I think it's a lot harder.... (My sister) was 14 at the time my mother died.... I was teaching, and I quit teaching to take care of my father and kept the house. Later on that summer (my sister) was married. It had already been planned. Her husband helped my father on the farm. So I went back to teaching again. Then I married.
>
> When I was a child living at home on the farm, all of our neighbors had grandparents living with them. When the grandparents got older they always moved in with one of the family.

> W9: Mom was awfully good. She was always helping others. She was always sending us up with a bun or loaf of bread or whatever she made. She taught us to be good to our neighbors. Like we couldn't take money, but whenever we had utility bills to pay, we went across the street to this older couple's place, got their bill. Since we couldn't take anything (the lady) would usually have a piece of cake

> for us. When we got that piece of cake we didn't eat it ourselves, we took it home and divided it among everybody at home. We shared.
>
> Then Dad, he was always telling stories. He sang.... He worked away from home a lot, but when he came home he was so good to us. He had his arms full of kids, neighbor kids and us too.
>
> We had a big wide rocking chair, and his arms were full of kids and he's sing for half a day, until meal time. He was kind and good to my brothers. He used to always think of them. They took up pole vaulting and he took out wood at one time. He'd send poles for them to use for pole vaulting on top of the pile of wood. A lot of little things like that. They were just really good to us.

> W10: Mother was a midwife out in the country.... She was always helping out in some way.

Commitment to family and community persisted through young adulthood. This is evident because the themes of family and community were pervasive in responses to questions about significant life experiences. Men were more likely to discuss both family and work, while women's answers focused almost exclusively on family themes. The inclusion of work experiences by men should not be surprising since that is where most of their time was spent, while most wives spent more time with home and family activities. Included with the work experience considered significant by men was military service during World War II. The following examples of significant experiences described by informants reflect the theme of commitment to family and community.

> H1: Crossing the English Channel. We were on the first boats in, and it was like Hell.

> H2: Go to work, go home, come back, go to work... I worked on the railroad, and that's about all our life was. Ain't no big deal.

> H3: I look up one day and there was a great big dirigible. We come out of that one, they just let it down. Then they took up and didn't get

the thing. It was a wonder that we all didn't get killed... before World War II got over with.

H5: I enjoyed being a consultant and then being a program director, but my first love was direct work with people.

H8: I lost both my mother and father when I was just a very small child.

H10: When she married me, that was the biggest thing that happened in my life. My life changed a lot. We had our own home and there wasn't anybody bossing me.

W1: After marriage we adopted our daughter. Then we got our first home.

W2: We were married eleven years and didn't think we were going to have a family... so we really appreciate our family.

W5: Meeting (my husband) was the Alpha and Omega of life, because the last thing I ever thought of was getting married.

W6: I lived most of my life for my kids.... We did everything we could for them.

W8: I think probably my mother's death... that was when I was a young girl. She was 43 when she died, but it was an accident. Of course being an accident I think it's a lot harder. You just never get over it, that's all.

W9: I was a country school teacher in one room schoolroom. I had to learn to fend for myself up there.... I liked the way the country people lived and shared.

## Commitment and Care

Commitment to others appears to be an essential element for provision of care. Participants in this study learned commitment to providing care within the family by observing others provide care or by taking on the caretaker role. Commitment to provision of care to family members throughout the life span is evident in descriptions of how care was managed within family units.

W2: Then my mother and dad both died of cancer, so we three girls were there 24 hours a day. We'd take shifts for six months. Then when my mother died, my dad wanted to stay in his house. (My sister) and I lived in town here and we'd go over once a day and eat with him.

W4: I was only 8 years old (when my maternal grandfather died). I just knew they had to do special foods for them. But we visited him. All the kids used to go to grandma's house.... She used to buy bananas by the stalk. They had to mash them up for him, and she always prepared his food first.

My grandparents were really caring people.... For years they never ate a meal alone. She was always entertaining. If anybody had sickness, she went and spent the night and carried food.... It was showing others that they cared.

W6: (His parents) lived with us. When we first took them from the farm because his dad (with dementia) had got that we just couldn't leave them. So they stayed with us. Then it got where we had to divide it up a little bit because I had five little kids at that time. So they'd go over to (my brother-in-law's) and stay for a little while. But then he got so bad that (this brother-in-law) said, 'There's something that had to be done.' So we sent him to (a state mental hospital).

Both families took care of his dad and his mother. But his mother was in a nursing home before she died.... (My dad would) stay with either my sister or me.... But these last few years, it's not good to have to have him up there (in a nursing home). But just like (my sister) and I were saying we never could get the wheelchair in the bathrooms to take care of him or he wouldn't be there.

W8: We took care of (my husband's) father for twenty-some years. We moved into his house because it was bigger than ours. He just didn't have anyone to take care of him. His wife died and he needed someone to live with. He never was sick, he died in his sleep.

Regardless of how or when one learns about family care, the knowledge gained contributes to the repertoire of experiences from which one can draw in later life when confronted with similar circumstances. The greater the repertoire, the easier it is to put new experiences into perspective. Commitment to family care is more likely to be maintained if perspective is maintained than if it is lost.

What follows are examples of how prior experiences with family care have helped caregivers put current experiences into perspective.

> W5: Now (my husband's brother-in-law, who has cancer) is taking care of (this sister who now has Alzheimer's disease. Their daughter is supporting her father in his caregiving). She took a sabbatical this year to be home with her parents. She's a teacher. It's horrible.... I see (them), I see what's going on, what's down the line. It's frightening, but you take each day as it comes, and you deal with it.
>
> W6: When we had his dad, if I went to the stove to stir, he was right there. When I was to the sink he was right behind me. He followed me just like he was a kid. Now, see I don't get out of (my husband's) sight.
>
> W7: He thought I was his mother.... It hurts, but I understand that that's the way they get, because that's the way my sister's husband did. He really hurt her. On morning (he) said, 'Where's my wife?' She wasn't expecting anything like that. 'I'm your wife.' 'No you're not.' 'Well who do you think I am?' she says. 'You're my mother.' It really hurt her terrible. But I knew that sometime I would hear this, which I did, and I have several times. It hurts, but then I just don't let it bother me that much.

Experiences with provision of care within the family are not always positive. Traumatic or negative experiences with family care, while not necessarily interfering with the commitment of family members to each other, may affect the capability of family members to provide support or care.

> W5: (His younger sister took care of their mother with Alzheimer's disease) and it had a profound effect on their oldest daughter. Her grandmother used to wander around at night, and always holler (her daughter's name) in the middle of the night. And she'd be going through drawers, walking into anybody's bedroom. It has affected (the granddaughter) in such a way that she cannot tolerate to be home at all. It's very hard for her.
>
> (His sister) took care of (their mother) until (she) got so bad. Here's (the mother), the daughter of two ministers, and she began

> using four letter words which in this family was not... acceptable behavior. Finally (my husband) was able to persuade (his sister) that her mother needed to be placed in a nursing home.

Current Commitment

Commitment to meeting the needs of the demented member and maintaining the dyad was directly articulated by some women. Statements made by two of the women show that the ability of these women to maintain strong commitment is related to expectations found in this cohort as well as support provided from extended family and social systems.

> W2: I feel this way. That's my life now. I know the girl across the street... the way she'll talk, you shouldn't give up everything. I said a daughter is different from a wife. I mean that's my life, and that's where I want to be. But it's good to get out.
>
> We've had a good life together. I feel that if I was sick I'd expect (him) to take care of me, which I'm sure he isn't able to, but he would if he was well enough. No, it doesn't bother me to stay home. I think it would have bothered me if we stayed up north because I have family here and we have friends stop in. Course we had friends up there, but I think your old friends are closer to you. We have friends that go way back. Usually every day somebody's here, and I do feel good with my son (here). He usually doesn't get home till after dark in the summertime, and I look forward to him coming home at night. I think that means a lot to me too.
>
> W10: You just have to do what you have to do. I really don't mind. The kids often worry about me that I should be more involved in things. I said, 'But the marriage vows said for better or worse, and you do it.' They don't agree. A couple of them have been divorced because the husbands wouldn't cooperate. So no, I truly believe in that. You do what you have to do. It's not so bad. You would feel worse if you didn't do it.

Often evidence of commitment to provision of home care was provided as women spoke of the challenges they faced and the steps they had taken to adapt to the ever changing needs of their husbands. The commitment felt by many was so great that threats to a wife's own health or safety were accepted as part of the challenge to be faced. The first wife interviewed attributed her recent cardiac problems, requiring outpatient care, to the stresses related to her husband's condition. She spoke of a friend in a similar situation with words that probably reflect her own feelings. "It's sad. What are you going to do? You have to accept it." The same words were used by wife four after describing the pain she and her children feel when her husband cannot remember who they are. "I said we have to accept it." (W4)

The fourth wife interviewed provided a clear picture of the many challenges presented by changing behavior patterns of the husband. Behaviors exhibited by the husband had placed both members of the dyad in jeopardy. Adaptations made to meet the challenges consume much energy and may in themselves prove hazardous in the long run.

> W4: He's sleeping more at night, but I don't sleep with him anymore for the simple reason that he's up and down all night.... He has a thing about going outside a lot, so my son's going to have the locks changed on the doors that he won't be able to do that.... I have his car keys hid, cause otherwise he would never be at home.... He kept losing his wallet and I finally just took his wallet and put it up.... I keep the guest bedroom and the den in there locked at night. Otherwise he's in all the rooms. Our bedroom's in the back so it's a straight shot down the hallway. I keep the bathroom light on. Most of the time he doesn't remember where the bathroom is, so you tell him where it's at. And I sleep there on the couch where if he opens either door, then I know it.
>
> I don't use (the wood stove) any more because he plays in the fire. It's too much of a fear of him burning the house down.... (He) opens it up every five minutes. So this winter we used gas. We have a furnace, so we used gas.

The difficulties these women experience with caring for their husbands are balanced by a sense of pride that is undoubtedly essential to continued commitment. Quotes provided below are examples of responses to a question about good things that were happening in the lives of the women at the time they were interviewed, quotes that reflect the pride felt in the ability to provide home care.

> W3: Being able to keep him, take care of him, even though it is trying, worse at times than it is at other times.
>
> W4: Just doing the best I can. The best thing is that I can just live each day for what it is.
>
> W5: I'm still OK.... I just hope I can take care of him as long as I can. And when the time comes when I can no longer, then other plans will have to be made.
>
> W8: Love and friendship from other people... and my kids. They're paying attention to him, helping me.
>
> W10: I hope I just keep my health, and this far I have, but it's... He depends on you. I never even thought of what to do about life. My health, so I can enjoy the outdoors. And I'm glad that (my husband) is holding his own. Some days he is and some days he's not. Then a lot of prayer. God hears my prayers and he gives me the strength to carry on.

The current commitment to their husbands has not diminished the commitment these women feel toward their children. They are aware of the responsibilities their children have, and indicate they did not want to burden them now or in the future.

> W2: My daughter-in-law, my son works on the railroad, she's over here more than he is, but she's a real... She wants to do something all the time. I just bite my tongue on saying 'I gotta do this or I gotta do that' cause then she thinks she'll come over and do it. When I need help they're there. Course (my daughter) and her husband both

> work. (My daughter-in-law) don't work, but she's got three kids. One comes home at noon, and one comes home at 2:30 or 3 o'clock, so she has to be home for them.

> W6: He has a life insurance policy that will take care of his burial.... I couldn't get life insurance because of health problems. So I don't have life insurance, but I've tried to save enough. We also have bought our own lot. We got the stones on it, and part of it's taken care of that we've already paid for, so it won't be something for the kids to worry about.... I don't like the thought of burdening the kids, cause I've had it all my life. We've had his folks, we've had my dad.

> W7: Like I told my daughter in Illinois I wasn't going anymore because not he's got so that he'll wet the bed and everything like that. 'Mom' she said, 'that's no problem here.' I just figured I couldn't ask anyone to put up with things like that. We used to go down to visit his nephew every year. We didn't go there this year because of that, but we did go to my one daughter's about a month ago. I took padding, rubber sheets and everything along. You put a rubber sheet on and padding on top of that so I don't have to tear the bed all apart. So that's what I have to do now. I have the laundry to do every night. It's hard.

> W9: We haven't seen (our youngest daughter) so much. I hated to see her driving all that way alone, from Cleveland.... We don't see her very much, and we don't see (our oldest son) very much because he's busy with the music.

### Commitment and Future Expectations

Wives are aware of the progressive nature of Alzheimer's disease and are taking steps to prepare for anticipated changes. They realize all involved must be prepared for what is to come, yet they realize that no amount of preparation will completely ease the pain they anticipate for themselves and their offspring. Even the anticipated changes and pain cannot dampen their commitment to providing home care.

> W6: When it will really be bad is when the kids come and he doesn't know them.... We just prepared them that the time is coming when

> grandpa isn't going to know who you are. That will really get this little one. She's the youngest of the grand kids.

When discussing future prospects half of the wives (W2, W4, W7, W8, W10) spoke of nursing home placement as a last resort if the husband's condition because unmanageable. Several (W2, W7, W10) were concerned that they might die or have their health deteriorate to the point where they could no longer manage care of the spouse. One wife cried as she shared instructions she has given her son on what to do if she dies first. "I know I told (my son) yesterday, if I go before Dad does, be sure he gets in a nice home and that he is well taken care of." (W2)

Reasons for not wanting to institutionalize their husbands are complex, with some of the motivation related to the lifelong commitment the couple made to each other. Comments made by wives indicate they are not willing to give up the interdependent relationship developed over decades.

> W3: My life depends on him. When he gets real bad I get bad too, I get down.
>
> W4: I hope to keep him home as long as possible because I don't want him in a nursing home. Financially it would be a burden, but still the think of it is, it's not finances. I know in a nursing home they don't get the good care that they should.... It'd be cheaper to have someone to come in than it would to have him put in a nursing home.... There's so many nursing homes that doesn't want Alzheimer's patients.
>
> W5: We'll be older, more feeble, but our dependency upon one another will not diminish.
>
> W10: I know his health will deteriorate. The doctor said don't plan anything. You know yourself that's a fact with Alzheimer's. So just be able to take it gracefully without ruining your life.

> (Our children) want me to put him in a home, an institution. And I may have to do that eventually, but not right now. Some days he doesn't know me at all, he's wondering who I am. I said if he ever gets to the point that he doesn't know me, what's the difference, why cope with it because he doesn't know who's taking care of him. Of course there's expense too. That would be terrific. I've been to lawyers, and funeral homes. I've tried to do everything in preparation. If something happens to me, then the kids can follow what should be finished.

## Coping with Progressive Loss

The second major theme of coping with progressive loss emerged from the extensive data provided related to current activities of couples. All participants were learning to cope with losses they were experiencing, including those which resulted from the progressive deterioration of functioning ability of husbands. Related subthemes revolved around efforts being made to minimize losses, put losses into perspective, and address needs of caregivers related to time and energy. Family and community resources were utilized to that end.

### Minimizing Losses

To minimize loss a variety of approaches were used. Historic interests and activities of the couple were maintained as long as possible; independent functioning related to self care was facilitated; and changes were avoided that would result in loss.

For as long as possible couples engage in activities they used to enjoy, adjusting their level of involvement to current functioning ability. Continuing such activities results in pleasurable experiences and reinforces the interdependent bond developed over time. Examples provided below are representative of those provided by wives.

> W1: We'll still golf this summer. We'll go out once a week at the most (as opposed to prior tournament play). We play cards with friends.... He makes a few mistakes, but they understand.... We still belong to our birthday club. There's six of us who go out on each other's birthdays, then go to somebody's house and play cards. Something like that, or graduations or weddings he'll still function all right.

> W3: We do get out together every day and go out to lunch, that's the only thing. I cut up his food (and order for him).

> W5: I'm a good supervisor, and (he) is strong, so I always tell him 'we make a good team' (speaking of gardening).

> W8: Now we do it just riding around here. It's surprising. There are roads two miles out of (town) that we've never been on.... It's really interesting. We've seen beautiful homes and beautiful farms, just really beautiful around here. It's just a joy to ride around. No traffic on the road, so you don't have to worry about that. Just for this last year, it's been a real joy.

As disability progresses, independent functioning can be maximized when caregivers learn to assist with self-care activities rather than performing them. Some wives indicated they were advised by professionals to use this approach.

> W4: He has to be told exactly what to do. When he takes a shower I have him take all of his clothes off and turn the shower on, be sure the temperature is right in the shower. Sometimes he will get in there and really bathe himself good, sometimes he's just in and out. When he does that I say, 'You did not take a shower, you have to go back.' I've been shaving him because he cuts himself when he shaves himself. I usually have to lay out his toothbrush with the toothpaste on it for him to brush his teeth. I'll tell him, 'We'll brush our teeth now' and get the gargle out for him, and so on.

> W7: You have to do everything for him. Have to help him get dressed. He can't even figure out how to put his socks on. Usually I go to the bathroom with him when he goes.... It's just like taking care of a kid, only harder, harder. I tell him to lift his feet so I can get underwear on or socks. He just barely lifts them off the floor and I have to get way down there.

> W10: He will dress himself if I pick out his clothes. I have to turn the water on and he cannot sit and take a bath anymore. It has to be

> standing up because he cannot get into the tub and out. He will wash himself, though I did scrub his back today because he has a rash. The doctor said it's just inner symptoms. He will dress himself if I give him the clothes. It takes an awful long time, but he doesn't have anything else to do. And the doctor said let him do as much as he can.

At times friends or relatives make recommendations which wives feel would result in losses that are unacceptable. Several women have rejected recommendations to move because of their assessment of related losses. Wife 9 will not move closer to her children because she is not interested in moving to a more highly populated area. She grew up in the country and enjoys it. Friends have suggested couple 6 should move into town rather than remaining in the country, but the wife has rejected that suggestion, in part because they now live next to a supportive daughter and her family.

> W6: If (she) wasn't here, or close enough that I could call her if I needed her, I'd really be in a mess out here cause there's nobody to home most of the time around us. So it's kind of a lonesome existence too, when you talk to yourself. I don't think that would be a good idea because he would be lost then. (We have been here) sixteen years. He knows where he can get around here. If he was in town he would be lost. The house he would be lost in now.

## Managing Threats to Safety

While independent functioning of husbands is preferred, wives are aware of the fact that this is not always safe. In these instances wives take on the role of protector in order to manage threats to safety. A week prior to the interview husband 4 had hitchhiked 100 miles south of his home, where the driver who picked him up finally dropped him off at a state police station. His wife will now be more vigilant, as are wives of others who wander.

> W6: I wouldn't dare to let him go walking in the woods. He might get down there and now know where he was at or know where to go.... Right out behind those evergreens there behind the pond the boys would feed the deer. He went out there to take some corn to feed the deer. I kept watch of him. I could see him out there. I didn't think but what he was looking around. When he come back in the house he said, 'You know, I was lost. I didn't know where I was at.' So I don't want him to go anywhere that there isn't somebody with him, cause I do know what happens.

> W8: I don't leave him alone at all to go anyplace.... You never know what somebody who isn't thinking right is going to do, so you don't take any changes. (The doctor) says, 'Never leave him alone' and that puts a load of responsibility on you. I do have a woman who comes in two afternoons a week so I can get out to do things. And there is a fifteen year old boy who will come down and stay for a couple of hours if I need to have somebody. But not if I'm going out of town or anything like that.

Some husbands were so confused that they become lost within their own home. Basic needs could not be met without someone to provide direction.

> W6: You'll notice that he's sitting there and looking to find out where to go. I'll just keep letting him go for a while and then I'll ask him, 'What are you looking for?' He might say, 'I'm wondering where I'm going to go to bed' and I'll say, 'You'll go right down the hall to the bedroom, right where you always sleep.' He doesn't know where down the hall is or where the bedroom is, so I'll get up, turn the hall light on, go down and turn the bedroom light on. Then he might come along here and he'll look in the bathroom. It's kind of eerie.... He's lost.

Placing limits on husbands in the interest of safety is not always pleasant or easy for wives, some of whom seem ambivalent about enforcing restrictions on driving. When told he cannot drive husband 1 becomes belligerent. His wife indicated "that's what hurts." While most men were reluctant to give up driving it should be noted that husband 7, who was informed of his Alzheimer's disease, was more accepting of this limitation. His response and that of others are presented below.

> W6: It really upsets him because he can't drive the car. When I had him over there... and I told (the neurologist) he was still driving 'My land,' he said, 'he's not driving the car.' And I said, 'Yes he is.' He kept right on driving after that for quite a little while. Then our family doctor said he shouldn't be driving. When I told him he couldn't be driving anymore, that was just the last thing because he drove the farm machinery, and he drove semi for a long time. One day when he was driving from (the city)... he turned north. I said to him, 'Where are you going?' 'I'm going home. Where do you think I'm going?' Then as soon as that happened I knew we was going to have to do something about this, but I couldn't tell him he couldn't drive.
>
> I told him the doctors thought he couldn't be driving any more.... Now he's got so, like yesterday... when we got ready to come in the house last night I said, 'I left the keys in the car. You can drive the care in the garage if you want to.' 'I don't want to. You can drive it in.' Whether he thinks he won't see it to stop the car or what, I don't know what's on his mind. But I'm glad he said he don't want to.
>
> I got an electric jigsaw and a band saw. he did cut out some wood things, and I'd paint them, and we'd take them to where they had sales, bazaars or something. But the doctor recommended I don't let him use electric tools anymore because he doesn't think. It was too dangerous. If there was something like I had to have a hole drilled in a board, I think by me being right there I could let him do it, but I'd have to be right there. But it's too nerve wracking to try to get him like to saw something on the saw. The last thing that we tried to cut out, and I tried to tell him where he had to saw... I can't take it. It really gets to you.
>
> W7: Just by talking to him, and explaining that he shouldn't be driving, and why he shouldn't be driving he just did it on his own. He just gave up his license by himself, which I was real happy about cause I hated to hurt him.
>
> W8: (He is not driving, but he did renew his license) so if there was an emergency and he needed to he could, but I'm hoping he won't be needed to.

The reluctance of wife 8 to admit her husband's limitations may be related to her own feelings about driving. Until a year ago, when she turned 80, she would drive her husband to visit their children in a city about two hours from their home. Now the grandchildren come to get them when visits are planning "which I don't think I like because while it is nice not to have to, I lost my nerve in driving and it isn't too easy to get your nerve again after eighty year old, driving. And I don't let that eighty stop me very much." (W8)

Putting Losses into Perspective

The women in this study have been seeking information that will help them understand the disease process with which they are dealing. The knowledge gained from others and their own observations help them understand and cope with behavior change by putting it into perspective. Wife 10 best articulated the relationship between knowledge and coping.

> W10: I have so much to learn... and this is a new situation. I read 'The 36 Hour Day.' It's a wonderful book. When I really get stumped I go back to the book again. There's lots of things I don't understand, and don't know how to handle. Just hang around long enough, I'll learn.
>
> You just cope with the problem the best you can. And you realize this week, last week the way you coped with it wasn't the best way, but you learn all the time. I can handle it, but my kids are a little worried about if something happens to me, then what?

In their attempts to understand their situations, wives at times recalled prior behavior that they felt was indicative of developing Alzheimer's disease. An example is provided below.

> W9: He would disobey traffic signs. I couldn't get out and work.... I noticed years ago if I were out and he decided to go out, he'd leave everything open.

Variation is evident in the educational resources used and preferred by wives. Both wife 4 and wife 10 have read and sought professional advice related to Alzheimer's disease, but their views differ in relation to support groups. Wife 10 will not return to the group where the researcher found her because she prefers professional advice to that given by other caregivers. Wife 4 has not been able to attend support group meetings yet, but made plans for a daughter to come up and stay with her husband so she can get to a meeting.

> W4: I need the support group. If nothing else, just to get somewhere and say I get real mad about things. I need it. I would like to know that there is other ways that you can handle the situation. Experience is the best teacher, so if anybody is living through that experience they can sure inform you a lot better than somebody that's not living through it.... A woman told me he would even get more passive than he is now. She said, 'You've got better days coming.' I said, 'Thank the Lord for that.'

When describing behaviors of husbands, wives were able to provide interpretations of why such behavior was occurring. The interpretations reflected both their own personal insights and knowledge gained from professionals. The nature of the interpretation can help the wife understand the behavior and can help guide her response to the behavior, but cannot always eliminate the distress caused by the behavior.

> W2: Just that one spell he couldn't walk. That's the last one. Before that if he had a spell he could walk if we would lead him. Like the doctor said, they've got depth perception. He felt there was bumps and water. That's what it would look like to him. It's thirty days now that he's been like this, and that's not hard to take care of.

That last spell he couldn't feed himself, he was shaking so. He couldn't stand on his feet.

W4: He tries to check things out with you, so you can help him remember.... A lot of times when we go to the doctor they want to talk to him. He wants me to answer his questions, but I've learned just to keep my mouth shut. If the doctor wants to know enough he'll ask me.

He wants all the windows closed and everything, like there's somebody out there who's going to get you, so you have to be very quiet. You have to be very careful.

He seems like he looks up to men more than women. There's something about a woman that he kindly shies away from.

W6: Yesterday (our granddaughter) was going to teach grandpa how to make cars and color. So that's what they did.... He set here at the table with her for quite a while and did that. Then she wanted to play Bingo. She went and got the Bingo set and she started out, but that didn't work with just her and grandpa, so she wanted me to give them the numbers, and they did that for a while. He'd see the numbers, and she keeps watch of him. If he doesn't put the button on she'll say, 'Grandpa, you got one. It's right there.' She's a good little teacher, I'll tell you. He doesn't ever get upset with (her) telling him.... Like with me, I'm being bossy, but with her he doesn't. He knows the difference in size I guess.

If there's any time that he didn't know (who family members are) he's very good at covering up because he knows that he doesn't remember.

W7: I really had to talk to him. I said, 'You're confused today, I'm the one that went to church with you this morning. I'm the one that got you ready for church. I'm the one that came home with you. I'm your wife.' I had to really talk to him. He said, 'Well maybe.' That's all he says, maybe. But he did come back to the table with me then, and he ate. And after that it was forgot about. It wasn't mentioned the rest of the day.

He thought I was his mother. I asked him... 'Who do you think I am?' 'My mother.' I said, 'No, I'm your wife.' But I couldn't convince him.... It hurts, but I just don't let it bother me that much.

> He fantasizes so much now. He'll see something on TV, like one night he was in the bedroom and I went up to see why he wasn't coming out. He said, 'Do you hear those indians out there?' It was on TV. He says, 'They're doing a lot of shooting.' I said, 'That's just on TV.' He'll see TV sometimes and imagine things. That makes it kind of bad too.

> W10: You know (his occasional uncooperativeness is) going to be because he doesn't understand it for longer than 5 minutes. But it really gets hard sometimes.

Obtaining the diagnosis of Alzheimer's disease and learning about the disease can help both the giver and receiver of care put life events into perspective. Many wives spoke of how knowledge of the diagnosis helped them understand behavior they had considered out of character for their husbands. The husband who spoke openly of his disease found knowledge of his condition helped him understand and accept his memory deficits.

> W7: He couldn't understand why he was getting that he couldn't remember how to do things. So after the doctor told him that (he had Alzheimer's disease) he understood then. I think it's been easier for us both.... So when he starts having problems... can't remember anything I say, 'It's just that disease' (and that usually settles him down).

Wife 5 was able to explain how knowledge gained from prior life experience can be critical to development of a positive perspective related to Alzheimer's disease.

> W5: It's sad. But hey, they've given us years, but they haven't put life into those years. What good is it to live to be 100 and be in a vegetative state? None of us will go out of this alive. I watched my sister die of cancer, and it was horrible. I'm watching (my brother-in-law with cancer) and it is horrible. I'm watching (my sister-in-law with Alzheimer's), and while it is terrible for all of us to see the deterioration in her, for me the saving grace is that she's out of it. She's not aware. She's happy. Everything's fine, and I think that's

> great. That's the one good thing about it. It's hard on the family, yes. It's just terribly hard.

Addressing Needs of Caregivers

Needs of caregivers that emerged from this study related to limitation of resources. Concern was expressed over the constant demands placed on their personal resources of time and energy.

Time. The most pervasive cause of resentment in the women studied related to loss of ability to manage their own time as they would like. Wife 4 is "bitter" about restrictions on her time. Wife 10 has given up some of her volunteer work to care for her husband and says, "I really have minded that a lot." Other wives spoke of how behaviors or desires of husbands can limit their ability to engage in satisfying activities.

> W7: We went over there and I played one hand of cards. He asked to come home before that. He said his legs hurt, so we asked if he wanted to lay down. But he'd go in there and he'd lay down a couple of minutes and he's ready to go.... He just isn't contented, and that's about the only thing that I really miss right now.
>
> The only thing I regret really is now we can't get out and enjoy ourselves too much. I have to take him everywhere I go because I can't afford someone to come in and stay, so it's kind of hard now. I would kind of like to go visit friends a little bit more, but he isn't usually too contented visiting. I don't know why. Just recently he's getting worse.
>
> W10: I would like to get out, and I figured after we got through with his doctors, which we're through now since last week, that I would be able to go shopping by myself and stuff and get a sitter for him. But he wants men sitters, and men have no sympathy for anything like this. So right now I'm looking for someone that will come to the home, and I can get out on my own.

Even necessary activities can be disrupted by husbands who are restless.

> W10: I start off getting groceries with a (long list, but soon he says) "We got to go home, we got to go home.' That's really aggravating.

Caregivers who wish to gain time to themselves must rely upon family or community resources which vary in character and availability.

> W2: (The Visiting Nurses Association) sent a sitter to me Thursday afternoon.... I look forward to that now, 'cause 'bout all I was doing without (my husband) was going up to my bridge club twice a month.

> W6: Now I don't get out of (his) sight. He wants to know where I'm at. This morning (my daughter) came down early. She tried to call me, and I was in taking a shower. He yelled that the telephone rang. Well I didn't hear it. When I come out through the door I see he was out on the font porch and he had the dishtowel, because he had washed his breakfast dishes. (Our daughter) drove in. 'I don't know where your mother is,' he says. I'm a mother figure to him. If I go outdoors I can't deal with it. You need to get a break from it once in a while.
>
> My one daughter-in-law, she did for a few times come and get him and take him over there. She does reupholstery work and she'd take him over and have him help her. But she hasn't been over for a month now to take him over. She tells him to pull the tacks and staples, and he does it. He's helped her move it around. He helps her deliver it back.

<u>Energy</u>. Energy depletion was described in a variety of ways by wives. They spoke of needing physical as well as psychic stamina, with patience being the resource they felt they ran out of most quickly. Interestingly, on the same morning two women spoke of how effective gardening was in helping renew this vital resource.

> W7: A couple of weeks ago I got real upset... on Sunday. Monday morning I was fit to be tied. About 9 o'clock I said, 'I'm going to go our and work in the garden....' I worked out there till almost twelve.... You know that relaxed me. You wouldn't think you could get relaxed from work, but you can out there in that garden. I felt better afterward.

> W8: Patience... isn't limitless. I exhaust it many times, but somehow I get it back on track again... sometimes (by) going off in a corner and crying. Sometimes just taking myself in hand and saying 'Come on this isn't what you do.' The best thing to do is get outdoors and get down on my hands and knees pulling weeds. That shapes me up I think the best of anything.

Wife 6 works crossword puzzles before going to bed in an attempt to relax, and continues her crafts which she finds therapeutic. She finds it helps to remain active, but feels she would benefit from more family support.

> W6: I've got to keep up with it or lose my senses myself. I had one breakdown when (my daughter) was first married, I don't need that to go along with this for sure.... Right now the kids don't come because they can't accept what's going on, but it makes it kind of bad too. You like to see them, even though Grandpa... They come in, he don't talk or anything, but he doesn't visit with me either. He just sleeps in the chair. That's why I have to keep busy sewing and writing life histories.

Energy is depleted by the need to adapt each day to changing behavior and remain vigilant 24 hours a day.

> W6: It's nerve wracking because you never know what's going to come each day.... If he gets out of bed, I know it just like that (snapping fingers) and I listen.... I said I'm going to invest in twin beds, and then I'm afraid I wouldn't hear him. You just don't know what to do.

> W7: I had a terrible time there for two or three weeks because he wasn't sleeping nights. There was some nights that he stayed up all night, just walking the floor. I wasn't getting my sleep. If I don't get my sleep, I can't do anything. So about two weeks ago I went to the doctor, and I took him.... I told him about him not sleeping, so he put him on different medicine.... He's been sleeping pretty good. It makes it easier for me because I couldn't have taken it much longer as it was.

At times creative solutions are needed to help minimize energy depletion. Wife 7 found that disposable diapers could not be managed alone by her husband on his trips to the bathroom at night, which meant she had to get up to help him. She sent away for special men's briefs with an absorbent lining. They worked fairly well but cost $24 for two pairs, so this wife studied how they were made and plans to buy water repellent material with which to adapt regular briefs to her husband's needs. In the meantime she is using a rubber sheet, covered by a pad, on his side of the bed. "It's worked good. I have to change it a couple of times per night. That's easier for me than messing with these here diapers." (W7)

She is also trying to get him to learn to sit when urinating because when he stands he dribbles down his leg and onto the floor. She has carpeting in the bathroom, but wants her son to put in tile so she can use rugs that she could wash daily, as she does his underwear. "I'm just trying to figure ways to make it a little bit easier. If I'm working outside or something I can't be there with him every minute, so if I have it so I make it easier for myself I can clean up in a hurry." (W7)

## From Themes to Theory

Generating grounded theory from research data is the final step of the process undertaken in this study. The themes described in this chapter provided the final layer of data organization needed to support the grounded theory described in the final chapter.

# CHAPTER VII. DEVELOPING GROUNDED THEORY

The themes described in the last chapter can be related to three theories: continuity theory, the science of unitary human beings, and ecological theory. The themes can also be related to concepts of hardiness and energy use within systems. The identified themes, in combination with these theories and concepts, provide a framework from which grounded theory emerges on the capacity of families to provide care.

## Relating Themes to Theory

### Continuity Theory

Continuity theory suggests that patterns of behavior are evident throughout the lifespan (Burbank, 1986) with preferences having both a personal and experiential base (Atchley, 1972). Data from this study which suggest that commitment developed over time, continues in the present, and affects future expectations are consistent with this framework. Data on commitment as it relates to provision of care also suggest that a pattern of behavior demonstrating commitment was learned early in life and is being maintained into late adulthood.

Atchley (1989) divided continuity into internal and external forms, both of which are essential to identify. Internal continuity helps us understand how we are related to the past. External continuity helps us understand how we relate to the social environment. Informants in this study readily related who they were in relation to prior life experiences. They were committed to maintaining continuity in the social environment to the extent possible. This was evident in strategies used to cope with progressive loss. Social activities enjoyed throughout life were maintained to the extent possible.

### The Science of Unitary Human Beings

Basic to the science of unitary human beings is the belief that there is a constant flow of energy between human beings and the environment in which they interact (Rogers, 1983). Individuals are recognized as part of the environment of other family members. This is consistent with the theme of coping with progressive loss which included data on energy flow within the dyads studied as well as energy flow between members of the dyad and resources within the support system.

The contention of Whall (1981) that intense energy expenditure occurs when patterns of energy expenditure within a family are not in syncrony is consistent with the situations being faced by caregivers in the study. Her further suggestion that patterns are influenced by past experience is consistent with study data on the learned nature of commitment to family and to family care.

### Ecological Theory

Bubolz and Sontag (in press) suggested human development, resource management, and family relations are concepts central to a family ecological perspective. Human development is addressed by the subthemes of development of commitment to family and community, development of commitment to care, and ongoing development of coping strategies. Resource management is also found in each main theme, with both personal and social resources being identified in relation to commitment and coping. The resources of time and energy were found to be critical to coping. Family relations are described throughout the themes and subthemes, including relations within the dyad and between the dyad and extended family.

When family routines were studied by McCubbin, Thompson, Pirner, and McCubbin (1988), they were seen as stabilizing factors that provide families with a sense of continuity and control when faced with change. Their findings were consistent with both continuity theory and the subtheme of minimizing loss through continuation of prior activities to the extent possible.

Findings from the McCubbin study indicated family time and routines were affected more by current demands than prior experience. While this may be true, findings related to commitment and coping suggest that prior experience establishes the framework within which routines can be adapted. Routines inconsistent with prior patterns of commitment and coping were not seen in this study.

Olson, Sprenkle, and Russell (1979) suggested families must maintain a balance between stability and change. That balance was seen in families of this study as they coped with losses by minimizing them and putting them into perspective.

## Interrelationship of Themes and Concepts

### Hardiness

The commitment, willingness to accept change as challenge, and maintenance of control which Kobasa (1979) links with hardiness were all evident in the themes of commitment and coping. Data which support the view of change as a challenge to be faced were provided in the section on current commitment. Control of the disease process is not possible, but decisional control of where care is provided and where the dyad will live has remained in the hands of the wives studied. The women demonstrated interest in maintaining cognitive control and maximizing their coping skills by seeking as much information as possible about Alzheimer's disease and related coping strategies.

The subtheme of putting losses into perspective is consistent with Antonovsky's (1979) suggestion that a sense of coherence is necessary if life experiences are to be understood. This also relates to the confidence in one's ability to find meaning that was identified by McCubbin, McCubbin, and Thompson (1987) in hardy families.

### Energy Use Within Systems

Family carrying capacity, dependent upon renewable energy resources, may be synonymous with family coping ability. The energy sinks described by Bubolz and Whiren (1984) were evident in data supporting the theme of coping with progressive loss. The data of this study support the contention of Bubolz and Whiren as well as Bortz (1986) that unless energy supplies are adequate to meet demands the survival of the family system is in jeopardy.

## Integration of Concepts and Theories

Kobasa (1982) contends that the concept of hardiness is based on an existential theory of personality as dynamically changing in response to personal or environmental alterations. Belief in the changing nature of humans and families in response to internal and environmental factors is consistent with the science of unitary human beings and family ecological theory. Study of fluctuations in energy requirements and use within systems fits into frameworks of both family ecology and unitary human beings. Continuity theory is consistent with Antonovsky's (1979) contention that a sense of coherence is essential to hardiness because it provides a sense of order or stability within a dynamically changing system.

## Summary of Relationships of Data to Theories and Concepts

The data suggest that caregivers maintained strong commitment over time in spite of complex challenges presented by functional deterioration of husbands. Data also suggest that the knowledge and skill needed to provide care develop over time as caregivers face challenges which required expenditure of creative energy in efforts to regain control. All of this occurs with families maintaining order by providing stability within the environment and continuing prior activity patterns to the extent possible.

Data from this study suggest that family hardiness may be a characteristic that enhances a family's capacity to provide care. Commitment to the family unit is apparent from the number of years married and the determination to provide home care as long as possible. While caregivers indicated they missed the shared decision making that used to be possible, they still prize shared memories, feelings, and experiences they are able to enjoy with their husbands.

Indications that confidence is maintained in these families include the strong sense of purpose expressed by the caregivers and their ability to plan for the future. While the caregivers at times expressed uncertainty about their skill or ability to provide care, they were confident that their husbands expected this of them, and most were confident that their husbands appreciated the care they provided.

The caregivers studied have accepted the challenge of caring for a spouse with a progressive disease, and are actively seeking information on how to continue providing care. Exciting new experiences are not being sought by these families since a familiar environment is most comfortable to the spouse with Alzheimer's disease. Instead the caregivers are trying, with limited success, to continue some of their prior social activities.

Most of the caregivers studied have accepted their husband's illness as something they cannot control, but can accept. All of the caregivers are maintaining some control of their environment. They have decided where it is best to live, and have made environmental adaptations that are protective in nature.

The sense of control felt by caregivers is directly affected by energy resources. As internal resources diminish, assistance is sought from the environment, with both control and responsibility being shared. Increasing energy demands result in family reorganization, with greater reliance upon extended family and community support.

## Grounded Theory Developed from the Data

Based on the data collected for this study, grounded theory was developed in relation to care and the dynamics of family care.

## Care

Based on the findings of this study a definition of care and a description of the capacity to care has evolved. As an extension of the theory generated by this study, this effort at conceptualization may help address the need for a description of care at the family and community level (Morse, Botteroff, Neander, & Solberg, 1991). Although some may argue with personal discomfort as a component of care, it is consistent with data from the study and with the original meaning of care as derived from "chary", which initially meant sorrow or sorry and later meant trouble (Shipley, 1945).

Care is the commitment of personal energy to assist, protect, or nurture another in spite of personal discomfort and without expectation of direct reciprocity. When dealing with care demands beyond one's knowledge and skill level, discomfort is felt and safety of the provider and recipient of care may be compromised. The level of personal discomfort one is willing to endure in order to provide care is related to the depth of commitment to the recipient. Overcommitment resulting in imminent threats to safety can occur, resulting in serious threats to one's capacity to care.

To provide care is to express one's energy commitment through activities of benefit to the recipient(s) of care. Skill in providing care is passed down through generations of caregivers. It is by utilizing those skills to benefit others that care is expressed. It is possible to gain knowledge and technical prowess related to care, but without dedication to others true care cannot be provided.

The capacity of individuals or families to provide care is dependent upon personal and environmental resources. An inverse relationship exists between energy resources and capacity to provide care. People providing care must receive it from others or their capacity to continue providing care will diminish in conjunction with their personal energy reserves.

Care is provided by individuals and groups, including the family. Families and groups provide a network within which personal caring energy can be exchanged. A collective capacity to provide care is thus established. Social organizations and structures can contribute energy to further enhance the capacity of an individual or a system to provide care. If energy flow is disrupted through any of the support systems, the energy supply of the individual or system providing care will be adversely affected.

### Dynamics of Family Care

The family that is capable of providing care to members is one that is dedicated to self-reliance, with reliance upon assistance from the social environment occurring when care demands exceed family resources. There is a limit to a family's resources related to care. When confronted with situations for which family resources will support safe care that the family is comfortable with providing, reliance upon community resources is not necessary. When faced with challenges that demand skill or energy in excess of family resources, community resources are vital to continued provision of safe family care.

With education and support from the extended family and community, families can learn to provide care that may be new and uncomfortable for them, but which they can provide safely with bolstered resources. Families faced with progressively demanding care challenges may eventually reach the point where family care is no longer safe for the provider and/or the recipient of care. At this point the focus of responsibility is likely to change, with community resources taking over the main responsibility for care and families taking on a more supportive role.

The capacity of a family to provide care for its members evolves over time as members develop a sense of commitment and gain caregiving skills in the context of family and community. The sense of commitment is based on an understanding of the interdependence of individuals within the family system and the interdependent relationship between the family and other social systems. Caregiving skills are learned as knowledge is shared and experience occurs with taking responsibility for meeting the human needs of others.

Life experience with care needs of members influences the ability of families to adjust to caregiving situations with which they are not comfortable. When such challenges occur, families dedicated to self-reliance initially try to regain control and comfort by using creative problem solving skills developed through prior experiences. If those do not work they seek assistance from the environment, often in the form of education or social support. Families capable of meeting such challenges incorporate the new experiences and skills into their repertoire of coping behaviors. They gain confidence in their future ability to deal comfortably with similar situations.

There are three zones in which family care is provided. When faced with care demands that fall within one's knowledge and skill level confidence is maintained and the caregiver functions in a safe zone. As care demands move beyond one's knowledge and skill level, confidence is dependent upon acquisition of new knowledge or skill. If caregivers try to meet those demands without added knowledge and skill, they find themselves functioning in an uncomfortable zone. Acquisition of the needed knowledge and skill, on the other hand, would expand the skills of the caregiver and the zone in which it is safe to function. Eventually care demands may move into the unsafe zone, where the knowledge and skill needed to meet care needs is beyond the ability of a family caregiver. At this point continued provision of safe care requires the skill level found in professional caregivers.

Families caring for a member with an irreversible, progressive condition eventually find themselves in a situation where continued provision of care by the family may prove dangerous to the care provider and/or receiver. Those families with the strongest commitment to each other will remain dedicated to provision of home care in spite of the dangers. Other families will not tolerate repeated signs of danger. Instead they will seek alternatives to home care once it is clear that continued provision of such care may result in illness or injury of a family member.

Each time a family is confronted with situations with which they are uncomfortable, energy is expended in efforts to cope. Families dealing with progressive deterioration eventually find themselves in that situation much of the time, experiencing energy depletion that is chronic and cumulative in nature. Energy is dissipated and a state of entropy occurs, accompanied by loss of a sense of stability and control. When that happened even those families with the strongest commitment of family care seek assistance with care, eventually considering alternatives to home care. When alternatives to home care are necessary, family patterns of commitment to care continue, although the type of care may change from direct to supportive care.

## Implications

The findings of this study relate to individuals with senile dementia, family care, and family research and theory. Discussion of implications is organized in relation of those categories.

### Individuals with Senile Dementia

Individuals with Alzheimer's disease are in large part an unresearched population. Family members and professionals providing care to these individuals have served as data sources for researchers, but data are lacking from the person with the disease. The data from this study suggest that with proper safeguards these individuals can be studied directly. Those who know of their diagnosis can provide valuable insights into how they feel about their diagnosis and their care.

In this study initial anxieties of informants with Alzheimer's disease with regard to participation in a research interview seemed to be relieved by the procedure used for data gathering. Factual data were obtained first, with both members of the dyad present to provide information for the genogram. While information regarding the family of origin of the member with Alzheimer's disease was requested, the wife was present to provide information and support as needed. By the time individual interviews with husbands were performed the men had become acquainted with the researcher and comfortable with the process. A similar approach may be helpful for others conducting research with such informants.

Data from this study suggest the date of diagnosis of Alzheimer's disease may have little significance to researchers. Often symptoms of the disease appear years before a diagnosis is sought. In designing studies researchers should determine if it would be more useful to gain information on when symptoms began and when they were first recognized as problematic. Such information can be used to understand the time frame within which adaptation has occurred, but it is not as effective as meaning at predicting stress or adaptation (Motenko, 1989).

Based on the data obtained in this study, families caring for a member with Alzheimer's disease or similar forms of memory loss may find reminiscence meaningful. Reminiscence may provide a framework within which positive family communications can be maintained. Reminiscences can be audiotaped or videotaped for storage with other family keepsakes.

Families can be provided with advice that may assist them in successful acquisition of taped reminiscences. With minimal training they should be able to successfully guide simple reminiscence (Losee et al., 1988; Rybarczyk et al., 1990; Thoits, 1986). The best time to record reminiscences appears to be prior to, or immediately after, the time when significant memory loss becomes apparent.

When factual data cannot be recalled accurately, families can be advised to try more abstract descriptive questions related to prior activities, work and family.

## Family Care

If the commitment and skills needed to successfully engage in family care are learned, who is being taught and who is doing the teaching? Some of the women in this study were concerned about what they perceive to be a lesser degree of commitment in younger generations. They were able to describe how the value of commitment was transmitted through five generations, but they also indicated they did not want their offspring to feel the burden of overcommitment. They did not want to burden their children with family care responsibilities similar to those they had accepted throughout their lives. What these women may be seeing, and contributing to, is cohort variation in the balance of commitment to community versus commitment to individualism (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985; Strauss & Howe, 1991).

It has been projected that from now through the first few decades of the twenty-first century the United States will be faced with an increasing number of dependent elderly and an insufficient number of professional caregivers (Nationan Institute on Aging, 1987). Expectations related to family care must change to conform with demographic trends. With more women working outside the home than ever before, society cannot assume they will continue to provide care to the extent they do today. It is imperative that we change our assumptions regarding the provision of care and the acquisition of caregiving skills. People of both genders must be taught commitment to others and caregiving skills. Both family and community organizations need to determine how they can promote commitment to care.

While personal faith was identified as a support by almost half of the caregivers, they did not indicate they were receiving support from organized religion. Instead they spoke of the barriers they had to overcome in order to attend church. Many churches have nurseries to care for the young while parents attend worship services. It may be time for them to explore the possibility of providing respite services in home for caregivers whose responsibilities prevent their active participation in church activities. Based on the preference of some men for male caregivers, traditional male service organizations could be encouraged to think about new community service projects related to provision of care.

The current socio-cultural environment in the United States has fostered reliance upon specialists rather than development of a sense of personal competence to work interdependently with family and community to solve problems (Grace, 1990). Instead of providing disabling help which promotes dependence, professional caregivers can best serve families by enabling them with regard to care (Benner & Wrubel, 1989; McKnight, 1978). By expanding a family's repertoire of caregiving skill professional caregivers can enhance the confidence of family members and their ability to cope with changing demands related to family care (Pearlin & Schooler, 1978). Such enabling practice is consistent with changes in family life anticipated by Settles (1987), who suggests families of the future will have more opportunities to choose from therapeutic and support options based on their knowledge of expected outcomes.

Professional caregivers can enhance safe care and widen the range of situations with which family caregivers feel comfortable by providing instruction on basic elements of care. This has traditionally been accomplished on an individual basis through home care agencies. There may also be a role for educational institutions to play. Basic concepts of care that are applicable to a wide range of family situations could be part of community education programs provided by academic institutions.

If we are to safeguard the health and security of those who give and receive care, community support must be available to families faced with home care challenges. For those who are uncomfortable with the caregiving requirements placed on them, education and support services may be all that are needed to help them continue providing home care. In situations where there are repeated and progressive threats to safety of either the giver or receiver of care, options other than home care are essential.

Public policy can be most effective if the goal is to support, not replace family care (Cook-Deegan et al., 1988). Public policy is needed that maximizes the family's capacity to provide care. Such a policy is only possible if the public accepts the concept that society has an obligation to provide services that will support caregiving families. To achieve that end family scientists must be willing to influence the debate on allocation of resources, standards of care, and the shared responsibility of family and society (Pratt, Schmall, & Wright, 1987).

## Family Research and Theory Development

More study is needed on the dynamics of family care since such research is limited (Morse et al., 1991). It is essential that we understand factors that help develop or diminish a family's commitment and capacity to provide family care. The dangers inherent in home care of demented individuals, and the possibility of overcommitment, need to be further documented. Further exploration of the concept of zones of care would clarify family experiences and resource needs. Such data could be useful as supportive evidence of the need for better alternatives to home care for the demented.

The concept of family hardiness may prove useful in understanding why some families are more capable or providing care than others. It may also help clarify the types of interventions families need and the situations in which specific interventions are most beneficial. If research verified the strong relationship between family hardiness and the ability of families to provide home care for disabled members, efforts to promote family hardiness might gain government support.

If the Family Hardiness Index were used on the families in this study they would fall short in several areas because of adaptations they have made to accommodate the member with Alzheimer's disease. The question is: Are the families really less hardy or must the index be adapted to measure hardiness accurately in families with members with disabling conditions?

Life histories provide rich data that must be analyzed within the context of culture (Jones, 1983; Watson et al., 1985). Family members are capable of providing life history data that describe both individual and shared experiences and meanings. Family histories provide insights into how family values, skills, and characteristics are transmitted between generations. As qualitative studies become more acceptable, the unlimited data source of family histories can be explored from an infinite number of perspectives.

Meanings ascribed to care can differ markedly between family members and health professionals (Hasselkus, 1988). Research on prevailing patterns of meaning and methods of clarifying meaning are needed. Replication of this study with male caregivers would contribute to our understanding of gender differences related to family care. Such a study might clarify intergenerational patterns contributing to gender specific differences that have been documented in relation to caregiver feelings, needs, and expectations of themselves (Dressel & Clark, 1990; Reker et al., 1987; Pratt et al., 1987; Smith et al., 1991).

## Summary

In this study qualitative methodology was used to analyze the relevance of life history to family care of a member with Alzheimer's disease. Life history methodology proved effective for generating a large amount of data describing family patterns over multiple generations. Historical data from genograms and interviews were compared with data from interviews and observations related to current functions of providers and recipients of care.

The main family care themes that emerged from the data were commitment and coping with progressive loss. Findings were related to continuity theory, the science of unitary human beings, and family ecological theory as well as to concepts of hardiness and energy use in systems.

Grounded theory on care and the dynamics of family care evolved from the data. Care was defined and the capacity to provide care was described. The capacity of a family to provide care was seen as dependent upon learned commitment to family and community as well as learned interdependence between social systems. Commitment to care was hypothesized to depend upon perceived comfort and safety of family members, energy requirements and resources, and cohort socialization. The concepts of zones of care within which families function was introduced. The boundaries of safe family care were described as they relate to knowledge and skill.

Implications of this study were discussed relative to individuals with senile dementia, family care, and family research and theory. It was noted that more research is needed which gathers data from people with Alzheimer's disease, focuses on the dynamics of family care, and clarifies the relationship between hardiness and family care. The roles of educators, professional caregivers, family scientists, and policy makers were discussed as they relate to empowering caregiving families.

# APPENDICES

# APPENDIX A

## Consent to Participate in Research

For over 23 years I have worked as a registered nurse, and am now on the nursing faculty at Saginaw Valley State University. I am in need fo families for the research project that will complete my doctoral studies at M.S.U. This research will provide professionals with information needed to improve their understanding of families dealing with Alzheimer's disease.

I need couples who are living together, with no other permanent resident in their home, and with at least ten years of marriage before the Alzheimer's disease was diagnosed. Men must be 60 years of age, diagnosed as having Alzheimer's disease at least six months ago, and capable of carrying on a conversation with a stranger. Their wives must be the primary person responsible for the husband's care.

Each couple will be interviewed in their home, with the visit lasting approximately two hours. Couples will be asked questions about people and life experiences that have been important to them. Interviews will be scheduled at a time you find convenient. It may be necessary to schedule more than one interview if all of the information needed cannot be gained on the first visit.

You may choose not to answer any question I ask, and can decide you do not want to continue participating in this project at any time. Conversations will be recorded on a tape recorder, so I can remember what you have said.

To assure your confidentiality I will only use family initials on any notes or tapes. The information I get from this project will be used for my doctoral dissertation and for professional speeches or articles, which will never include your name or information that would allow anyone to identify you.

If you are willing to participate in this study please provide the information requested on the attached sheet. You can keep this page for your own information.

Thanks for your help. I will phone you to schedule my visit.

Margaret M. Flatt 790-4131 (work)

# Consent to Participate in Research

I consent to participate in the research, and understand the conditions noted on the explanation sheet.

Signature: ______________________________ Date: __________

Wife's name: ______________________________

Husband's name: ______________________________

Husband's date of birth: ______________________________

Wife's date of birth: ______________________________

Date of marriage: ______________________________

Month and year Alzheimer's diagnosed: ______________________________

Husband's medications: ______________________________

______________________________

Address: ______________________________

Phone: ______________________________

# APPENDIX B

## Communication Guides

Telephone contact to schedule first visit

Hello Mrs. ______, this is Margaret Flatt. Thank you for agreeing to participate in my study of couples living with Alzheimer's disease. I would like to schedule my visit to your home during the week of ______. I am available on ______ from ______ to ______ o'clock. Would any of those times be good for you?

When I come I will be asking for information about you, your husband, and your family trees. I am interested in knowing about people and experiences in your lives that have been important to each of you. You may have some family pictures or objects that remind you or your husband of those people or experiences. If so, please share these things with me when I come to your home.

After we finish the family tree I will ask some questions, first of your husband and then of you. Is there some way that I could do this in private? Is there a place where I can talk with each of you individually, without the other overhearing? I have questions to ask about your experiences with caring for your husband.

What does your husband know about his diagnosis? Do you talk about his condition in his presence? If so, how does he deal with that?

I will see you on ______ from ______ to ______ o'clock.

Explanation for informants with Alzheimer's disease

Hello Mr. ______, I am Margaret Flatt. Your wife agreed that I could come talk with both of you about the people and experiences in your life that are important to you. If that is all right with you we would like to have you join us as we talk.

Genogram

I want to construct a family tree that will help me understand the families you and your husband came from, as well as the family you and your husband started.

Interview Guide

There are five main questions with related probes, some of which (cg) are only for the caregiver.

1. Who would you identify as the people who had the greatest impact on your life? (cg: Were you exposed to any people who took care of other family members? How did their experiences with caring for family members compare with your own?)
    a. What important lessons did you learn from these people?
    b. What influence did they have on the values you hold today?
2. What experiences in your life had the greatest impact on you? (cg: How have these experiences contributed to, or hampered your ability to care for your husband?)
    a. What was the most important thing that happened in your life?
    b. What was the happiest day of your life?

   c. What was the saddest day of your life?
   d. What are you most proud of about your life?

3. How would you describe a typical week in young adulthood and middle age?
   a. How did you spend most of your time?
   b. What hobbies or leisure activities did you enjoy?

4. How would you describe a typical week now?
   a. How do you spend most of your time?
   b. What hobbies or leisure activities do you enjoy now?
   c. (If changes have occurred) What factors have caused changes in how you spend your time? How do you feel about the changes? What impact do they have on you?

5. How would you describe yourself at this point in your life?
   a. What is the best thing happening in your life right now?
   b. What is the worst thing happening in your life right now?
   c. What lessons do you hope your children have learned from you?

6. What do you think your future will be like?
   a. What will remain the same?
   b. What will change?

# APPENDIX C

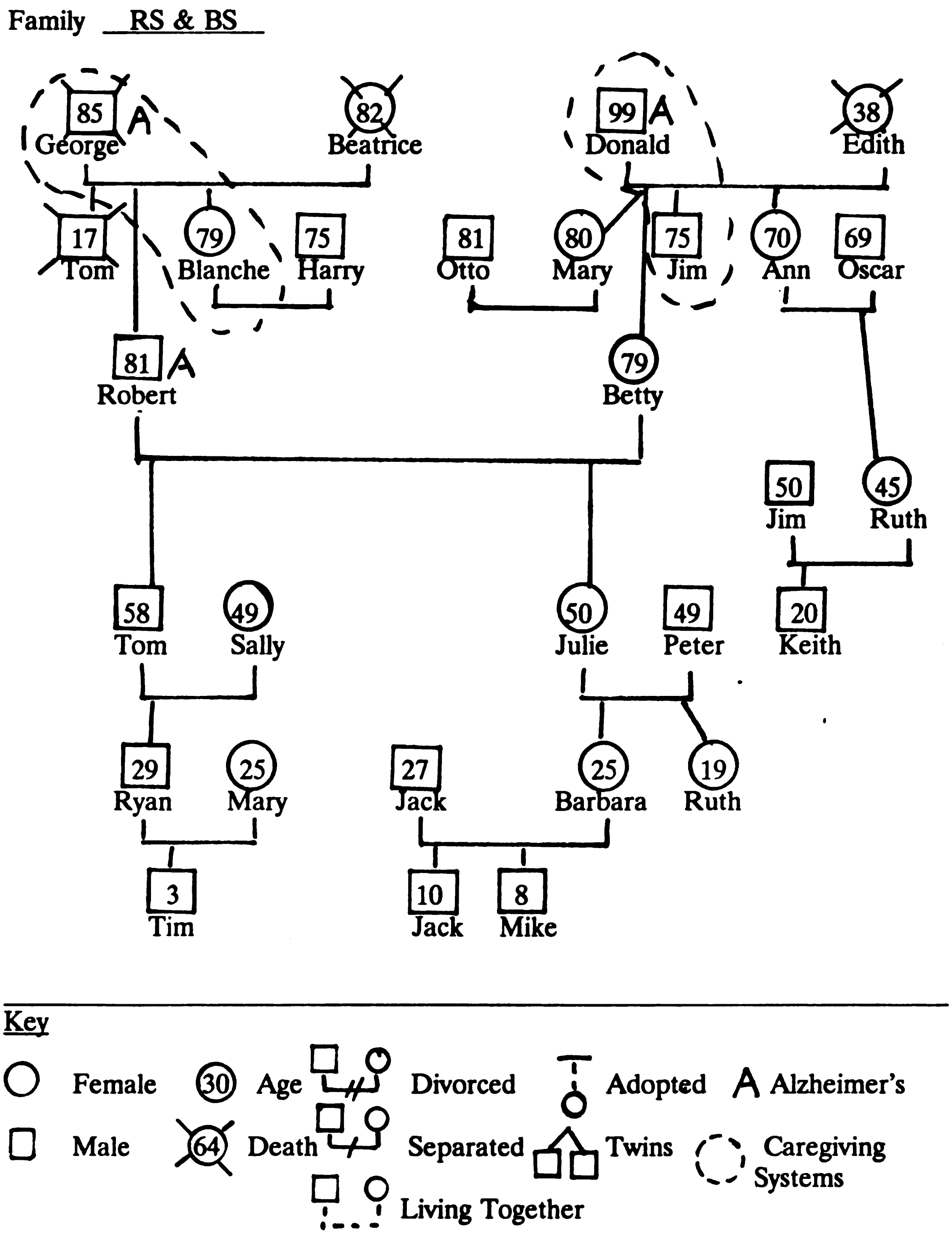

Figure 1: Simulated Genogram

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