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Connecting: Meeting the needs of family caregivers.

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Connecting: Meeting the needs of family caregivers

Rawlins, Shirley Rogers, D.S.N.

University of Alabama at Birmingham, 1989

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CONNECTING: MEETING THE NEEDS OF FAMILY CAREGIVERS

by

SHIRLEY R. RAWLINS

A DISSERTATION

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Science in Nursing
in the School of Nursing in the Graduate School
The University of Alabama at Birmingham

BIRMINGHAM, ALABAMA

1989

ABSTRACT OF DISSERTATION
GRADUATE SCHOOL, UNIVERSITY OF ALABAMA AT BIRMINGHAM

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Individuals who engaged in caregiving responsibilities for dependent family members in the home setting faced challenges that were little understood by others outside the circle of care. Because a large portion of energy was devoted to caregiving tasks, caregivers potentially failed to devote attention to meeting their own needs. The purpose of this study was to develop a beginning substantive theory describing the needs perceived by caregivers and the processes by which these caregivers were able to get their individual needs met. Grounded theory methodology was used to facilitate the identification of these needs and processes. This study concluded that the needs for help, hope, and happiness were the most crucial needs of family caregivers. The basic social process of connecting was identified as fundamental to meeting caregiver needs. Subprocesses of misconnecting and disconnecting were identified as concurrent processes that existed as functions of connecting and affected the connecting process. In their struggles to find ways to meet their needs for help, hope, and happiness, caregivers initially experienced misconnections with those people and agencies that were perceived to be in a position to help.

Through efforts that were mostly trial and error, caregivers learned how to disconnect with resources that were fruitless and connect with those that were helpful. Those caregivers who were most successful in finding ways to meet their individual needs were those who could endure the frustrations and heartbreak of the misconnections and disconnections eventually to connect with positive, energetic resources that empowered them to survive by fulfilling their needs for help, hope, and happiness. The connecting process was seen as an organizing concept which could give direction to the teaching and practice of nursing care for caregiving families and which could lay the foundation for continued research and theory development. Recommendations for future research included such questions as how these needs and processes might apply to in-patient settings for nursing care and how the nurse's needs for help, hope, and happiness might influence the ability to meet these needs in others.

Abstract Approved by: Committee Chairman ____________

Program Director ____________

Date ____________ Dean of Graduate School Terry L Hickey

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With the successful completion of any worthwhile endeavor, there comes a realization that special people offered themselves to facilitate the achievement of that goal. In ways they do not recognize, they have offered those precious gifts of presence and love that gave life to a creative spirit that was seeking to learn and to grow.

To Buddy, the patient encourager, I give my love and appreciation for helping me to connect with a secure time and place to do my growing. His positive outlook toward the future was a stable rock for the pursuit of a life-long goal.

To Libby and Kelly, two beautiful young ladies, I say thank you for allowing me to take a part-time sabbatical from their lives and continuing to say they loved me.

To my friend, Susan, I say thank you for keeping me excited about my learning and for sharing with me her sensitive insights into the valuable things in life.

To my chairperson, Dianne Piazza, and my other committee members, I say thank you for their uplifting even when I perceived my efforts to be rusty.

And finally, I say thank you to those special family caregivers who taught me how to be more sensitive to unspoken needs. They were willing to share intimate thoughts and feelings related to their struggle to connect, and they showed me the importance of being a helper who inspired hope and gave others permission to be happy. My heart goes out to these brave people who fulfill difficult roles in order to maintain their connections to the people they love.

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CHAPTER I

The Research Question

The family has been considered the most important contextual influence in human growth and development (Belsky, Lerner, & Spanier, 1984). Families are an integral part of society and provide a strong foundation for the development of individual social and cognitive skills. The family unit is a major contributor to the formation of adequate coping strategies in the development of an individual's personality and has the potential for providing an ill individual with equilibrium in the face of stress. Stanton (1984) pointed out that individuals who have been able to have basic needs consistently satisfied prior to an injury or illness will have the ability to withstand the thwarting of needs that might occur with that injury.

How a family reacts to real or threatened illness strongly affects attitudes, coping, health practices, and other aspects of family life (McGuire, 1984). In studies of families of cancer patients, Thorne (1985) discovered that families valued a positive attitude as central to its ability to deal with crisis. Families also came to realize that their own intuitive reactions were more reliable than advice from authorities and enabled them to create more useful ways of coping with illness and disability.

Nurses have long been involved in providing direct care to families, especially in psychiatric and community settings (Murphy, 1986). The increased public demand for home health care services has provided an opportunity for even greater expansion of nursing services to families in the community and has afforded many unique opportunities for research.

Historically, research on families by nurses has focused on the individual within the family rather than the family unit (Murphy, 1986). When research limits its focus to individuals, the conceptual and methodological difficulties associated with studying the family as a unit are bypassed (Thorne, 1985). However, this approach seriously limits using the findings for anything other than relating one individual's experience. If nurses are to be effective in the delivery of services to families in the community, research efforts must focus on the holistic needs of those family systems and how those needs are met.

One specific group that would benefit from nursing research and intervention in the community is the group of family caregivers who are engaged in home health care activities. Economic, sociological, and political factors have combined to increase the numbers of ill or disabled individuals who are being cared for in the home setting. Since nurses are the primary professional health care providers assisting with home care, and because research needs to focus on family needs rather than individual concerns, nursing research was conducted on families related to the caregiving role in the home. Specifically, the focus was upon the needs of family caregivers and the processes by which these needs were met as the basis for a qualitative research study.

Statement of the Problem

Two major trends in health care have accounted for an increasing popularity of home health care. The institution of prospective payment systems has resulted in shorter hospital stays for acutely ill persons, and the number of health care services that can be performed in the home has greatly increased (Gutierrez, 1985). Families are responsible caregiving agents who provide substantial physical, emotional, social, and financial support to ill members, especially to chronically ill elderly relatives. National health statistics indicate that families provide approximately 80% of all home healthcare for elderly persons who need support (Brody, Poulshock, & Masiocchi,1978).

As families face crises in their lives, the individual members of those families are subjected to changes in routines. Kaplan, Smith, Grobstein, and Fischman (1977) pointed out that individuals do not resolve personal crises independently but rely on their family unit to assist them. In a situation of chronic illness, certain family members may find their roles changing such that they take on the caregiver role. This caregiver role is an all-consuming one that affects almost all aspects of a person's life (Goldstein, 1980). In order to provide optimal assistance to family groups affected by a member's illness or disability, nurses cannot limit the focus of their nursing intervention to only the ill member; it is important to study the family as a unit.

Family caregivers frequently are expected to provide the major social support system for the ill individual and to serve as the major link between the patient and the community. These same caregivers often are expected to put the patient first and neglect their own needs, thus fulfilling the caregiver role without clearly defined rewards or values clarification (Rew, Fields, LeVee, Russell, & Leake, 1987). With a health care focus on the needs of the identified disabled person in the family, those who fill the role as caregiver frequently are left to struggle alone in balancing role changes and added responsibilities.

One frequently noted occurrence in families who have a chronically ill member is that those who become the caregivers are vulnerable to developing stress-related disorders. For these reasons, nurses and other health care providers need to focus attention on the actual or potential health care needs of other family members (Sexton & Munro, 1985).

Family centered nursing care is important for many reasons and will facilitate effective interventions for individuals as well as families. Feetham (1984) has urged nurses to focus on the family system in order to better identify and test research questions and to examine variables which may be most predictive of family well-being.

To date, the majority of research by nursing and other disciplines on family caregivers has been done in relation to caring for elderly family members in the home (Bowers, 1987; Chenoweth & Spencer, 1986; Crawford, 1987; George & Gwyther, 1986; Soldo & Myllyluoma, 1983; Winogrond, Fisk, Kirsling & Keyes, 1987). Nursing research has focused on care of the elderly as well as on more specific needs of family caregivers such as role fatigue (Goldstein, Regnery, & Wellin, 1981). Research also has been done specifically on families of cancer patients (Hinds, 1985), psychiatric patients (Rose, 1983), and hospitalized neurotrauma patients (Richmond & Craig, 1986). Other nursing studies have briefly addressed characteristics of caregivers (Goodman, 1986) and caretaking roles (Davis, 1980). However, no theory-generating approach to the needs of family caregivers has been done by nurses. The process related to how family caregivers get their needs met has not been described or explained in such a way as to formulate the beginnings of a theoretical framework for nursing intervention for this group in the home setting.

Significance of the Problem

The lack of a clear substantive or formal theory related to caregiver needs and how these needs are met potentially handicaps nurses in the delivery of care to families in the home. Although nurses may have become aware of family caregiver needs through interactions with these families, no theoretical basis for specific intervention with this group has appeared in the literature.

Chinn and Jacobs (1983) have stated that theory development in a practice discipline such as nursing must occur through research. The first stages of theory development are concept analysis and the construction of theoretical relationships. These two preliminary steps must precede the testing and validation of theory, two additional steps required for full theory development. Concept analysis and the construction of preliminary theoretical relationships are needed in relation to family caregivers to provide the foundation for further development and testing of the emerging theory. A qualitative study conducted on the process of caregiver needs being met can develop into an initial substantive theory which can be developed into a formal theory by additional research.

Research Questions

In light of the established need for theory development related to family caregiver needs, the following research questions were proposed: What are the needs reported by family caregivers? Are those needs being met? What are the basic processes by which caregivers get these needs met?

Assumptions

The basic assumptions of this research study were as follows:

1. There are basic processes for getting needs met which are common to all groups of family caregivers, regardless of the nature of the caregiving tasks.

2. Family members are able to share verbally their feelings related to the caregiving experience.

3. The researcher's own life experiences will influence data analysis and theory development (Gilliss, 1983).

Definition of Terms

The major terms used in this research study are defined as follows:

1. Needs--tangible objects or nontangible feelings or states of being perceived and reported by an individual to be necessary to well-being or survival; for example, a tangible need might be money or friends, whereas a nontangible need might be love or concern.

2. Family--a group of interdependent people who are bonded to each other to varying degrees by heredity, marriage, adoption, or choice.

3. Family caregiver--an individual layperson engaged in tasks aimed at eliminating perceived physiological, psychosocial, emotional, or spiritual burdens of another

individual who is related by heredity, marriage, adoption, or choice.

4. Home--usual place of residence of the identified ill or disabled individual which is not in a formal hospital, extended care facility, or other public institution.

5. Basic processes--dynamic methods used and reported by most individuals for achieving certain outcomes; these processes explain a considerable portion of the behavior of individuals (Glaser, 1978).

Limitations

Acknowledged limitations of this study are as follows:

1. The researcher's ability to conduct in-depth family interviews and analyze the information may influence data collection and the resulting depth of the emerging theory.

2. The presence of a tape recorder during the interviews may affect the degree of comfort in verbalization by some family members.

3. Generalization of the findings of this study cannot be made beyond the sample surveyed.

Conceptual Framework

The qualitative approach to this research study was guided by grounded theory methodology. Inherent in this methodology is an entrance into the research setting with as few predetermined ideas as possible, especially logically deducted hypotheses. With the grounded theory approach, a theoretical framework is constructed from the data rather than a previous framework being identified to guide data collection (Glaser, 1978). For these reasons, it is not appropriate to identify an initial theoretical framework. Despite this deliberate choice to postpone identification of the theoretical framework until it emerges from the data, the researcher inevitably will approach the research project with some prior philosophical beliefs that serve to shape the project.

One very basic operating theoretical framework which has served to guide the framing of the research questions and which has guided the researcher's approach to data gathering and analysis is family systems theory. According to Fawcett (1975),

> the family system is a living open system, constantly exchanging energy with the environment and increasing its differentiation. It is an integral, unified whole which is more than and different from the sum of its parts. The family is patterned and organized (p. 114).

The existence of this operational framework in the research approach was consistent with the grounded theory methodology, which views the basic social processes of life as being dynamic methods which explain the actions and behaviors of people. Another inherent characteristic of the grounded theory methodology is the necessary emersion of the researcher in interaction with the family and in the collection of data. Family systems theory likewise acknowledges that the family readily exchanges its energy with others and that these interactions have a mutual effect on all participants. According to family systems theory and grounded theory assumptions, both the families and the researcher will be changed by the research process. The grounded theory methodology, in itself, provided a framework for conducting the study. This approach allowed for considerable creativity from the researcher while requiring certain procedural steps in the conduct of the study. An adherence to the accepted standards of the methodology related to sampling, coding, memoing, analyzing, and conceptualizing also defined boundaries for the project, thus establishing a framework. The combination of a systems framework with grounded theory methodology provided a harmonious and appropriate approach to this study.

Summary

The family was identified as having an important influence on the health of its members. Nurses' involvement with families and their health concerns was established with a demonstration of the need for more nursing research with family groups. Health care trends and the potential effects on the home health care issue were examined in relation to the increased necessity for family members assuming caregiver roles. The lack of a clear substantive or formal theory on the needs of family caregivers stimulated the development of three research questions to be addressed in this study. A view of the family as a dynamic system will be combined with a grounded theory methodological approach to generate theory pertaining to the process of meeting the needs of family caregivers.

CHAPTER II

Review of Related Literature

The Family System

A theoretical approach relevant to health care that permits viewing the interrelatedness of the dynamic family member within a dynamic family unit has been recommended by Gilliss (1983). Since it has been established that an illness in one individual affects the entire family unit, a study of how the family relationships impact on the adjustment process is vital to an understanding of family dynamics during crisis or illness.

Fawcett (1975) defined the family as a group of interacting individuals that comprise the basic unit of society. The family system is greater than the sum of its individual parts, and family health or well being is more than the sum of each family member's health status (Litman, 1974).

Wright and Leahey (1984) expanded this basic view of the family system in a description of five concepts related to the family. First, the family system was seen as part of a larger suprasystem such as a neighborhood or church community, as well as being composed of many subsystems such as the parent-child relationship. Second, the family was seen as a whole system. Observation of the entire family system in its interactions was seen as an important way to more fully explain individual family member functioning. Third, a change in one family member affected all family members. As one family member changed, the other members would be unable to respond as they had done previously because of that family member's altered behavior. Fourth, the family was viewed as having the ability to create a balance between change and stability. When sustained change occurred, a shift to a new position of balance or normality occurred. The last concept was that the behavior of family members was best understood from a view of circular rather than linear causality. Each individual's behavior influenced that of other members in a fluid interaction.

Ericksen and Leonard (1983) described two major components of the family: processes and functions. Family functions included those of maintenance, support, and identity. The adequate achievement of these functions varied according to the family's values. Family processes included structure, interaction, community interplay, and health behaviors. These functions and processes were offered as a framework for family assessment and intervention by nurses.

Friedman (1980) discussed family structure and function. Structure was conceptualized as the organization of the family members and the pattern of relationships among them. Structure encompassed communication patterns, role relationships, value systems, and power structure. Family function was viewed as the purposes or goals of the family system which encompassed the promotion of individual growth and development and the adaptation to internal and external demands to maintain viability. The family system was able to grow while maintaining itself through adaptation to change.

Murphy (1986) pointed out that the family context made a significant impact on the health outcomes of individuals. The concept of family fit into the nursing paradigm in two primary ways. The family could be perceived as the client which was the recipient of nursing care, or it could be viewed as the context or environment that influenced the health of members within the family system. For the purposes of family study, a framework that viewed individuals and families both as the person and the environmental concepts was suggested as a way to analyze the family. In this way, the individual's impact on the family as well as the family's impact on the individual might be studied.

Stressful life events were seen to create change in the family system to such an extent that crisis could occur. Differences occured in the ways families responded to these changes and attempted to regain equilibrium. Hall and Weaver (1974) have proposed six processes that are crucial to survival of a family during change and crisis. Cognitive mastery involved raising the family's level of awareness about the situation to allow purposeful problem solving to occur. Families strived to obtain compliance from the environment as a means of meeting survival needs. The family also sought to exercise control over the situation, a process that occured best when individual family members were committed to the group and its goals. Coalition formation described the way family members aligned themselves in relationships within the family system. For example, a strong marital dyad facilitated a supportive environment for children. The communication process was viewed as the most important determinant of the quality of family life. Open family systems have the potential to experience growth as the result of crisis. Choice of alternatives was a process based on family values and norms which enabled the family to work toward common goals related to survival of the crisis.

Bowen (1978) described the concept of "emotional shock wave," a network of subtle "aftershocks" of serious life events that could possibly occur in the extended family system in the months or years following serious emotional events or losses in a family such as illness or death. This process occurred most often in families with a significant degree of emotional fusion. Any human problem could trigger delayed symptoms of physical or emotional problems such as increased incidence of respiratory conditions or allergies, as well as depression or psychotic episodes. Social dysfunction could occur in the form of alcoholic drinking, failure in school or business, or an increase in accidents. The process was not directly related to the expected grief process and generally was not recognized or was denied by the family. Health practitioners were urged to be aware of this possibility when dealing with families that had endured traumatic life events.

Individual characteristics of the particular researcher influenced the outcome of studies of the family system. Gilliss (1983) suggested that a researcher's philosophy about the family governed what would be looked for and discovered in a study of the family. The investigator's feelings and thoughts about his or her own family inevitably affected the research process.

Preliminary to an understanding of how family systems experienced change was an exploration of the characteristic strengths of functional families. Feetham (1984) urged researchers to examine concepts common to healthy families and to examine how families grew and developed in spite of illness. A focus on these family strengths would help identify predictors of family health.

Family Caregivers

Goodman (1986) conducted research on the characteristics of the informal caregiver. A review of the literature by this researcher revealed that the family was the primary responsible caring unit in the community. The principal helpers in the home were age 50 years or more and usually were female. Daughters tended to carry the major burden of caring for dependent parents, even when sons were available to potentially give assistance. When an elderly parent was living in the home of a daughter, the daughter's husband rarely gave direct help to the wife in the care of the dependent relative, even when the wife also was employed. Women were the key caregivers in care of mentally ill individuals in the community. A publication by the Equal Opportunities Commission (1981) concluded that family care often was a euphemism for care by the nearest female relative.

Parker (1985), in conducting research into the health and welfare of caregivers, concluded that public services were allocated irrationally and were discriminatory when the caregiver was a woman. These resources also were fragmented in their organization, rendering them of little use to the caregiver.

Davis (1980) compiled five categories from the literature that served as a framework for examining the emotional and social patterns which arose in families who cared for an adult disabled person living at home. These categories were the weighing process, therapeutic process, interactional system, social context, and adaptation to perceived misfortune. The weighing process was a decision-making process that led to the initial choice of home care and assumption of the caregiving role. Several factors affected this weighing process and included such facts as the nature of the handicapping condition, the age and health status of the major caretaker, and family values and beliefs about responsibilities. The therapeutic process involved aspects of family caregiving that included actively stimulating the disabled person's potential and encouraging the use of residual areas of functioning. The interactional system described various patterns of relationships families adopted in response to the presence of a disabled adult. These patterns ranged from the disabled individual-centered to family-centered home environments. Differences were noted in characteristics of male caregivers compared to female caretakers, and in the inclusion of children in these various interactional patterns. The social context was described as the family's relationship to the social environment which consisted of health professionals, educational agencies, other relatives, neighbors, and strangers. The last category of adaptation to perceived misfortune was a continuous process by which the family became accustomed to a strained way of life. The range of family responses changed over time and eventually tended to lead to four identified resolutions: (1) positive action or creation of what was needed, (2) commitment to carry out a duty, (3) accommodation to the situation, or (4) conflict, resulting in vacillation between resentment, rejection, and acceptance.

Damant (1984) described the existence of two types of caregivers: the professional and the natural (or layperson). A combination of love and caring with technical competency was seen as the best combination of characteristics of caregivers. Those persons who had a loving relationship with the ill individual were the best candidates to be trained to provide competent care in the home, thus providing the patient with the best possible type of care.

Disruption of the family function was described as a potential consequence to families that assumed caregiver roles. Bruhn (1977) perceived the effects of illness on a family as being disintegrative with role changes being necessitated. Help outside the family could help the family restore equilibrium. Soldo and Myllyluoma (1983) identified the family's vulnerability to disruption, especially if the family was providing home care to an older, unmarried relative. Another unimpaired adult in the household could reduce the direct responsibilities of the primary caregiver or offset additional competing demands of child-rearing, employment, or care of other household members. Richmond and Craig (1986) described one way of maintaining family equilibrium to be a nurturance of the family by themselves. This intentional self-nurturance, which should be encouraged by health care providers, would then enable the family to invest effective energy in helping the patient.

Caregiver strain or burden has been described extensively in the literature. Cantor (1983) demonstrated that the closer the bond between the ill individual and caregiver, the more stressful the caregiving role. The amount of continual day-to-day involvement compounded the impact on the caregiver, and emotional strain was the biggest problem experienced. Goldstein et al. (1981) identified the concepts of role conflict, role fatigue, and role constriction in caregivers. Confinement of the caregiver in the home and restricted activities were the most severe problems and led to role fatigue. George and Gwyther (1986) studied the impact of caregiving with a focus on aspects of caregiver well-being rather than burden. Overall caregiver burden was experienced primarily in areas of mental health and social participation. Caregivers indicated three times as many stress symptoms and a lower life satisfaction than a comparison group. Inability to pursue social activities, hobbies, and relaxation also were distressing.

Caregivers' responsibilities in elder care was a prevalent theme in the literature. Brody et al. (1978) found that different levels of functioning did not predict placement of elderly ill individuals in institutions or in the community. The presence of "caring units" in terms of a spouse, children, and other relatives was a critical variable in predicting institutional placement of disabled people. Bowers (1987) discovered that much of the stress associated with family care of the elderly was unrelated to the need to perform instrumental tasks, but was related to protective caregiving. This protective type of caregiving was seen to protect the impaired individual from consequences of that which could not be prevented, with an emphasis on protection of esteem and self-image. Hirschfeld (1983) described the concept of mutuality in which the caregiver had the ability to perceive the impaired person as reciprocating in meeting the needs of the caregiver by virtue of the disabled individual's continued existence. This level of mutuality was a significant factor in delaying institutionalization in favor of caring for the individual in the home.

In a research study of families caring for cancer patients in the home, Hinds (1985) discovered several significant needs of caregivers. These included assistance with physical care, a place to discuss fears, financial needs, affective needs, psychological needs, and respite needs. In similar studies with the families of Alzheimer's disease individuals, Chenoweth and Spencer (1986) described the major difficulties expressed by families as the need for constant care and supervision of the ill relative, confinement to the house with isolation from friends and activities, and lack of sleep due to the 24-hour care that was necessary. Hildebrandt (1983) confirmed the existence of these type needs in families and described the lack of affordable respite programs in the United States to help meet these needs.

Fitting, Rabins, Lucas, and Eastham (1986) studied the differences in perceptions of men and women in caring for their demented spouses. Results demonstrated that husbands and wives had the same degree of burden, but females had more depression or demoralization, especially younger wives. Women indicated a greater feeling of constraint in the role of caregiver. Younger wives and older husbands were identified as those most in need of sensitivity from clinicians in relation to feelings of burden.

Blackford (1988) conducted a study of the effects of chronically ill parents on children in the family. Parental chronic illness was seen to interfere with the nurturing of children in the family, resulting in the development of a multitude of somatic complaints in the children. Extended family members were seen as important in providing this nurturing to prevent these difficulties in the children.

Family social support was a concept that emerged from the literature as a valuable contributor to the well-being of family caregivers. Fengler and Goodrich (1979) interviewed wives of elderly disabled men and found that isolation and loneliness were described as significant problems for these women. Support from friends and relatives was seen to correlate positively with a higher life satisfaction score. A need for health care professionals to care for the family while they were actively involved in caregiving was stressed, rather than waiting to intervene when the family could no longer cope with the demands of the caregiver role.

Zarit, Reever, and Bach-Peterson (1980) indicated feelings of caregiver burden were not so much related to behavioral problems in the impaired person, but were associated with the social support available, especially in relation to visitors in the home. Neighbors and community volunteers were seen as valuable resource people to fortify this natural support network.

Alloway and Bebbington (1987) offered the buffer theory which postulated that social support moderated the power of psychosocial adversity to precipitate episodes of illness. Social isolation and social impairment were similar processes seen in families caring for chronically ill individuals (Tilden & Weinert, 1987). Families experienced exhaustion over time because of caregiving roles that led to a sense of impaired competence. The social network gradually withdrew support of the family and the ill individual, especially as the ill person's ability to reciprocate was impaired.

Young and Dowling (1987) studied dimensions of religiosity in elderly individuals. Religious activities and private devotions were important in the support of elderly individuals, but these activities did not make up for social or personal deprivation. Strong family and friend networks contributed to the spiritual well being of elderly individuals by affirming wholeness in their lives.

McNett (1987) studied the relationship between social support and coping abilities in the functionally disabled. Findings indicated that the perceived availability of social support, not the use of social support mechanisms, was significantly and positively related to coping effectiveness.

Summary

In summary, a review of selected relevant literature has provided a description of the family system and its various components and interrelationships. Family functions, structures, and other processes that affected a family's health and well-being were discussed. Characteristics of family caregivers provided a foundation for examination of those life experiences that threatened disruption of the family unit. Various aspects of caregiver burden or strain were described in relation to care of different types of patients in the home setting, and potential caregiver needs were identified in both the adult and child family members. Family social support concepts were examined to illustrate the theoretical relatedness of caregiver needs and the ability of social support to moderate those needs. The family system will serve as a backdrop for conducting research on the needs of family caregivers and identifying the processes by which these needs are met.

CHAPTER III

Methodology

Methodological Overview

Different research questions require a variety of research methods, and researchers must take care to use appropriate methods congruent with the context of the problem (Munhall & Oiler, 1986). Qualitative research methods allow for determination of significant variables which can be the basis for experimental research and theory building (Gilliss, 1983). Qualitative studies are a means to an end and provide empirical grounding for more rigorously structured research (Knafl & Howard, 1984).

The purposes of qualitative research are "to gain knowledge and understanding of people, events, conditions, historical factors, and other phenomena of concern to humans" (Duffy, 1986, p. 237). The frame of reference of the subjects involved is of primary importance, and the researcher strives to approach the study in a holistic manner. An assumption of qualitative research is that the subjective and objective are meshed in a highly tangled, convoluted way with people tied to their worlds and comprehensible only in their contexts (Munhall & Oiler, 1986).

Grounded theory methodology is a systematic form of research that allows for the collection and analysis of qualitative data for the purpose of explanatory theory generation. This inductive theory generation explains basic sociological patterns or processes of behavior (Chenitz & Swanson, 1986). The best situations in which to utilize the grounded theory approach are in investigations of "relatively uncharted waters, or to gain a fresh perspective in a familiar situation" (Stern, 1980, p. 20).

This methodology embraces many unique characteristics. First, the conceptual or theoretical framework is generated from the data rather than from the literature or previous research. Second, the researcher seeks to identify basic dominant social processes or behaviors rather than to describe the subjects under study. Third, a constant comparative analysis of each piece of data to every other piece of data is completed to identify emerging concepts and themes. Fourth, data collection is modified according to the developing theory. Last, the researcher works within a matrix of simultaneously occurring research processes as opposed to conducting research in a linear progression of steps (Stern, 1980).

Glaser (1978) has identified four criteria for the evaluation of grounded theory methodology. The first criterion is fit. Categories of the theory must fit the data, and this criterion will be met when the categories are generated directly from the data. The second criterion is that the theory should work. The theory should be able to explain what is happening in the area of substantive or formal inquiry and also should be able to predict what will happen. Relevance is the third criterion and is achieved when core processes and problems are allowed to emerge naturally without preconceived theories. The last criterion is modifiability. Basic social processes that occur in the lives of people are ever changing. For this reason, the theory must be modifiable so that it can be built and improved as life processes change in the world of the subjects.

Investigation of the family as a unit in research is a complex skill and difficult to do adequately. Measurement of the component parts of a family has created methodological problems evidenced by a lack of agreement as to what should be measured (Gilliss, 1983). Data reported by families as groups are inherently more complex and contradictory than that reported by individuals (Thorne, 1985). Because these methodological difficulties exist, application of the grounded theory methodology offers a creative way of analyzing data from families that allows for important concepts to emerge. These concepts then can be synthesized into theoretical frameworks that provide a clearer direction for theory testing and theory building. The use of grounded theory methodology in this study of the needs of family caregivers allowed for the initial identification of caregiver needs as well as the basic social processes used by the family in getting these needs met.

Data Collection

Seven families from the local community who were engaged in caregiving activities were selected as a purposive sample and invited to participate in the study. These families were located through referrals from friends of the researcher, local ministers, local social workers, and other professional nurses. The families were contacted initially by telephone by the researcher in order to explain the purpose and scope of the study. As the family caregivers were contacted, all agreed to participate in the study and expressed an interest in sharing their stories. The families were sent a letter of invitation which further explained the details of the study and assured the confidentiality of the information shared with the researcher (Appendix A). Each adult family member (older than age 14) who wished to participate was asked to sign a "Participant Agreement Form" (Appendix B) verifying a willingness to participate in the study and to allow the data to be shared with other professionals by the researcher. The format and methodology of the study received expedited review and approval by the Internal Review Board of the University of Alabama at Birmingham in order to protect the rights of human subjects.

In order to answer the two research questions posed in this study, data collection was accomplished through one-time interviews with family caregivers. This type of qualitative interviewing served the purpose of constructing records of the behavior processes of people who had engaged in the specific behaviors many times (Lofland, 1971). A set of semi-structured interview questions (Appendix C) was utilized to guide the conduct of the interview and to gather comparable data from all family units. The interviews were tape recorded and transcribed for data analysis.

The setting for each of the interviews was in the family's own home. The familiar surroundings were thought to be more conducive to relaxation of all participants and the sharing of feelings by the family members. A convenient time for the discussion was negotiated in most cases such that the entire group of adult family members who were caregivers could be present during the interview. No time limits were placed on these interviews in order to allow families the freedom to tell their stories at their leisure. The sessions ranged in length from 45 minutes to three and one-half hours, with the average time being approximately two hours.

The initial two families interviewed were known to the researcher and were selected because they had been engaged in caregiving activities in the home within the past year. Glaser (1978) had suggested that researchers begin studies by selecting a sample from local groups, a strategy used to maximize the possibilities of obtaining data and getting direction for further sampling. The caregiving process was the only commonality required among the families, and other demographic or process variables were not controlled. Regardless of the wide differences in structure, functions, and tasks which were present in the different family groups, these families were only compared based on the one mutual process variable of meeting caregiver needs. Glaser (1978) rationalized this inclusion of outwardly different groups by noting that "apparent noncomparability is irrelevant if the variable to be compared has a value in each group" (p. 42). Glaser further illustrated the point by stating apples and oranges could be compared if the purpose was the discovery of vitamins which could be found beneath the skin. Differences in groups were seen not to disqualify the comparison but to enrich the data.

Subsequent family caregivers were selected for interview by theoretical sampling. The process of theoretical sampling was proposed by Glaser (1978) as the foundation of data collection in grounded theory methodology. This process of data collection involved a joint collection, coding, and analysis of the data with a subsequent choice being made by the researcher as to which subjects to sample next. As the developing theory began to emerge from the data, deliberate choices were made for sampling sources which were likely to continue the process of theory development. Data collection was controlled by the emerging theory. There was not a predetermined commitment to a specific sampling group, and groups were chosen as they were needed. Demographic data (Appendix D) were collected for informational value as well as for the purpose of assisting in theoretical sampling. The sampling process facilitated selection of families that exhibited a range of such variables as age, sex, and occupation of the caregivers, socioeconomic status of the families, age of the family member receiving care, and type of problem experienced by the dependent individual.

As data from the initial interviews were coded and analyzed, theoretical sampling decisions were made that allowed for depth to be achieved in the emerging theory. The first family interviewed had been caring for an adult temporarily disabled by back pain. The family had been engaged in caregiving activities for only six months. The second family had been caring for a 16-year-old daughter who had been developmentally and physically disabled from birth. These two families provided contrast in the perception of caregiver needs over time as well as contrast in the perceived potential for recovery of the disabled individual. Neither of these families was caring for an acutely ill family member.

The third family, which was also known to the researcher, was selected through a logical, deductive sampling decision in order to illustrate similarities to and differences from the preceding two families. The caregiver in this family was a wife, age 58, who was caring for a husband who was 65 years of age. This caregiver had assumed increasing amounts of responsibility over a period of years as her husband's health deteriorated due to chronic physical and emotional problems. The prognosis for this dependent recipient of care was poor, and this caregiving wife was dealing with a dying spouse.

The fourth family was referred to the researcher through a local minister and provided a different set of caregiver needs. A wife in her late 50's and an adult son in his middle 30's found themselves assuming an insidious caregiver role as they slowly realized that the husband and father of the family was suffering from Alzheimer's disease. Unlike the preceding families, these caregivers initially were not aware they were becoming caregivers of another adult with a deteriorating mental capacity. These two individuals represented caregivers who were fulfilling a very unclear role over a period of at least eight years.

The fifth family interview was with a grandmother of a retarded 4-year-old boy. As the primary caregiver, this woman provided a contrasting situation as she cared for a child who was the youngest of the dependent individuals in this study.

The sixth family consisted of a woman in her late 50's who had been caring for her 80-year-old mother for the previous eight years. This family represented the first situation in this study in which the recipient of care was an elderly individual. This family's circumstances provided a geriatric perspective to the study.

To further expand the data related to caregivers of elderly family members, the seventh family was purposively selected. Two sisters, ages 73 and 76, were caring for their elderly aunt who was 101 years old. These two ladies were not only dealing with age-related limitations of their dependent family member, but they were also facing their own set of problems with deteriorating health. One of these caregivers had been recently diagnosed with recurrent breast cancer and was facing possible surgery or other treatments. These two caregivers were having to support each other in addition to caring for a third individual, a situation that was unique in this study.

The data collected from the sixth family interview reflected the same categories of needs and processes as the previous five families. No unique categories or properties of categories emerged. A decision was made to conduct a seventh family interview to be certain the categories were exhausted and the core variables had been identified. When the seventh family interview also failed to supply new concepts or variables, a decision was made to conclude the interview process. The total of seven families, which included ten individual caregivers, provided the data which were then analyzed in depth.

The logical, deductive sampling decisions that were made facilitated the selection of families that illustrated both similarities to and differences from the preceding families. Contrasting situations were sought to develop properties of the coded categories and to illustrate varying conditions under which the basic social processes of meeting caregiver needs differed.

Data Analysis

The processes of data gathering and data analysis occur simultaneously in grounded theory methodology. The constant comparative method is a matrix operation rather than a linear process, and comparisons of the data are made continuously (Chenitz & Swanson, 1986; Stern, 1980).

As data analysis of the interviews began, a system of open coding was applied. These substantive codes reflected the substance of the words and behaviors of the people interviewed. Thus, Glaser's (1978) criterion of fit was met in that codes were generated directly from the data. The exact words of the subjects were used in some cases to extract the essence of what was said as suggested by Chenitz and Swanson (1986). According to Gilliss (1983), coder bias was inherent in this process because the investigator would inevitably interpret the incoming data in light of personal perceptions of his or her own family. This bias was assumed and was not necessarily viewed as a limitation of this study.

Examples of initial codes that emerged from the data and that related to caregiver needs were such words as "needing more," "other people," "burdens," "answers," "prayer," "purpose," "time," "honesty," "knowledge," and "control." As caregivers continued to identify their needs, commonalities became apparent. Codes were compared and similar codes clustered into categories with an initial label. The researcher consciously looked for main themes or core variables during the coding and development of categories.

Three core variables emerged that seemed to encompass all other coded needs. These variables were help, hope, and happiness. These core categories demonstrated consistent relationships with the other coded variables and categories and served to integrate all identified needs. These three core categories recurred frequently in the data and had relevance and explanatory power.

In the search for processes that occurred in the meeting of caregiver needs, several initial codes appeared. These processes included such coded words as "changing," "doing more," "revolving," "getting things together," "wearing hats," "controlling," "not knowing," "learning," and "connecting." The process of connecting was mentioned initially in the second family interview, and these exact words recurred in subsequent interviews.

Caregiver descriptions of the processes by which they sought need satisfaction appeared to cluster into the main category of connecting. Two subprocesses also occurred as categories which accounted for a large proportion of caregiver behaviors: misconnecting and disconnecting. The identification of this core process variable of connecting appeared to link the categories of identified needs with the process of meeting needs, thus allowing for relationships to emerge as a beginning of theory development. These initial codes and subsequent core variables emerged naturally from the data without preconceived expectations, thus showing consistency with Glaser's (1978) evaluative criterion of relevance.

The process of theory generation was dependent upon the writing of theoretical memos. These memos were ideas about codes and their relationships that occured to the researcher during the coding process. As memos were sparked by the data coding, notes were made in the margins of the transcribed interviews and on a separate sheet of paper to capture thoughts related to the data, the categories and properties, and theoretical relationships which began to emerge. Theoretical memos served to connect the data with the final analysis and raise description to a conceptual and theoretical level. Theoretical properties of the codes were eventually saturated through the definition of boundaries, empirical criteria, conditions, connections, and significance to the data and the emerging theoretical themes in the data as suggested by Glaser (1978).

As the data were analyzed and core categories identified, a tentative framework was generated using the data and the theoretical memos. Sorting of theoretical memos allowed for integration of the conceptual categories into general theoretical relationships which were validated by the data. The core process variable of <u>connecting</u> which emerged focused the development of theoretical relationships and allowed for an integrative fit of the concepts. A selective sampling of relevant literature was woven into the observed theoretical relationships to supplement the emerging theory.

Glaser's criteria of workability and modifiability could not be evaluated at the time of this study since these characteristics can be seen only as a theory is developed and used. As this beginning substantive theory is applied to future practice, it hopefully will be evaluated as workable in the sense that it will explain and predict certain behaviors in caregivers. As it is utilized, the theory ideally will be flexible enough to withstand modification and will be applicable to different situations. Theory testing and refinement will provide the opportunity for evaluating these last two criteria.

Establishment of Validity

Evaluation of the degree of validity in this study using grounded theory methodology involved procedures that differed from those measures applied in quantitative methodologies. Face validity was assessed for this study for the purpose of evaluating the degree to which the truth was reflected in the data. Face validity involved an assessment of the truth of the research product by asking study participants to substantiate the emerging categories (Atwood & Hinds, 1986; Brink, 1987).

To validate the identified needs and processes, a seven page questionnaire was sent to the family caregivers with only one questionnaire going to each household (Appendix E). A cover letter explained the purpose of the survey and invited additional input from the caregivers. The questionnaire contained a narrative summary of each of the three needs of help, hope, and happiness. The summaries gave the researcher's perceptions of how each of these needs was manifested in the data. A space was given at the end of each need summary for the caregivers to respond in a narrative, open-ended manner.

A second section of the questionnaire dealt with the meeting of caregiver needs and described the basic process of connecting as well as the subprocesses of misconnecting and disconnecting. The interrelationships of these three processes with the three needs for help, hope, and happiness were described in narrative form. The caregivers were asked to respond to this composite summary of interrelationships and not to each process separately.

To encourage the return of the questionnaires, a self-addressed, stamped envelope was included. A second mailout of the questionnaires was done for four families when they had not responded after four weeks.

A total of five caregiving families responded. The comments indicated unanimous agreement with the three basic needs identified. Three respondents added comments to reiterate their needs for help in the way of education from health professionals and relief from the continual care necessary for their dependent family member. One caregiver re-emphasized the role that honesty played in allowing for realistic hope. This same caregiver offered additional thoughts on getting family support to relieve the burden of confinement which led to perceptions that there was "no light at the end of this tunnel." Another caregiver shared comments related to her state of happiness, which was enhanced when other people offered her praise and encouragement.

Agreement was offered with the synthesis of the processes for meeting caregiver needs. None of the caregivers indicated disagreement with these identified processes. One caregiver made a comment that summed up what could be considered an ideal situation of meeting caregiver needs:

> There needs to be some way that <u>all</u> connect with the proper service. . . .Everyone should be in the system somehow to receive services to make all lives better.

No caregivers disagreed with the needs of help, hope, and happiness that were identified, nor did any caregivers dispute that connecting with external and internal resources was the primary process utilized for need satisfaction. Thus, face validity was offered for the analysis of the data and for the relationships proposed.

Summary

In summary, grounded theory methodology was used to guide theoretical sampling of data from a purposive sample of family caregivers. Data analysis was accomplished through a process of coding and categorizing data until core variables began to emerge. These core variables were the basic needs perceived by family caregivers and the basic processes by which these needs were met. The theoretical relationships between these core needs and processes identified by the researcher were shared with the family caregivers for the establishment of face validity for the analysis and interpretation of the findings.

CHAPTER IV

Concept Formation

The basic caregiver needs will be discussed initially using data from the transcribed family interviews. Supporting literature will be interwoven to validate the identified needs and offer expansion of the theoretical relationships. The two subprocesses of misconnecting and disconnecting with need satisfaction will be described in relation to each of the three identified needs, followed by a description of the connecting process. The process of misconnecting with help, hope, and happiness will be followed by a description of disconnecting with help, hope, and happiness. Finally, the caregivers' processes of connecting with help, hope, and happiness will be presented. This general format for discussion follows the usual order in which caregivers proceeded to achieve their own need satisfaction. In most situations, caregivers engaged in a series of misconnections and disconnections with need satisfaction prior to their being able to connect with resources that met their needs. Selected literature support again will be offered to strengthen the theoretical foundation.

Family Caregiver Needs

Three recurring caregiver needs emerged from the wealth of family interview data. These needs were help, hope, and happiness. These exact words were used in some of the interactions with the families. Caregivers knew that these needs were basic and that satisfaction of these needs was necessary for adequate coping with their caregiver roles.

Help

The first core variable that emerged was the need for help. Caregivers used such expressions as "doing more" with "not enough time." Tasks were "heavy" and in one case described as "more than I can stand." Caregivers spoke of having to wear a "different hat" and to do things they had never done before. "Doing the best" they could was offered almost as an apology for not being able to do everything that was needed. One family caregiver lamented that she "couldn't count on hired people" to afford her the assistance she needed. These words of frustration from caregivers in describing their new roles as well as the inadequacy of help from hired assistants indicated that help was a primary need in these caregivers' lives.

One of the major areas identified by caregivers in which help was needed was that of giving direct care to the patient or disabled person in the home. Family members were named as those persons who were expected to offer this help. Some family members helped and some did not. Situations ranged from families in which there was a very active participation by immediate and extended family members in caregiving tasks to situations in which one primary caregiver was abandoned to care for the ill person without family assistance. Family support was identified as important for the maintenance of positive mental health of the caregivers. Without the support of family and significant others, one mother of a retarded child predicted she would "crack up." Those families that did experience willing participation in caregiving by its members counted themselves fortunate. Leininger (1978) recognized the value of support systems by identifying people as sociocultural beings who needed other people to help them throughout life. This support was viewed as vital to life itself.

One of the most profound help needs expressed by caregivers was the need for respite or relief from the burdens of caregiving. Caregivers overwhelmingly perceived respite as positive, vital, and "at the top of the list of needs." The recipient of the care did not necessarily view the respite of their caregivers as positive. More often, they perceived the absence of the primary caregivers as a state of aloneness that was frightening, even when other individuals were available to assist them.

The caregivers' roles were described as situations of "expecting more" and "doing more" where "taking care of things" became a heavy duty. The overwhelming nature of the caregiving tasks depleted the caregivers of energy, sometimes to the point of allowing illness to develop. One caregiver described chest pain that forced her to seek medical help; another caregiver sought professional counseling for depression. Research conducted with families of Alzheimer's disease patients pointed out that as many as one-third of caregivers reported exacerbations of existing physical illnesses as well as the development of depression and other negative emotions (Ferris, Steinberg, Shulman, Kahn, & Reisberg, 1987).

Caregiving tasks were seen as rough, full-time jobs that must be done. The role of protector was assumed by many caregivers with constant surveillance needed for the disabled person. Having to "have somebody there" necessitated 24-hour per day care that required help. Families found they needed to cooperate by changing schedules and altering daily activities just to provide a constant caregiver. Extra time was required for everything. As one caregiver stated, "We have to work out our schedules so the whole family can try to help."

Two of the family caregivers identified a need for help that focused on decision making. Hurting families "don't think straight" and thus had difficulty taking control of the situation, especially in the beginning. Families felt a loss of control as "things kept coming and coming," and this loss of control led them "not to believe their own minds." Stress has been shown to prevent those closest to the patient from problem solving and proper action. Memory and thinking processes can be disrupted due to fear and distress (Benner & Wrubel, 1989). These distraught caregivers who were struggling to adapt to changes that would affect their total being expressed a need to have a caring, competent individual to assist them in the initial decision making. Learning what to do and what to expect was vital, and caregivers perceived they often groped in the dark and made misinformed decisions. Eventually, as family caregivers made the necessary transitions into new roles and life patterns, the ability to make wise decisions returned. One caregiver of a retarded child summarized this accomplishment as a time when one learned to "major on the major and let the minor things go."

Caregivers needed help from health professionals, particularly in the area of teaching. All families, without exception, voiced frustration at receiving less than adequate preparation for dealing with the caregiver tasks at home. Although they were willing to assume these extra responsibilities and were receptive to learning, they perceived that they were not offered the information needed to cope effectively. This situation left them feeling vulnerable and afraid. As one parent of a disabled youngster shared:

> Connections are difficult to make with physicians. They don't take time, don't explain things where they can be understood, and don't show any sensitivity. Doctors don't always know the answers. . . .Many times they are wrong. They need courses in how to communicate.

For some families, the lack of knowledge was not merely frustrating, it was life-altering. The son of an Alzheimer's victim described his family's experience this way:

> I think a tremendous amount of suffering could have been alleviated, or it sure would have changed everything, if we had known about this disease. . . .If they [the doctors] could take their minds off the next patient just long enough to save us five years of pure hell. . .it would be a nice gesture.

The feelings of vulnerability due to lack of knowledge and control were almost overwhelming as one caregiver so profoundly described:

> But what they don't understand is that people are hemorrhaging like we were from every crevice--it was devastating.

This devastation was the kind that "rips through" a person's being.

Caregivers also expressed a need for help and understanding from employers. Many caregivers described the necessity for shifting work schedules or even resigning totally from their jobs to assume full-time caregiving tasks. Lucas (1986) validated this need in other caregiving situations by describing how many caregivers were forced to choose between employment and caregiving. Those who tried to work often had many difficulties with lateness, unscheduled days off, and excessive use of the phone. Wagner (1987) noted that employees who were caregivers used company health services more often and were more subject to stress symptoms of anxiety, depression, headaches, and weight changes.

Family caregivers got "tired out" and "worn out." As one caregiver explained, "Caring for others can only be a challenge for so long, then it gets you down." Friends were identified as another source of help, but their involvement was perceived as being different from that of family. Caregivers needed friends to come in and offer the cared for person something different in the way of stimulation. Boredom was often present in the ill or disabled person, and caregivers exhausted their resources for relieving this problem. The presence of nonfamily visitors provided a freshness to the situation that offered a different, but equally valuable kind of help. The assistance that these friends offered was a non-task-oriented help, but served to re-energize the family group. One caregiver described how close friends from her church served as extended family and helped by offering "precious things" in the form of visiting in the home. Holing (1986) noted that the expenditure of emotional energy was often greater than the expenditure of physical energy by caregivers, especially if the home situation involved a dying patient. These visits from friends appeared to be one source of help that provided that greatly needed emotional lift.

In situations where a caregiver's spouse was also involved in caring for the disabled person in the home, the concept of teamwork was identified as important. This valuable partnership in the caregiving tasks was viewed as enabling for the family and positive in terms of facilitating coping. Soldo and Myllyluoma (1983) proposed that the presence of another unimpaired adult in the household had the potential to reduce the direct responsibilities of the primary caregiver or to offset the additional competing demands of child rearing, employment, or care of other household members. Other research has shown that a primary caregiver did not experience relief from burdens just by having other adults present in the household. Other adults needed to assume the burdens of care in order to benefit the primary caregiver (Wasilewski, Clark, Evans, Feldman, Kaplan, Rips, & Mellins, 1988).

Hope

Family caregivers used another category of words with expressions such as "looking for strength inside" and "God uses these situations to build strength". One caregiver stated she "needed to hear that there was always hope," and another stated she did not ever want to be given "false hope," but desired honesty. These descriptive phrases led to identification of the second core variable, the need for hope.

Hope has been defined by Lynch (1965) as "an arduous search for a future good of some kind that is realistically possible but not yet visible." (p. 23) Hope lies at the center of every human life (Fischer, 1988), and these caregivers recognized its importance. In interviews with families of chronically ill patients, Thorne and Robinson (1988) discovered that hope did not mean a cure to these families; hope meant being able to manage problems presented such that life could be comfortable and productive. Hope has been described as an intrinsic element of life (Miller, 1989) and a buffer for earthly stress (Korner, 1970).

The caregivers in this study verbalized a need to be offered hope from two sources: from God and from other people. Miller (1989) also found that seriously ill individuals identified family or significant others and religious faith as the most important sources of hope. The faith in God held by family caregivers in this study was frequently deep-seated and enabled them to grasp the hope that they would be cared for through those trying times. Soeken and Carson (1987) described the same type of hope in God that surpassed all transitory aspirations. The hope in God was an eternal abiding hope that kept other hopes alive.

Many caregivers expressed a belief that there was a purpose in everything that happened and that God used these human situations to build spiritual faith. This knowledge allowed hope for a better future to flourish in the minds and hearts of these caregivers.

Caregivers wanted to be told by other people there was always hope. When asked what she would like to hear from health professionals, one caregiver of a retarded grandson responded in this way:

> Give that person the support they need. Tell them there is always hope. A doctor told us there was no hope he would do anything. I asked the doctor if he didn't think we needed hope. He said, 'Yes, but we needed to be realistic.' I don't agree with this. Who knows what can be done? Who knows whether that stroke patient hears what you're saying? Who knows about that child?

Caregivers needed to know they could make a difference and that their efforts could keep hope alive for positive changes. Soeken and Carson (1987) stated, "Hope is derived from relationships with others, oneself, and the world where a person believes that what is desired is possible" (p. 610). One caregiver summed up the feelings of several others in this way:

> I guess I have done more for him because I've been hell-bent and determined I was going to do it. And that's what a caregiver needs. They need to know they can make a difference.

The perception of being able to make a difference was one way caregivers could begin to feel at peace in their roles. Research with oncology patients and families by Owen (1989) concluded that the achievement of an inner peace appeared to herald a hopeful state. The same dynamic relationship between peace and hope seemed to exist in these family caregivers.

Happiness

Caregivers used many negative words and expressions to indicate unhappiness. They spoke of being "angry," "in a horrible mood," and of "not being able to smile anymore."

Descriptions of birthdays without recognition, a loss of "life's pleasures," and having to "bypass what I want" were words that emphasized the need for happiness.

Receiving needed help from others and working to maintain hope were seen to contribute to happiness, but there was another aspect to this state of being. Caregivers recognized that they were responsible for their own happiness and that fulfillment of this need must come at least partially from within themselves.

Without exception, the family caregivers voiced some degree of unhappiness in their roles. They described their arrival at this realization in different time frames. Some caregivers knew from the initial day they assumed a caregiver role that there would be many aspects of their duties that went unrewarded. Other caregivers gradually became aware of this fact with the passage of time. Although there was some degree of reward in offering competent, loving care to a dependent family member, the caregiver role could not adequately meet all needs for happiness.

Research by Fengler and Goodrich (1979) demonstrated that support from friends, sympathizers, children, or relatives made the difference in life satisfaction for caregivers. Caregivers needed support in an expressive nature as well as in an instrumental nature. Family caregivers needed and expected support from the extended family network. Lack of this support created anger, frustration, hurt, and depression in the caregivers. One lady who had cared for her disabled husband several years at home acknowledged that caregivers hurt for some caring friends, companionship, and company at home. She perceived the task of "connecting up" with others by inviting them to visit as a difficult one.

Married couples expressed difficulty in finding time to nurture their special relationship through spending time together alone or through enjoying a vacation. Children often shared the burdens of caregiving and carried an adult weight on their young shoulders.

Expressions of love from other people such as family, friends, and ministers were highly desired. Caregivers needed emotional support which included concern, trust, caring, liking, or love. Appraisal support was feedback that affirmed self-worth and allowed a person to see himself or herself as others did (Tilden & Weinert, 1987).

Caring rituals were valued as an important link to happiness. Leininger (1978) described caring rituals as events that functioned to help people maintain security and provided guides to living, decision making, and coping with recurrent life stresses and problems. One caregiver described the absence of caring rituals in her life and the subsequent unhappiness that resulted:

> Even at Christmastime last year, not one person offered to let me go with them to a shopping center except my mother. I went one time to the shopping center and was not able to do much shopping. . . . I didn't even get Christmas [presents] last year; it was like another day.

In their research on the caring patterns of families, Patton and Childs (1988) proposed the basic idea that an adequate concept of care for others required recognition of the need to care for oneself. These family caregivers demonstrated varying degrees of awareness of this important idea. Some caregivers actively pursued outlets to nurture their own state of happiness. Others talked of their desire for happiness and then floundered in the inability to take charge of getting their own needs met. In essence, they remained victims of unhappiness due to their passive inability to assume control of their lives. Some family caregivers were able to put their need for happiness in a realistic perspective, and one caregiver shared one thing she had learned through the years: "without the lows, you can't appreciate the highs."

Three primary needs have been identified in family caregivers. These basic needs for help, hope, and happiness were foundational in that they subsumed all other expressed needs and provided a holistic context for examining the processes by which these needs were perceived to be met.

The Meeting of Caregiver Needs

Family caregivers recognized that making connections with viable, helpful resources was crucial to their experiencing a meeting of their perceived holistic needs. One family used the words connecting up to describe the process they used for getting help. This basic social process of connecting was later identified as a major process common to all family caregiving situations. The processes of misconnecting and disconnecting also emerged and were functions of the connecting process.

Caregivers frequently described the time when they first entered their roles as a period characterized by many difficulties. In their efforts to meet their needs for help, hope, and happiness, caregivers groped for meaningful connections and often found they had made a misconnection with a resource that was not helpful to them. Caregivers used words such as "not knowing," "missed opportunities," "distasteful things," and "too much pride." These phrases seemed to indicate that there was a process that occured that was less than ideal and which prevented caregivers from connecting in helpful ways with other people or events. This was eventually labeled misconnecting and was a process that frequently preceeded connecting.

When the caregivers came to the realization that their needs were not being met, they engaged in a process of withdrawing from that nonsupportive or draining relationship and sought other ways to cope. Caregivers shared how a person's "mind was gone" or how people "just stay away." They talked about "escape" being critical at times and how friendships would "disappear." These phrases pointed to another process that was occurring that was characterized by a definite separation of one person from another or the separation of a person from a situation.

This process was eventually identified as disconnecting and was a more definitive process than misconnecting.

A final process was discussed which was related to the processes of misconnecting and disconnecting, but was more positive in enabling caregivers to have their needs met. Coded words and phrases such as "knowing would make life go in a different direction" and "needing to learn" indicated that education from others was crucial. Descriptions of "family support" that "made things go easier," church friends who did "precious things," and "connecting up" with others illustrated how contacts with other people were important. Further phrases such as "believing what you're doing is right" pointed out a need for coming to an inner peace. All of these descriptive phrases and coded words indicated a process by which a connection needed to be made, either with other people or within the self. This was labeled the connecting process.

Families were engaged in the processes to varying extents. Some families continued in a cycle of misconnecting and disconnecting until a connection was eventually made that was perceived to fulfill their needs. Other families described their experiences as a frustrating series of misconnections that never evolved into positive, helpful connections.

Another aspect of the connection process occurred within individual caregivers. Misconnections were made within their own hearts, minds, spirits, and bodies that created tension and distress for them. In their efforts to sort their feelings about their roles as caregivers, family members engaged in this same process of misconnecting and disconnecting with a constant search for an intrapersonal connection that would be positive. As one caregiver described it, this was a search for a "peaceful spirit."

The processes of misconnecting, disconnecting, and connecting were each manifested in relation to the caregiver's needs for help, hope, and happiness. These interrelationships formed the heart of the connecting process.

Misconnecting

Misconnecting, or missed connection, was a process in which two or more people or a person and a meaningful situation intended to join together in thoughts and actions, but failed to do so. The bond was intended to be a positive connection that would be mutually beneficial, but other variables interfered with this process such that the connection could not occur or occurred in a negative way that did not meet the needs of the caregiver.

Misconnecting with help. Caregivers described situations in which they misconnected with their caregiver roles such that they "floundered like a fish out of water." In research with families of Alzheimer's victims, Wilson (1989) noted that families decided to become caregivers not knowing the full demands and implications for the role and they had few acceptable or existent alternatives. This difficulty encountered in assuming the role depleted energy and blocked their ability to look elsewhere to get needs met.

Bowers (1987) found primary caregivers to be more involved in protective care while health care professionals focused more on preventive and instrumental care. This discrepancy in the approach to caregiving created conflict between caregivers and health care workers. When caregivers fulfilled the role according to their own priorities, they were sometimes criticized by health professionals who expected them to function in a different manner. This criticism compounded the caregivers' frustration in trying to adapt to new situations.

The overwhelming nature of the caregiver role became more apparent to caregivers as they realized the constancy involved in their roles. As one caregiver described, the person being cared for in the home is always there and always in need of attention and protection:

> He is ever-present. What I've had to do for him has been life-consuming, that's all.

Another caregiver shared the same perceptions as she described how her elderly mother demanded attention:

> She consumed me. I felt like she just swallowed me whole. Everything I did revolved around her. When I did get together with my family, we talked about her until we finally realized what we were doing. We might as well be there with her as to have her dominate our lives even when we were away. And she could do that.

In a study of the impact of the caregiver role, Cantor (1983) proposed that the closer the bond between the caregiver and the dependent individual, the more stressful the role. The amount of continual day-to-day involvement compounded the impact on the caregiver, resulting in emotional strain, which was the biggest problem for caregivers. The presence of minor children in the household also exacerbated the daily stresses of caregivers who were torn by multiple family responsibilities (Soldo & Myllyluoma, 1983).

In research conducted with terminally ill children, Marsden (1988) identified that caregivers often made four unspoken promises to the dying patient: (1) promise to cure, (2) promise to care, (3) promise to treat with dignity, and (4) promise to stand by in death. Although this research related to professional caregivers in a hospital setting, the researcher proposed that these same promises possibly were made between other caregivers and patients. The unspoken promise to cure created multiple stresses for caregivers because of its difficulty to fulfill. Most caregivers cared for persons who were permanently disabled or terminally ill with little realistic chance for cure or complete rehabilitation. In promising to make their loved one better, they were setting themselves up for frustration and failure.

One caregiver had made an emotional promise to her elderly, combative mother never to place her in a nursing home. In her fidelity to keep this promise, this caregiver placed herself in an unbearable situation as her emotional, physical, and spiritual energy depleted rapidly. Research by Rew, Fields, LeVee, Russell, and Leake (1987) noted that when caregivers felt isolated and trapped, they also were less affectionate toward the patient and the incidence of abuse and neglect increased. Weisman (1981) noted that distress experienced by the dependent patient was possibly the result of emotional burdens felt by caregivers and secondarily placed on patients. Exhausted caregivers could not be expected to carry out unrewarding duties with forebearance and understanding.

Weisman (1981) also discussed situations in which caregivers would expect to receive something from the dependent individual in exchange for the care they rendered. Hirschfeld (1983) presented this same idea as the concept of mutuality in which a caregiver had the ability to perceive the impaired person as reciprocating by virtue of his or her existence. The existence of a dependent individual in the home served to meet the needs of some caregivers in emotional ways. Nageberg (1959) expanded this idea of mutuality further in noting that intended help could be destructive if it caused interference and fostered dependence.

Caregivers often perceived that they were expected to fulfill their roles with maximum control over the situation. This misconnection with their roles also created difficulties for them:

> It's always been something that we couldn't control. . . .We have some control in that we take good care of her. . .but even with that she's still had problems.

Another caregiver stated:

> I have felt we were at the mercy of whatever her illness brings. We can't just run over to the local hospital when she has a problem; we have to go halfway across the world. You're at the mercy of having to travel to specialists. We never know when she's going to have to go. We have no control over that whatsoever, nor does anyone else for that matter.

One caregiver described her lack of control as resulting in depression that "broke the spirit." In research with terminally ill patients, Siegal (1986) noted that unhappiness arose out of attempts to control events and other people over which one had no power. These futile attempts were born out of fear and resentment and served to weaken the individual.

Benner and Wrubel (1989) described the role of the omnipotent rescuer which was taken on as a way to cope with feelings of vulnerability and fear that the person cared for might leave or die:

> Overinvolvement as help may raise excessive needs to control and dominate the situation to ensure that one's own interests are protected. Boundaries between self and others become blurred, and the one caring may take on the role of omnipotent rescuer, overlooking the responsibility, integrity, and resources of the person and the situation. (p. 374)

This situation was observed very vividly in one family in this study. An adult daughter made the decision to move into her mother's home to become her mother's caregiver after her father died. This occurred despite the fact that the elderly woman was physically able to function. As a result, the older woman gradually became more dependent and less capable of self-care activities, allowing the caregiving daughter to take care of her completely. None of this caregiver's siblings chose to participate in this situation. Thus, the daughter caregiver became the omnipotent rescuer, a role that eventually depleted all her resources for help and brought her dangerously close to complete mental and physical collapse.

Some individuals experienced misconnections with their caregiver roles because of other family problems. These situations rendered them less able to deal with caregiving tasks. One family suffered from a lack of help because of illness in the extended family. Another family was helping a daughter through a divorce while also fulfilling caregiver tasks. The family caregivers' involvement in multiple crises at one time proved to severely limit their ability to fulfill their acquired roles.

Many times caregivers faced an emotional struggle akin to the grief process prior to being able to fulfill their caregiving roles. The states of shock, denial, anger, and acceptance were seen to varying degrees in most families. One caregiver shared:

> So I went through that period of grief and denial, and then I had to say, 'O.K., we're stuck with this situation, and what is the best way I can contribute to it?'

Some people could not connect positively with a caregiver role; they simply could not cope. The role was so utterly unacceptable that major avoidance behaviors occurred:

> The boy's father was working such long hours and that's when he had his bad heart attack. He cannot cope. There are family members who simply cannot face it and B. was one of these.

As family caregivers began their new roles, they looked initially to health care professionals as a source of help. Many families were frustrated and disillusioned when they realized that the health care system was a maze that engendered misconnections. Chenevert (1988) described the system this way:

> The health care team is a myth and . . .service provided often ranges from inadequate to abysmal. Our health care system can compound existing stress and create new stresses of its own. Patients must deal not only with their health problems but with the side effects of a caregiving system that can strip them of everything from their dignity to their life savings. (Chenevert, 1988, p. xi)

One very evident problem encountered by family caregivers as they interacted with health care professionals was a lack of attention to the holistic aspects of both the patient and the family:

> I saw in some magazine that some medical organization is going to require board certified people to have a certain degree of bedside manner--that they be able to relate to the person. That was a bright spot that I've seen lately. . . .They need to know how to treat the whole person.

In one situation, visiting nurses who came periodically to assist a wife in caring for her disabled husband were perceived as touching only isolated parts of the family situation. They gave no consideration to the depression experienced by both the patient and his wife, nor did they inquire as to the caregiver's needs:

> The nurses who come out here come to take care of H.'s foot. They won't touch anything else. They come out here to take care of what they're paid to come out here and take care of, and they don't bother anything else. I guess they think if they do something and later it got worse, I would sue them. Sometimes I need advice about other things and it's hard to get that advice, too. . . .They call, they come, and then they leave.

Health care professionals were perceived to offer inadequate help to caregivers in the way of providing information. This lack of understanding robbed the families of control and rendered them vulnerable to fear, sadness, and heartbreak. In recounting the story of how he first learned his baby had been born retarded with multiple birth defects, one father shared these perceptions:

> I remember when L. was born and the doctor came out and told me, I didn't know what he was talking about. . . .The doctors said they needed to send her to another hospital where there were special doctors. . . .We rode in an ambulance and I was thinking all the time about this. The doctor explained to me the best he could, but I just couldn't understand what he was talking about--I just knew we had a serious problem.

The mother of this same child shared the father's perceptions with this viewpoint:

> My gynecologist came in the door walking out. . . .Poor thing, he didn't know what to say to me. He hardly got his head in the door. Why is this guy sticking his head in the door and asking 'Are you O.K. today?' and trotting on? A nurse told me what was wrong with the baby.

The wife of an Alzheimer's victim confirmed the fact that family caregivers did not receive adequate information from health care professionals:

> You have to play the guessing game and figure out for yourself what's going on. If just one medical doctor had sat down and said, 'Listen, this is what I think it is'. . . .I did have one doctor tell me in 1982, 'You do know what Alzheimer's disease is, don't you?' If we had known, it would have saved a lot of suffering.

When the family was eventually told the father and husband had Alzheimer's, great relief was felt because the patient could finally be vindicated for his unexplained behavior and the family could finally know what the enemy was. Although research with families of Alzheimer's victims cautioned leaders of support groups to be aware of the potential negative impact of too much information for caregivers before they were ready for it (Winogrond et al, 1987), families did want to know the facts. They struggled to educate themselves in the face of insensitive health care professionals. Additional research has suggested that institutionalization of Alzheimer's disease victims could be forestalled or prevented if families received proper education on management of the patient's problems, advice about coping techniques, and enhancement of social networks (Ferris et al, 1987).

Caregivers perceived that the course of events could be different if physicians or other healthcare professionals would take the time to explain resources or make referrals. Caregivers expressed anger at the medical profession for failing to refer the family to agencies for appropriate help:

> I have had so much anger at doctors who don't put more emphasis on therapy. They never pushed therapy with us. They put him in therapy in the hospital but that

> was all. They never asked us if we wanted a therapist. They never said this child ought to have therapy. We did that because we knew. . .that there might be something that could be done. And we did that on our own. Nobody suggested we should do it.

Research by Thorne and Robinson (1988) on the relationships of health care providers with families provided a framework that was congruent with the processes described by family caregivers in this study. The first stage was a relationship of naive trusting. Families assumed its perspective was shared with health care professionals and that these professionals would act in the sick member's best interests. Families soon realized that their subjective experiences were not as important to these professionals as disease management.

The second stage was one of disenchantment in which family members were dissatisfied with the lack of help received from health care professionals. The family became frustrated, fearful, and angry, especially because of the difficulty of obtaining accurate information. The trust level diminished and families began to view the sick member as vulnerable and needing protection.

The last stage was that of guarded alliance in which families began to state their own perspectives and expectations more clearly. They promoted negotiation of a mutually satisfying level of care for their family member.

Misconnections with help from society also have been experienced by family caregivers. When some families were able to go outside the home and take their disabled family member with them, they experienced how little others understood about these situations. In public situations, strangers stared at the dependent family member; this experience bothered the family, expecially if they had recently entered the caregiving situation. They felt a need to explain the disability to others:

> Society hasn't done a lot to help handicapped individuals. When we go to a restaurant carrying a cushion with a hole in it, crutches, and a cushion to sit on, you're embarrassed.

Popper's research (1984) described these same situations as people in public often gave hostile stares, made judgemental comments, offered murmurs of pity, or made intrusive requests for personal information. The insensitivity of society to the plight of caregivers created an additional embarrassment and burden for the families. Benner and Wrubel (1988) also captured this feeling in noting, "A major source of stress and a major stumbling block lie in society's devaluation of caring and the lack of social recognition and rewards accorded to caregiving" (p. 1074).

In looking at society in general, one caregiving son of an Alzheimer's victim offered his perspective on how society set priorities for dealing with devastating health problems:

> Our society just isn't set up for this disease. Our society is set up real good for cancer or things that take a few months to die, car wrecks, something like that. But something that takes fifteen years to die from--we're just not set up for it.

The support systems offered by society were not adequate to help this family. The prolonged nature of the illness in this family's dependent member caused their plight to be lost in time and importance to potential helpers.

Society attempted in many ways to influence how caregivers functioned in their roles. Family caregivers often encountered people in public who did not understand the situation, yet tried to tell the family what to do to better care for their dependent member:

> You have to fight people about a lot of things in dealing with these [retarded] kids. You say, 'Look, what I'm doing is the best thing.' He's got to learn to face the world and do things for himself.

Caregivers had to learn that what they were doing was right for their family and not let outside people who did not understand try to influence the situation. Caregivers who perceived themselves to be more secure in their caregiving roles did not identify society's interference as a major problem in their lives. They spoke instead about the public being friendly and relating warmly to the disabled family member. Perhaps time and life experiences accounted for the differences in these families.

Caregivers would sometimes experience misconnections with friends and other family, thus making their efforts at seeking help less productive. Richmond and Craig (1986) described the concept of enmeshment. In times of crisis, family members became enmeshed with each other. If enmeshment continued for a long period and there were extreme differences in the degree of enmeshment among members, then discord occurred in the functioning members, especially in role-related areas. This disharmony was observed in one family in which one daughter was obviously enmeshed to a greater degree in the care of her mother than were the other siblings. This fact created many hard feelings and eventually resulted in the other sons and daughters withdrawing themselves almost completely from the caregiver role:

> My brother. . .would come over and sit in the living room to talk, but he'd never go into the room to see her. They just left it up to me to keep her. They decided I should get some money for keeping her, but my brother had the money in the bank and he wouldn't release it. . . .One sister told me she'd come every Tuesday to stay. She came twice and then called me to say that was the only day she could play cards with her friends and she wouldn't be back.

Some families perceived that their extended members did not help because they were afraid they would not know enough or do the right things:

> We were fortunate in that our daughter-in-law can keep L. No other member of my family has kept L. overnight before, and I think it's because of fear of everything she's been through. My mother has never attempted the catheterization and I know there is a lot of fear.

Hildebrandt (1983) noted that families often were embarrassed about needing help. They often would allow themselves to become distraught before seeking help. Lynch (1965) described how people repressed their need for help. This repressed need had a tendency to be manifested in unexpected ways with individuals looking for help where they really did not need it or could not get it. One caregiver shared these same feelings:

> I don't want to bother anybody. . . .If you've got to ask people for everything, I would rather just spend the money for it. Maybe that's too much pride, I don't know.

This caregiver further shared that asking favors from others sometimes caused people never to feel inconvenienced:

> Others say, yes I'll do it, but I never hear from them again. . . . I let those people alone because I don't want to bother anybody.

Other caregivers were able to ask for help as needed and these requests generally were met by others:

> I finally came to the point where I told J. I had to have some help and she arranged for someone else to keep him on Fridays.

This ability to ask for and receive help differed with the individual caregivers, a difference which possibly could have been related to the personality of the caregivers or their ability to communicate their needs clearly.

Several families perceived their ministers as potential sources of help and support. Haugk (1976) noted that physicians and ministers were the gatekeepers in the helping system with the pastor being an enabler of laymen in his congregation. In some situations, the family caregivers realized that misconnections also were possible with these helping professionals as well as with health care providers. One caregiver who had been caring for her bedridden elderly mother had not had a visit from the minister in three years. He finally made a token appearance when the elderly lady died. Another family described how their minister appeared very awkward when he came to visit and did not know what to say:

> Ministers need to know how to be sensitive to those who have handicapped children and how to talk and deal with them. That should be in the curriculum of every nurse, doctor, social worker, minister, on down the line. And not just a little short course, but an in-depth course and have parents there to speak to them.

Families sometimes experienced misconnections in communication with others:

> I don't think I would be comfortable with a support group. There are some things I would have said different. So, I'm not too sure if I could talk with strangers.

Failure to talk about the difficulties being experienced by the family was perceived as a way to avoid pain, conflict, and argument. However, this lack of the sharing of feelings could lead to resentment, frustration, and a burden on the mind. This process for handling stresses proved ineffective. One caregiver expressed a need for her family to just sit and talk:

> My mother will come to help. . . .She'll come up here and do some things. I can never get her to come and sit and relax and just talk to me like you're doing. She's a worker.

Talk seemed to be painful for some families, and they handled this discomfort by involving themselves deeply in instrumental care, thus avoiding the sharing of feelings.

Caregivers experienced misconnections with themselves as basic human needs were unmet during fulfillment of their caregiver tasks. One of the most frequently mentioned problems was lack of sleep:

> Back in the beginning, he cried 18 hours per day; he slept about four hours per day. Somebody had to keep him. The crying drove us crazy.

Another caregiver shared this account:

> Mother could scream really loud. I finally went back into the back room where I could try to sleep at night, but I could still hear her. She was so demanding of us. I told her I had to have some sleep. . . .She told me to sleep when she slept. I told her I couldn't just lay down and take a nap any time. I'm not the best sleeper in the world, anyway.

Research conducted on people who had altered sleep patterns due to work schedules demonstrated increased stress and an accumulation of sleep deprivation. This deprivation led to decreased effectiveness in completing tasks (Akerstedt, 1985). These caregivers not only had to complete multiple tasks, but they often had to function in a depressed physical state secondary to sleep deprivation.

Misconnections occurred in many facets of a caregiver's attempts to seek help. These misconnections occurred with health care professionals, with other helping professionals such as ministers, with society, with role expectations, with family and friends, and with basic human needs. These misconnections greatly interfered with a caregiver's ability to obtain adequate help from internal and external resources.

Misconnecting with hope. Misconnections also occurred with sources of hope as caregivers struggled to make sense out of life's circumstances. Lazarus, Stafford, Cooper, Cohler, and Dysken (1981) noted changes in the stages of hope exhibited by caregivers over time. An initial expectation for many caregivers was for a magical solution to their dilemma. This thinking was soon followed by disappointment when answers were not found. O'Malley and Menke (1988) noted that healthcare workers could threaten a patient's state of hope when information was not provided or when patients' needs were not met in a timely manner.

As family caregivers fulfilled their tasks, there were natural periods of emotional highs and lows where their hopes for positive changes wavered. Even though they expressed faith in God to support them in their burdens, it was difficult for hope to be ever present in their thinking:

> I don't feel like there's anything that can happen to you that, if you have faith in God, you can't mount it. Sometimes my faith, though, wants to run downhill like a glass of water. . . .

Caregivers and their families desired tactful and gentle honesty from other people. The literature supported the idea of honesty and realistic hope as being desirable. As people tried to cheer up other people, a hopelessness was nourished by setting up an impossible ideal. This approach failed to take into account the harsh realities experienced in the world (Fischer, 1988). Lynch (1965) noted that not everything could be hoped for and that "nothing leads to more hopelessness than the naive theory that everything can indeed be hoped for" (p. 48). Siegal (1986) noted that a false hope that was maintained regardless of the situation was destructive. Hasty reassurance was viewed as a way to keep others at arm's length and failure to take the other person seriously.

Boyle (1983) referred to this process as the unpeopling of persons.

This misconnection with false hope and reassurance was described pointedly by one caregiver:

> One thing I don't like, though, is the kind of people that tell me what they think I want to hear: 'You're going to do good' or 'It's going to work out.' And you know durn well you're facing a really tough road ahead and it's not as easy as people think. I don't know if they're trying to be soothing and saying the things I want to happen or whether they are unaware. You want to have friends, but it would be nice to have someone who will level with you. And yet you don't want them to be too blunt--honesty without being blunt.

Caregivers wanted to have hope, and they needed a family and friends to offer them that hope. Sometimes the manner in which that hope was offered actually increased the caregiver's distress by encouraging a level of hope that was ideal and unreachable. These misconnections with hope were more destructive than helpful.

Misconnecting with happiness. In the midst of their search for help and their grasping for hope, caregivers also yearned for happiness. The reality was, however, that caregiving tasks in many situations were so life-consuming that there was no time to pursue the activities or relationships that afforded happiness. Research on caregivers of elderly persons (Arling & McAuley, 1983) confirmed that restrictions on personal time and the emotional strain were by far the greatest problems encountered. These nonfinancial factors accounted for a large proportion of unhappiness in persons fulfilling caregiving tasks. Most caregivers tried to find some happiness in a variety of ways, but their efforts were often frustrated as they misconnected.

Caregivers described their initial feelings as they learned that a traumatic life event would change their lives forever:

> Let me start by telling you about the beginning and how I felt then. One of the things that people don't realize is the depression that hits people when something like that happens in the family. I went through months of real deep depression; in fact, I had to go for some counseling to cope with the grief. There is a definite grief, just like a death, and I couldn't believe this whole thing could happen to us.

Being thrust into a caregiver role released a flood of feelings in the caregivers, and they used such words as "traumatic," "frustrated," "cruelty," "agony," "sorrow," "devastating," "cheated," and "exhaustion" as they described their situations. One caregiving wife of an Alzheimer's victim shared these feelings:

> Taking care of a sick person in the home is no easy job. . . .The part that is devastating is the heartbreak of seeing someone you know and love not know your name. We were driving along the street and he looked over at me and asked, 'Where do you live? Do you have an apartment?' Then he realized what he had said and he broke down and started crying. . . .It was a horrible thing to see the strength of the family in a position where he was crying.

Weisman (1981) had noted the same reactions that occurred among patients also could occur in caregivers. The sadness, anger, frustrations, and helplessness felt by ill and dependent people also were reflected in the caregiver's emotions.

Caregivers were aware that their attitudes could be transferred to the individuals for whom they were caring, and they were concerned that they not contribute to the caregivers' state of unhappiness. One caregiver perceived that her mother was being selfish and her demands exceeded what the caregiver was willing or able to give. She worried about becoming bitter and resentful toward her elderly mother:

> She used me as a crutch. Those were long years for me. There was a lot of hurt, and I reached a point in my life where I thought I was just going to hate her--and that scares you.

Weisman (1981) proposed that caregivers may become impatient, irritable, and even antagonistic should a dying patient exceed predictions and live longer than anticipatory grief requires. One caregiver shared how this theory applied in her family situation:

> When we brought her home from the hospital, they gave her only a few weeks to live. Of course I gave her everything. When I realized she wasn't going to die, I had to get us back on a regular schedule I could live with. . . .I know this is a horrible thing to say, but I felt they [the other children] wanted her to die. And then I don't know how my own feelings were. I didn't ever actually wish she was dead, but I wondered why things were happening like this.

As caregivers experienced some days as "trying, fumbling, and chaotic," they found it difficult to find happiness and a peaceful spirit, especially in the beginning of their roles. Feelings of confinement and lack of control were expressed. The families' perceptions of the degree of this lack of control made a difference in their perceptions of the situations which were seen either as a demon to terrorize their lives, or a handicap to inconvenience their daily schedules. The greater the lack of control and uncertainty experienced, the more negative view of the problem the family described:

> I see it [physical injury] as a demon. It's almost like a monster that won't go away and leave us alone. No matter how we try to please it or bid it goodbye, it just won't go away. It's always here and ever-consuming. It involves our time, our money, our energy, our activities; everything we do revolves around it.

Caregivers described another variation of a misconnection that interfered with happiness. Involvement in the care of a disabled person enmeshed the caregiver in an involuntary connection that pulled that caregiver along in a negative direction:

> It's impossible to keep your own mind if you're continually subjected to nothing but a demented person. . . .When a person is degenerating and you're taking it on, you're going the same way they are--downhill, too.

Some caregivers acted out their frustrations instead of stating their needs directly and assertively. Bruhn (1977) proposed that family members other than the ill or disabled person might become sick to call attention to themselves or to the need to reallocate tasks, especially if they felt overshadowed or overburdened by the ill family member. One caregiver shared this experience:

> One time I hadn't slept for night after night and I had gone to the doctor with pain in my chest. I asked my sister if she would keep mother three or four days while I recovered. At first she said yes, then she called me back and said no.

Caregivers sometimes had difficulty asking others for help and became bitter when they were not offered help and attention from others. This nonassertive, inactive role in seeking help to meet their needs was frequently a source of unhappiness. They were miserable because they could not, or would not, ask for assistance:

> I'm not one to ask people for help. . . .I got tired being with S. all day. I felt ignored by my girls when they came in and flocked to their father. . . .I felt bitter and couldn't for a long time express it. Finally, the other day, I just blurted it out. . . .I'm not one who can normally say, 'Look, I need some help'. . . .I'm afraid of offending somebody. . . .I have been defensive about anybody doing anything for me. . . .I don't like the feeling of being totally dependent on somebody or even partially dependent.

Family caregivers who had younger children in the home recognized these children needed special care and attention. Each child was recognized as having individual needs and each needed to be included in family activities. Parents were sensitive to the fact that children should not be overburdened with extra chores and adult responsibilities, yet they found it difficult to prevent this situation from occurring. In one caregiving family, the eight-year-old child began to worry about the welfare of her parents and asked questions about the strength of her parents' marriage. She worried that they would get a divorce. Separation anxieties in the child became evident to the point that the child wanted to cling to her parents, especially the disabled mother. The mother described her daughter's behavior this way:

> She doesn't understand why we can't just pick up and go to Six Flags. . . .I tell her I can't walk that well. She even says if I'll go she will push me in a wheelchair. I tell her she can't push me that far. She doesn't understand it; as bright as she is, she is still only a child and she has a hard time. I tell her to go some place and she says to her friends she can't leave her mom because she might need her. . . .When she

> goes to a friend's house, she calls to check on her mom a dozen times.

The children struggled with the harsh realities of disability and the burdens of caregiving. Blackford's research (1988) proposed that parental chronic illness interfered with the nurturing of children. When friends or family visited the home to offer help, they often did not center on the child's needs, but on the needs of the ill adult. Children of ill parents were vulnerable to negative effects in their psychosocial development unless extended family provided the nurturing that parents were unable to give.

The misconnections with happiness stemmed from many sources: frustration and helplessness in the caregiving role, resentment of the demands placed on them, lack of control that made the situation frightening, involuntary enmeshment with an ill person that pulled the caregiver into depression, inability to ask for help, and lack of parental ability to nurture children in the household. Caregivers who were unable to recognize and remedy these misconnections continued in their unhappiness as they fulfilled caregiving tasks.

Disconnecting

The process of disconnecting was operant in the lives of family caregivers and affected to what extent the needs for help, hope, and happiness were met. Disconnecting was conceptualized as a breaking of a bond of cooperation or relationship. The process could be either intentional or unintentional, conscious or unconscious.

Intentional disconnecting occurred as family caregivers came to the realization that the resources they were using were inefficient and did not meet their needs. Purposeful decisions were made by some caregivers to terminate relationships with these individuals or agencies with the intention of searching for more helpful resources. Sometimes certain tasks were intentionally terminated as caregivers disconnected with aspects of their roles that were overwhelming.

Unintentional disconnecting was a process that occurred occasionally between the caregiver and the family member receiving care. In some caregiving situations, the nature of the disability in the dependent family member was such that a gradual division developed between the caregiver and the cared-for individual. Progressive physical, emotional, and spiritual deterioration of the disabled family member widened the gap between caregiver and family member, thus making communication and interactional efforts less effective.

<u>Disconnecting with help</u>. As caregivers continued to function over time, many of them realized that they had disconnected with certain resources and situations. Sometimes the disconnections were of benefit to the caregivers, and sometimes the disconnections prevented needs from being met.

Disconnecting tended to occur with friends and other family, not necessarily by choice of the caregiver:

> The only people who have called me in these last six months are the people who do care. . . . Let's face it, the people who initially called don't call or come around to see me any more. The longer the duration of something like this, the less people you will find who really care; you can count your true, real friends on one hand. They just quit calling and coming around. After about two weeks, it just ended like that, and I have had six long months of being by myself dealing with a situation where people don't really care.

Another caregiver described how her family had disconnected with her and her disabled husband:

> It bothers me because she doesn't ever check on either of us and that denotes a lack of concern. Even with a busy schedule, if I had a family member as sick as he's been, I'd be checking in on them to see what's going on. I don't understand a family like this.

One of the most poignant descriptions of disconnection with family and friends was offered by the caregiver son of an Alzheimer's victim:

> By my observation, most of the people, family, friends, and such, disappear. It's almost like a cancer house because no one wants to come around. . . .Even the best intentioned friends and relatives don't want to go out of their way to visit a place that's so depressing. It's not that they don't want to help, it's just that it's a tremendously depressing thing and people just stay away. The best friends that we had just quit coming around because there is so much misery and pressure in the house. . .There are things that are distasteful, so naturally you don't do them. It's a natural reaction. The net effect on the family is that the caregivers are in isolation. Not only do you have a problem, but you've got it by yourself.

The family caregivers who spoke most positively about their ability to receive help and to maintain hope and happiness were those who chose to involve themselves in activities outside the home. Families who made a deliberate choice not to interact with people outside the home in essence disconnected themselves from sources of help. Kane (1988) proposed a framework for understanding how families were able to have needs met. The family that failed to engage in reciprocal relationships or refused to engage in the process of receiving feedback diminished its family social support capacity and limited the resources available by restricting the family's versatility and resourcefulness.

There were times in the lives of caregivers that purposeful disconnections were made with the caregiving role. The overwhelming nature of the day-to-day tasks made the idea of respite a vital one for caregivers. Goodman (1986) used the term emotional disengagement to describe this process of disconnecting, and one caregiver described its importance to her:

> I took some time to sit down and drink some coffee this morning. I've learned to do that for a few minutes. I have to keep my sanity. . . .That is something caregivers need to do. There are respite care areas that give some time, but a respite of a few hours doesn't help me. . . .The caregiver has to have some respite and time for self.

Another caregiver shared the same need for relief:

> You just have to have some relief. There's no other way you're going to make it. . . .You have to have it because you do it 24 hours a day for every day of your life. Even if you love that person dearly, you just need some time away from that routine or you will go bonkers.

Thorne and Robinson (1988) acknowledged the importance of this purposeful disconnection in order for family caregivers to regain control and cope more effectively.

Family members used selective inattention to limit the amount of information and number of concerns they dealt with at any one time. This allowed them to maintain a manageable perspective by choosing to deal with some concerns while postponing dealing with others.

One of the most devastating types of disconnection occurred as some caregivers experienced the gradual, irreversible slipping away of the body, mind, and spirit of the person for whom they were caring:

> At home he stays in one position all the time. The only things he moves are his hands and his head when he has a crick in his neck. He sits like that all day long--no response, no questions, no answers. . . .

Another caregiver described her mother's withdrawal:

> I don't know if this is God's way of preparing you for death that nothing seems to matter. Mother lived in her own little world. She wanted me there, but she shut out everyone else. This may be the way God prepares an old person to die. It's strange.

The wife of an Alzheimer's victim described her husband's deteriorating physical condition with his sagging face and blank eyes. She was so overwhelmed and grief stricken to watch her mate's deterioration that she turned to writing poetry as an outlet for her frustrations:

> I hold his hand, I rub his brow,
> I talk to him and it helps, somehow.
> I try so hard to ease my pain,
> And I ask, dear God, where is his brain?
> He walks so slow, his heart is frail;
> His head hung low, his speech will fail.
> My heart will break ten times today
> To see this man so far away;
> With eyes so blank and dull again;
> But still, dear God, where is his brain?
> He's gone from me forevermore;
> I die inside to love no more.
> Great days of sorrow and sleepless nights,

> Long years of dying, unresolved.
> How can you do this, I ask again?
> To leave this man, but take his brain?

Disconnecting with help from others as well as from the cared for individual made the caregiver role a difficult one to fulfill.

Disconnecting with hope. Although many examples were found to illustrate how caregivers disconnected from sources of help and happiness, no evidence of a disconnection from hope was found. None of the family caregivers interviewed gave any indication that they had completely given up hope in their individual circumstances. As bleak as some of the situations were, hope was still alive in the hearts and minds of the caregivers. There were some misconnections evident with unrealistic hope, but hope had not died.

Disconnecting with happiness. Throughout the course of each caregiver's experience, there were times when these individuals found themselves disconnected from sources of happiness. For many, the disconnection occurred insidiously as an evolving process. As the caregiving tasks became more life-consuming, happiness appeared farther away.

Caregivers disconnected with people they loved and missed time spent with other family members, especially with children:

> It's real important to try to give them [children] as much of yourself as you can. Sometimes I feel like ours got left out down the road because we did have so many problems. Maybe we weren't always there for them

> like we would have been if she had not had all the problems. You just do the best you can and go on.

Caregivers also recognized a tendency to disconnect with their spouses and struggled to deal with changed feelings and shifting circumstances that threatened the stability of the marriage. One husband who was also a caregiver described the loss of doing things as a couple:

> We can't do things. . . .I think when things get back to normal, or as close to normal as they can, we can possibly be the way we used to be, involved again at that level.

Another caregiver shared a similar determination to combat the potential marital interruptions:

> For a husband and wife, regardless of the circumstances, they should not let anything come between them. . . .The best you can, you don't neglect that relationship.

Disconnections occurred in a caregiver's social life as tasks necessitated a large degree of confinement. A lack of a means to get out of the house reduced the availability of social support from family and others:

> Your social life goes out the window--you don't have a social life. When every waking moment is taking care of him, that's not much of a life.

A lack of fulfillment was seen in caregivers having to bypass what they really wanted, such as going out to get a barbeque sandwich. One caregiver described this as missing out on life's pleasures, those events and opportunities that so many people take for granted.

Another disconnection occurred with a lack of touching. One person described herself as being out of touch and really needing a human touch. Another caregiver described how she needed to be touched by people who cared for her as a demonstration of their love and support for her:

> Touching, helping, support--you couldn't function without them. I would have been a basket case without them.

Montague (1978) proposed that touching was vital to the quality of life. Living creatures that did not receive touching would become ill and die. The phenomenon of touch profoundly affected an individual's holistic health in a positive way. Lack of touch was potentially life-threatening. Some caregivers were sensitive to their lack of physical touch and described the sensations of pain, lack of energy, pressure, and coldness that accompanied this deficit of human touch.

One of the most distressing sources of unhappiness was a caregiver's disconnection with himself or herself. Fleeting desires to reach outside the oppressive situation to fulfill the self in creative ways were often not acted upon. Needs or desires for self-fulfillment were unmet for lack of a means to participate or a lack of energy to invest:

> The more I had to look after him, the less I was able to be my own person. I gave more of me over to his needs and there was less of me to do anything else.

A caregiving wife shared her dream of writing and publishing poetry. She wanted to join a poetry club at the Cultural Arts Center, but she perceived there would be no way to arrange her husband's care for her to be able to do these things. Fengler and Goodrich (1979) also noted that caregiver wives felt isolated and desired more freedom for expressive and personal pursuits rather than getting out to commute to work or fulfill other routine instrumental tasks.

Caregivers often found it necessary to disconnect with their dreams and their futures. They perceived time to be running out with their chances for dream fulfillment diminishing rapidly:

> There are times when I feel sorry for myself. I see other retired couples who can pick up and go to Florida, who can go on a camping trip with a group, who can plan vacations. . . .We haven't had a vacation in years.

Distress in caregivers abounded at having been cheated out of the golden years and at being robbed of the opportunity to develop and nourish long-term friendships.

Connecting

The process of connecting was conceptualized as creating a bond of relationship, cooperation, or mutual effect. Its occurrence could be intentional or unintentional, and its net effect on individuals could be perceived on a continuum from negative to positive. Connecting was the basic social process that enabled caregivers to realize a fulfillment of their needs for help, hope, and happiness.

Connecting with help.

Bowers (1987) proposed that family caregivers needed help with five different categories of tasks. Anticipatory caregiving involved behaviors and decisions based on anticipated needs of the patient. Preventive caregiving included activities to prevent illness, injury, or deterioration. Supervisory caregiving provided for checking on the dependent individual periodically. Instrumental caregiving was assistance in providing for a person's physical well being. Protective caregiving was protecting a person's esteem and self-image.

Family and friend support systems offered all of these types of help at varying times. One of the prerequisites to accomplishing any of these caregiving tasks, whether performed by the immediate family or by extended support systems, was a shifting of life activities. Research by Liehr and Flores (1988) on cardiac patients introduced the concept of living on the edge. In these situations, families experienced a shifting togetherness as they participated in re-evaluating their situation. A caregiver husband shared these perceptions of how his family shifted things:

> E. used to take care of most things. . . . Now things have pretty much shifted from E. doing most everything to me doing most everything. . . .It changes your whole perspective.

Another caregiver described her thoughts on shifting this way:

> Sometimes you have to shift times of doing things. Shifting things has to be done. I couldn't push myself to do extra things--I didn't have time. . . .Families being understanding and sharing the responsibility is important.

Connecting with needed help was accomplished many ways. All of the families indicated a desire for more education. As they began to assume caregiver tasks and gain control over their situations, they became assertive in seeking educational help from various resources. This greater knowledge, in turn, enabled them to gain even more control. Miller (1989) described the sense of being in control as a perception that one's own knowledge and actions can affect an outcome. People who were informed felt less powerless. One caregiver shared these thoughts:

> For a long time we did not know who our enemy was. The enemy was the deteriorating brain. In the early stages, that caused untold suffering for this family. . . .The one thing I would ask to relieve the suffering that families have is that we could have had an early diagnosis. If we had had this, our life would have gone in a whole lot different direction. . . . Once I learned what the disease was, I tried to learn everything there was to know about it. I read all the newsletters and have tried to educate myself.

Much learning occurred over the years for these families. The gradual education of the family and health care professionals in how to deal with situations allowed the family to be more functional. There was less fear seen with greater understanding. Time made a difference in the degree of connectedness. An experience of 16 years allowed a family to have more stability than one of six months' duration:

> There's been a lot of education along the way that has made life better. . . .Otherwise, 20 years ago, where could you take a child like that? They didn't know what a respite home was. . . .There wasn't anything else for us to do but bring her home. . . .I think time has probably done more to educate us. We've come a long way.

Caregivers realized that learning could occur in a committed, cohesive family. Since learning was sometimes difficult, yet so vital, families had to work at learning the right thing to do. Learning how to deal wisely with caregiving tasks was time-consuming.

Caregivers learned that lay people could master technical skills and could function well in assisting a patient when they were informed and aware:

> A lot of people have a misconception that because a [handicapped] child is medically involved, you have to have a nurse there. And that's so wrong. . . .And many times we've been afraid to bring her home, but we've managed to do it. And other lay people could do it, too. I think that is a fear people have. If you just look at her chart and read it, you immediately think, 'Well, she'll have to have a nurse. . . .' But any parent could learn to do the same things we do.

Support networks for caregiving families were seen to be crucial to their ability to cope. A variety of modes of help came from these family and friend networks in both tangible and nontangible ways.

Boyle (1983) reflected on her own need for support systems:

> Needed, desired help is beautiful and healing. It draws people close. Indeed, I think it is God's own delegated love. But unneeded, undesired help tells its victims plainly that they are not being cared about but used. (p. 155)

Natural neighbors and community volunteers were seen as able to fortify natural support networks (Zarit et al., 1980). However, sources of help outside the family could help the family restore equilibrium, but this alone could not hold a family together (Bruhn, 1977). Family connections were vital.

The literature provided an abundance of validation for the importance of these networks. Crawford (1987) defined a support network as a group of people who provided consistent communication concerning expectations, help with tasks, evaluation of performance, and the giving of rewards. These networks assisted people in using psychological resources, provided needed supplies and information, and gave guidance (Caplan, 1974). Constructive change was promoted by stimulating people to identify options (Bruhn & Cordova, 1982). People who utilized their support networks had greater opportunities for making informed decisions and receiving needed help.

Gallo (1982) offered the buffering hypothesis, a theory on how social support promoted health. Social support facilitated coping with crisis and moderated its effects. Support in the form of information led people to feel a sense of self-esteem and personal worth. The feeling of belonging to a network provided a context wherein personal change could be made readily.

Thoits (1982) proposed the direct effect theory in which social support directly affected health and well-being independent of major life changes or crisis. Self-evaluation and social identity originated in social interaction and were perceived to be important aspects of well-being. Social support helped to maintain or strengthen self-esteem and social identity. Social integration enhanced well-being, and membership in a socially cohesive group involved a sense of certainty and purpose with traditional and stable values governing behavior.

The concept of nurturance was identified as important in helping families accept physical and emotional help from support systems (Richmond & Craig, 1986). Members of this support system also had a need to nurture the family in order to minimize their feelings of helplessness. The ability to offer nurturance to the caregiving family allowed individuals in the support networks to perceive themselves as helping.

Kane (1988) proposed a model of family social support in which this support was conceptualized as positive, nurturing, and encouraging. There was mutual interdependence in support relationships characterized by reciprocal helping relationships. The basis of family social support lay within the interactional realm in which the family shared perceptions of itself with others and received evaluations from others as to how the family was perceived. This reciprocal relationship of the family to its support systems facilitated health and the access to helpful resources. The concept of emotional involvement was also a major part of Kane's model and connoted positive emotional bonds such as love, caring, warmth, and compassion between family and others.

Family caregivers in this study perceived that family support systems would make their tasks easier:

> I know these things happen to everybody and since I've dealt with S., I've seen so much that does happen to other people that I feel how fortunate we are that events and family support systems have made ours much easier than that which happens to other people. . . . Without that family support, I would have caved in long ago.

Caregivers discovered that caring for another individual involved a double motivational burden that contributed to their need for family support. Not only did the caregivers have to be motivated to fulfill tasks, but they, in turn, had to motivate the dependent persons to participate in their own care, to eat, to be optimistic, and to care about everyday affairs. Connections with other family and friends were vital to obtain this support:

> Some people come through like champs, though. Some people are there by your side. They're there to help, especially after everyone understands what the problem has been. . . .I've got a sister who stood right by my side. My neighbor across the street and two or three good friends at church insisted on sitting with B. while I did other things. The little things they would do that did not disturb him at all meant an awful lot. . . .But we've all stood by each other and held hands to get through the dreary days.

Listening to others with full attention, sharing sorrows and joys, being honest--these were needs of people of all ages and were treasures only another person could give (Boyle, 1983). Literature reviews noted caregivers expressed the need for help and support through a confidant (Fengler & Goodrich, 1979). Finding time to talk was hard to do because there was so much demand on caregivers' time. When caregivers did find time to share feelings with people they were close to, an emotional outlet was provided that greatly enhanced their sense of well-being:

> I needed someone to talk to who could understand. I talked to a friend who had put her mother in a home. I could call on her anytime. Here was a woman who would do anything for anybody. . . .The big need is for somebody to talk where they can say things they wouldn't say to others. I called it belly aching.

This sharing of feelings and concerns with another individual seemed to provide an outlet that was appropriate as well as helpful in relieving caregiver burden.

Respite opportunities were treasured by caregivers. Scott, Roberto, and Hutton (1986) conducted research with families of Alzheimer's victims. Their findings noted the types of help to caregivers that seemed most appreciated were visits and having persons stay with the patient so the caregiver could take a trip, rest, run errands, or get out of the house for social activities. When one daughter caregiver was asked what her greatest personal need was, she answered this way:

> Time alone. If I could have worked it out where I would know there were certain times where this would be my day or hour. If I had that to look forward to--a time I would do just exactly what I wanted. . . .The time alone was important.

Benner and Wrubel (1989) noted that respite and recreation were important, but also that the person experiencing burnout needed to be reconnected to sustaining relationships and meanings in order to overcome the alienation. Patton and Childs (1988) offered the idea that friends choose to do what family are obliged to do. One caregiver shared the importance of his friends in this respite process:

> I had friends who were not associated with this family who helped me and probably saved my life. I probably would have jumped off a building somewhere if it weren't for my being able to go outside this household. I'd go somewhere to relax and exercise and go on trips. That kept me from going crazy. . . .One of the things I had to do was exercise and get with friends--up friends so I could laugh a lot and take a trip from time to time to get out of the environment completely. Or go to the movies. That escape was critical. Friendship relationships are critical. . . .

Caregivers were able to realize some degree of help and burden relief as they learned to take pressure off themselves. Many of them gradually realized they could not do everything they would like to do for their ill family member and they became more realistic in the expectations of themselves. Weisman (1981) recommended that caregivers learn to cope better by making the least possible contribution:

> A little goes a long way; the least possible contribution is the one with the least strain but with the best chance of making a difference, however small. Having made this contribution, which may be very insignificant against the background of need, one can make another contribution, and still another, until something quite unanticipated but substantial results. Morale in everyone seems better, care is effective, plight is less painful. Least possible contribution does not, of course, mean doing as little as possible, but doing only a little bit beyond the ordinary, something that most closely reflects the caregiver at his or her best (p. 167).

Critical relationships with health care professionals, with family and friends, and with self were the basis for caregivers' connecting with help. Through learning, through supportive networks of family and friends who cared for and nurtured the family, through providing a safe place to talk and share burdens, and through the offer of respite to rest the mind, body, and spirit, caring people enabled caregivers to partially meet their perceived needs.

Connecting with hope. Maintaining hope was a basic need for family caregivers, and they connected with hope in two basic ways: through communion with God and interactions with people. This discovery was consistent with Lynch's (1965) discussion that described hope occurring between persons and between man or God.

God's special caring for us was perceived by Boyle (1983) as the foundations of security, hope, courage, and love. The caregivers also reflected on God as the basis of their hope. All of the families professed their religious beliefs to be Christian, so the feelings and thoughts shared were a reflection of the Christian faith and not necessarily consistent with those of people of other faiths. Fischer (1988) described Christian hope as living in the matrix of faith. Faith was seen as "neither a magic formula nor a naive optimism, nor a bargaining tool for a miraculous divine cure" (p. 34). Lynch (1965) stated that hope imagined the real. A strong relationship was seen between hoping and wishing, and individuals who could wish were moving toward hope.

Searching for a purpose in the situation was part of the process of connecting with hope. Caregivers and their dependent family members for whom they were giving care together sought the reasons for events happening:

> Maybe the Lord is trying to tell me something; but what is it He is trying to tell me? Things don't happen unless there is a message or purpose in it.

Luehrman (1977) proposed that life crises and times of struggle enabled people to get in touch with meaning for their lives:

> Through suffering, many people find some of the most important meanings of their lives in relation to God, their fellow creatures of the world. . .suffering purifies, refines, and enobles people in their inner being. (p. 18)

Caregivers perceived that God would use trying situations in life to build human strength:

> God can use these things--I know that. If He can use these things to build strength in others, I'm glad to be a part of it.

Fischer (1988) viewed hope as open-ended and based on a trust that God's promises would be fulfilled. God's promises were seen to provide a wider perspective for all our limited hopes. Caregivers saw connections with God as vital:

> I see the blessings we've got and the rest of the family we've got, and the good things about living. And God has said He would not leave us comfortless, and He has not.

Fischer (1988) stated that hope enabled us to see things differently in that "we put the pieces of our life into a pattern never tried before. We insert something novel into the pattern or throw a new light on something old" (p. 34). Through hope, people were seen to be able to expand the boundaries of what was possible in life.

Caregivers shared an optimistic outlook that included an ability to cope effectively with God's help:

> I keep going back to that verse in the Bible that talks about how God uses brokenness. . . .It's a challenge in one big word. I know I can do it with God's help, because I don't feel like anything is laid on anybody that is too hard for them to do. It's a proving ground, I guess.

Despite faith and hope, caregivers still felt discouragement and could acknowledge these times of low ebb in their hope levels. Yet they chose to connect with resources that helped them through those low times:

> Through all of this, I've said, 'Lord, you're so good to me.' Still, those are the battles you fight--feeling sorry for yourself, anger. . . .My faith helped me even in the beginning. I went straight to the Bible and got help there. . . .

A survey of American spiritual life (Better Homes and Gardens, 1988) reported that 68% of people across the United States used prayer and meditation to guide them. Of the respondents, 73% reported feeling closer to God during this prayer time than during religious services. Caregivers, too, used prayer to connect with God and to sustain their hope:

> When I found out what was wrong with S., I asked a friend to be my prayer partner. We prayed about it.

Kushner (1986) offered a beautiful description of God's role in facilitating human connections that enabled people to help and inspire hope in each other:

> The image of a God of power is never totally forgotten, but it is soon overshadowed by the image of a God who shares with us the task of building a humane world on the foundation of people caring for each other, even as He cares for each of us. (p. 57)

Fischer (1988) proposed that people could not achieve hope alone. Hope was seen as an act of communion in which we created hope in one another. Lynch (1965) also noted that people developed hope in each other, a hope that they would receive help from each other. Family caregivers were able to achieve some hope through honesty from health professionals. The truth was valued because it then enabled caregivers to formulate realistic ideas and hopes. Not being able to discuss the situation realistically was devastating and robbed families of hope.

Grimm, Soeken, and Carson (1986) identified four components of hope: a future orientation, the setting of goals, taking action to meet goals, and the importance of interpersonal relationships. Caregivers reflected their hope through these same components of future orientation and goal setting:

> I don't know of many families who are more united in the things that are going to happen. We just do the best we can. . . .Hopefully with God's help and everyone else's, we'll survive and I will have attained my goal.

Finally, family caregivers connected with hope as they achieved resolution or acceptance of the reality that was necessary to achieve control:

> I have finally come to realize that we are born into this human situation. . . .Just look around. You have to get to the point where you accept things. Once you do that, you do a lot better. . . .That's the way life takes us and we're not going backward.

According to Lynch (1965), hope became steadier and more mature as time passed and as individuals became better able to live contextually.

Hope could be achieved, but it was not automatically achieved. Effort was needed to maintain levels of hope, yet caregivers seemed to be willing to put forth the effort to connect with that hope.

Connecting with happiness. Connecting with happiness was the final process observed in the caregivers' lives. The degree of caregiver happiness was frequently described in relation to the amount of love and concern expressed to them by other people. In turn, caregivers found strength to convey that same love to the person for whom they cared. Siegal (1986) also described this loving relationship: "Out of the resonance between the sick man and the one who tends him there may spring that profound courtesy that the religious call love" (p. 18). Patton and Childs (1988) described care for others as a "normative expression of human creaturehood, uniting love and work" (p. 27). These authors further elaborated on the concept of relationality in which they stated it was not possible to live humanly and not consider others; people were created to live with each other.

Caregivers perceived their tasks as necessary if there was a shared love in that family situation:

> This is a necessary thing--it's going to have to be. I love this child and I want him to be as much as he can be.

The process of caring for another person was seen as important as the outcome. Caregivers were willing to devote a portion of their lives to another person for whom they were caring, thus sacrificing or postponing the meeting of their own needs. This giving of a person's self was, in some cases, a source of happiness.

Caregivers connected with happiness when other family and friends took an individual interest in them. The needs for love, acceptance, and encouragement were part of the matrix of happiness, and these needs could be met by other people who were sensitive and who cared. One caregiver described her feelings about herself and how people who loved her shared that love:

> Oh, to have a pastor that loves you. Oh, to have a church people that love you and say they appreciate you. This helps. I've had to let myself go. I've felt so self-conscious about this mop of hair, my wrinkles; my physical attributes are gone. Just for someone to say, 'You look good today' or 'I love you and care about you.'

The concept of temporality was discussed by Patton and Childs (1988): "Because the time we have is not infinite, its importance is greatly enhanced; we must take advantage of what has been given to us for stewardship" (p. 37). Two couples who were engaged in the caregiving process with retarded children stressed the importance of working to strengthen the couple relationship by spending time together. One caregiver emphasized the temporality aspect of her marital situation in this way:

> You should not neglect doing something because you're waiting for someone to die or to become independent.

The happiness of other children in these caregiving families was a concern to the caregivers. In research with families who had disabled members living in the home, Davis

(1980) noted children were happier and less stressed when they felt a sense of cooperation in a family-centered group, as opposed to a patient-centered situation. One family in this study shared how they attempted to sustain the happiness of their other children by including them in the entire situation:

> One more thing we haven't talked about is the siblings in the family. I think special care should be given also to the children. It's real important that families be honest with the other children and let them know to what degree it [the disability] is. It's important to be up front and tell it like it is, so if something does come along it's not so hard on them. If they're involved with that person, they're going to feel better about it--not have as much fear if they understand it better. If the parents try to spare other children by not telling them anything, it can be devastating. We always wanted to be right up front every time we went to the hospital. It's important to be up front with the other children; they have a right to know. I always felt it was just better not to hold that kind of stuff back--let them feel like they're a part of what's going on.

The outlook or attitude associated with a caregiver's thoughts and actions affected the degree to which happiness was achieved. Attitude has been described as the altitude of the heart and mind (Grimmer, 1988). Caregivers were sensitive to their own fluctuations in attitude:

> Attitude is a great part of it. I have to talk to myself sometimes and build myself up. . . .I have had to put it in perspective. You go up and down, up and down emotionally. Without the lows, you don't appreciate the highs.

Another caregiver stated:

> I have to stop and remind myself 100 times a day I can't let myself show any depression to him because it's not going to help him any. And I can't let him get to me because that won't help either of us.

Connecting with happiness through the fulfillment of self was viewed as important by caregivers. This was a difficult thing to accomplish, however, and caregivers continually struggled to find ways to do this. Smith and Bengtson (1979) noted that because of the continuing nature of caregiving, some caregivers believed they were giving up or suspending their own futures. Caregivers noted that great mental and physical strain made the time for self very important. One caregiver assertively asked for help when she perceived a need for respite; other family members usually responded to meet her need. Another caregiver took time to sit in her recliner and write poetry. She later shared this poetry with friends. Patton and Childs (1988) confirmed this self-care concept by proposing that a person cannot care for someone else until they understand their own needs for care; caring involved being as well as doing.

Propositions

From the analysis of data related to caregiver needs and processes used for need satisfaction, several propositions can be made:

1. The needs for help, hope, and happiness were directly interrelated such that a failure to meet one of these needs also contributed to a failure to realize other need satisfaction. For example, when a caregiver perceived that the need for help was not being met, then feelings of hopelessness and unhappiness were likely to result.

2. The needs for help, hope, and happiness were primarily met through the process of connecting with resources that supported caregivers in their roles, in their interpersonal relationships, and in their intrapersonal beings.

3. Misconnecting with resources contributed to a failure of caregivers to realize need satisfaction.

4. Caregivers who were able to disconnect with nonhelpful and nonsupportive resources and continue their search for more positive connections perceived their needs to be met to a greater degree.

5. The major process of connecting and the two subprocesses of misconnecting and disconnecting occurred continually throughout the family members' experiences as caregivers. The processes did not occur in a linear fashion but in a matrix fashion with the family caregivers enmeshed in all processes at all times and to varying degrees. Connecting with resources in a positive way was seen to facilitate achievement of help, hope, and happiness in the caregivers.

6. The connecting process occurred over time. The temporal aspects differed with each family situation and among the individual members of the same family group. Some family caregivers were able to grow more efficient at their tasks over the months or years by developing workable routines that provided adequate care while allowing them more freedom to meet their own needs. Other families did

not seem to benefit from time and experience and continued to struggle in their roles. Families who had been caregivers only a short while perceived their duties as heavy and in some cases overwhelming. The passage of time had not yet made a difference in their learning to cope effectively.

7. Quality of communication made a difference in the families' abilities to connect with resources for meeting their needs. Those families who possessed self-confidence and demonstrated assertiveness were more likely to interact with helpful resources in a facilitative manner. The nonassertive families found their needs continued to be unmet.

8. In the initial stages of their roles, caregivers perceived health care professionals to be the primary sources of help, hope, and happiness. As time passed and caregivers became more secure in their new roles, social support from family and friends was perceived as more important than interventions by health care professionals.

These statements of relationship offer varying degrees of linkage between the identified concepts. Descriptive, explanatory, and predictive relationships exist between some of the needs and processes to the extent that the beginnings of a substantive theory can be seen. Grounded in the data and structured by the identified limitations of this study, the emerging relationships between concepts have provided the basis for continued refinement and development of theory related to the meeting of caregiver needs.

Summary

The caregiver needs for help, hope, and happiness were recurrent themes in each of the family interviews. These three basic needs existed concurrently, and the behaviors aimed at meeting these needs were ongoing processes. The basic social process of connecting accounted for the primary way in which caregivers were able to have their needs met. Inherent in the connecting process were two subprocesses of misconnecting and disconnecting, both of which occurred simultaneously with connecting (Appendix F).

As caregivers grew in their abilities and self-confidence, more positive connections were made with resources that enabled caregivers to care more efficiently for the dependent family member at home. Thus, the need for help was addressed and potentially met. The fulfillment of hope also occurred through a connecting process in which caregivers found resources in God and people that would offer them realistic hope and encouragement. Lastly, caregivers met their needs for happiness by looking to themselves and their self-care capacities as well as reaching out to other sources of love and support from people who cared for them.

CHAPTER V

Discussion

Conclusions

Help, hope, and happiness were the three basic needs perceived by family caregivers. These needs were constantly present in their lives, and immediate circumstances determined which of these needs took priority at the moment.

Caregivers used three basic processes in their attempts to have needs met. Ideally, a connecting process enabled these individuals to enter into relationships with others to receive the proper help and to hear the words of hope and encouragement that brought peace of mind. These connections also potentially offered happiness in a realization of the pleasures and beauty life had to offer. Circumstances that robbed people of control and critical thinking ability led caregivers to make misconnections with sources that were only a mirage of help. These bonds were fruitless in that they offered little source of help or hope, and they brought frustration and sadness rather than happiness. Disconnections occurred that could be perceived as helpful, painful, or both. This process had the potential to enable caregivers eventually to make positive connections and allowed the perceived needs to be met.

Implications

Methodology

Grounded theory methodology has been an effective research approach for this study. Direct analysis of data that was grounded in the life experiences of caregivers provided a realistic view of these family members' perceived reality. Caregivers' descriptions of their needs and the processes utilized to meet these needs provided a first-hand picture of their lives that was unimpeded by researcher-developed data collection tools. The freedom offered by theoretical sampling procedures to select families that would enhance the theory development allowed for richness in the data. The relatively small size of the sample allowed for more depth to be achieved during the interview process, thus potentiating the possibility for relevant information to be shared. More time was spent with these families than could have been reasonably accomplished by use of more quantitative methodologies. Families seemed to know that their contributions would make a difference in the lives of other people as the study results were disseminated to other health care professionals and possibly other families.

The complexity of the family system has created numerous methodological problems for researchers in other situations. There is not one primary way to conduct family research that controls the multitude of personality, relationship, and process variables to the extent that a clear picture of the family may emerge. However, grounded theory methodology has allowed the researcher a freedom from the constraints of excessive efforts at variable control. Because grounded theory methodology assumes the participants are the best informants and can verbalize their perceived needs better than any questionnaire can elicit the data, this methodology has been quite effective in this family study. There was an approach operant in this study that simply accepted the family members as they were and took all of what was said as important words that had meaning to their lives.

Theory Development

From an evaluative standpoint, the beginning conceptual relationships that have emerged from this study have appeared consistent with Glaser's (1978) criteria. The initial categories evolved directly from the data, thus meeting the criterion of theoretical fit. The second criterion of workability is in the process of being met. At this time, the conceptual relationships appear to have definite explanatory power related to caregiver behaviors. Further utilization of these ideas in research with family caregivers may demonstrate that these descriptions of substantive relationships are capable of predicting caregiver behavior. The core variables in the form of needs and processes were allowed to emerge naturally during the course of the research without a preconceived framework to force their appearance. Thus, the criterion of relevance was met. The last criterion of modifiability also is in the process of being met. As the conceptual relationships were described through the course of this study, the concepts were modified as more data were obtained to develop the ideas. Continued utilization and development of these grounded relationships should demonstrate that this beginning substantive theory is modifiable.

The theoretical relationships between caregiver needs and processes for need satisfaction that emerged from this study are a beginning point for future theory development. The propositions offered have given barely a glimpse of what might emerge in continued study. The propositions serve as building blocks that have offered a foundation for additional research into caregiver needs. In combination with pertinent research from other professionals who have investigated the lives of family caregivers, this study may serve to give direction for continued theory development.

Nursing's Involvement with Caregivers

Nurses are engaged in a caring practice and are in a position to be with other people in a way that acknowledges a shared humanity (Benner and Wrubel, 1989). This shared humanity is the basis for nurses choosing to become involved on personal and professional levels with other people.

The constancy of caring is one characteristic that sets nursing apart as a profession that is totally involved with individuals who need their help. To this extent, nurses cannot compartmentalize their caring into an eight hour shift or a five day work week. People who are hurting need and deserve more than this limited involvement from nurses. A sensitivity to persons within the nurses' own immediate, extended, and community families is vital to the heart of true caring in nursing.

Nurses are in a position to offer a great deal of themselves to family caregivers in the community. Equipped with solid professional education and blessed with multiple talents, nurses can potentially revolutionize care to people in the community.

Organized nursing has reached out into the community through many different associations that offer home health services. From the earlier days of public health nursing, the profession has evolved into a position to offer more extensive nursing services in the homes of clients. Rapidly developing technology has enabled clients who previously would have died in a hospital to survive reasonably well for many years at home. However, those family members who have taken on the constant tasks of caregiving for these homebound clients have become a group who needs special attention from helping professionals. Their needs are not so much different from those of all other people, but the meeting of their needs is more difficult because of the nature of their caregiving roles.

Nurses are in a position to offer these caregivers a source of help in a holistic nursing approach. By supporting family caregivers, nurses are indirectly caring for the ill or disabled clients. The caregivers who perceive that they are being supported and that their needs are being met are potentially empowered to offer effective, loving care to their dependent family member.

It is time that nurses look closely at the communities in which they live. Nurses who are alive with the energy of the profession should be aware of the needs around them. Reaching out to share their knowledge and skills with the community that nourishes them should be an obligation for every nurse. This sharing of professional gifts by nurses can be accomplished in large or small ways, but it should be done in a spirit of generous reciprocity to the community in which they live. The world cannot be nursed to health, but there are smaller concentric circles of concern that can benefit from the involvement of a caring nurse. Thompson (1981) has proposed that these circles of concern begin with self-care and then proceed with a gradual reaching out to touch others by drawing them into the circle.

None of the needs expressed by family caregivers in this study are out of reach for the professional nurse. The meeting of the needs for help, hope, and happiness can be partially facilitated by a concerned nurse who is willing to invest a part of the self in these home situations. There are ways that nurses can assist families in recognizing the misconnections that frustrate them in their struggles to have their needs met. Nurses can assist with the necessary disconnections or support the caregivers through the process of inevitable personal disconnections that are so painful. Nurses can assist families in making those positive connections that will enable them to realize help, hope, and happiness.

In a discussion of the implications for nursing's involvement with family caregivers, it must be understood that the needs being considered and the processes being examined are interwoven in such a way as to be inseparable. The nursing role for facilitating the connections with resources to meet caregiver needs will be discussed for each separate need that the caregivers identified. These needs and processes, in reality, cannot be separated so neatly. Interventions to offer help to the caregivers also will influence the levels of hope and happiness. Likewise, a higher level of hope in caregivers will enable the caregiver to be more assertive and optimistic in receiving needed assistance. A high level of happiness may energize the caregiver to need less help or to be able to ask others for help. A holistic framework for the discussion of implications must not be lost because the caregivers' experiences have been reduced and confined to the limitations of this explanation.

Connections with Help. Nurses can offer crucial help to family caregivers. In so doing, however, nurses must beware of assuming the omnipotent rescuer role as described by Benner and Wrubel (1989) in which self-serving interests supercede the purpose for helping others. Nurses cannot provide all the help a family may need, and they should not even try to meet all the needs in a situation. To attempt to do so sets the nurse up to fail miserably and the family to become disillusioned.

One of the most important challenges for nurses and other health care professionals is to sustain the family's commitment to care and to strengthen the informal caregiver system (Heagerty, Dunn, & Watson, 1988). The strengthening of this system can be accomplished using an organized approach to nursing involvement.

One of the first steps in assisting families is for the nurse to help the family explore the availability of resources. An assessment of the family's needs and a mapping of the available support network is a basic starting point. The inclusion of these resources in a family plan of care will expand the potential sources for help.

A second step is assisting the family in the formulation of a daily schedule for care. The establishment of a routine offers the family caregivers more of a sense of predictability and control. Decision making and the application of technical skills are more efficient in a controlled situation. Thompson (1981) offered the wise advice that "nothing becomes dynamic until it becomes specific" (p. 80). For this reason, the planning of daily routines should include a specific structure and sequence of tasks in order to optimize the caregiver's control. Along with this establishment of a routine, however, should come the advice to caregivers that rigid adherence to a structure actually creates more stress. A happy medium of flexibility and established routine is desireable.

The sharing of factual information with the families is important. Nurses have always fulfilled teaching roles, and family caregivers are one group who could benefit greatly from this intervention. One of the biggest identified needs for help in caregivers was the need for education. In so many situations, proper teaching was perceived to make a crucial difference in a family's ability to cope. Damant (1984) proposed that the best equipped caregivers were the ones who were able to combine love and caring with technical skills in the care of family members. Those people who had a loving relationship with an ill person were perceived to be the best resources to whom training should be offered.

Counseling is another method whereby information can be shared with caregivers. Rather than the nurse providing factual information, this approach would involve the nurse assisting the family in exploring how relationships between family members might affect that family's ability to cooperate in caregiving tasks. Tobin (1978) proposed that it was essential that care be given to families while they are actively involved in caregiving and not just when the family could no longer cope. The caregivers were perceived to be as needy as the patients. Nurses should involve themselves in preventive care of families by facilitating the verbal sharing of feelings, thus providing an emotional outlet for the stresses of caregiving.

Shetland (1965) noted that it was not instinct to love those to whom one was related. The caregivers in this study also shared doubts about their feelings toward one for whom they were caring. The feelings of guilt sometimes expressed by caregivers at not wanting to care for another person on a long-term basis need to be accepted by nurses interacting with these families. Allowing the family members to verbalize their ambivalence in their roles and giving them permission to ventilate negative feelings is an important nursing intervention. Nurses can fulfill the role of a nonjudgemental listener.

Families also need assistance in accepting the diagnosis and limitations of the disabled person. Deterioration of the patient is inevitable in some cases despite competent care from the family. Since some families have promised to cure the patient, this fact creates distress for some families (Marsden, 1988).

Helping the family understand that cure is not always realistic can be a valuable nursing measure.

Referral to proper resources is crucial for families. Especially important is helping the family make connections in an emergency. There needs to be a clearly identified support network for those times when families cannot cope. Nurses can help families preplan these measures and establish these networks before a crisis occurs. Here is an opportunity, also, for caring nurses to supply the family with suggestions for additional community agencies or services which can supplement the already established resources.

An involved nurse can track the progress of the patient and the caregivers to monitor and evaluate the total situation. Shetland (1965) suggested that a caloration of risk must be done. This involved a helping professional such as a nurse helping the family evaluate how much risk is reasonable to expect. There is a point at which the risks to the well being of the caregiver may determine the direction of the caregiving situation. The nurse needs to observe for stress-related disorders in caregivers such as symptoms of hypertension, tension headaches, weight changes, or cardiovascular problems. Alternative modes of care may become necessary if the health and welfare of the caregivers is in jeopardy. The nurse can facilitate the family's acceptance of alternate care if this becomes necessary.

Indirect care to families can be facilitated by nurses establishing and supporting informal caregiving networks. Leininger (1978) has suggested that "the discipline of nursing needs to take seriously people's needs for personal, social, and cultural-based support systems that will help them grow and realize their full human potentialities" (p. 369).

Family caregivers indicated that their family was an important source of support to them. Hinds (1985) suggested that families could benefit from a combination of volunteer companions and professional back-up resources. Nurses who would organize support systems for family caregivers need to consider the immediate and extended family members as primary sources of help.

One nurse cannot meet the needs of several family caregiver groups in the community, but the nurse can look to other established institutions that have a vested interest in the welfare of the caregivers. Local churches, schools, and businesses can serve to connect caregivers with sources of help.

Since caregivers expressed a need for educational help, various community centers might be persuaded to offer their facilities for a nonprofit series of presentations by nurses or other professionals aimed at providing useful information to caregiving families. Cantor (1983) proposed that churches, unions, and neighborhood groups were well suited to act as organizers and catalysts for nonrelated persons in the community who desired help.

Community resources with perhaps the most potential of all are the local church, temple, or synagogue. These religious institutions could not only offer their facilities for community programs, but could also sponsor programs to support family caregivers. The idea of church involvement is not new and already has been piloted in cities in the United States (Dean, Jorgensen, Loose, and Duffy, 1988; Flood, 1988). According to Westberg (1984), churches are gradually waking up to the fact they are in the health care business without realizing it. These religious institutions provide a place for individuals and families to go for inspiration and hope, the healing of broken relationships, inner peace, and opportunities for the development of their own caring nature. All of these activities promote health and could facilitate the effectiveness of caregivers. Connections with churches could enable caregivers to find one source of help for multiple needs.

Nurses who are actively affiliated with a local church have a gold mine of a resource at their disposal. Assuming that the church is composed of a congregation of people who share common values of love and concern for others, the nurse could become a catalyst to stimulate church people to become involved in caregiver support. A project could be initiated by any concerned nurse who was willing to devote the time to training others to be helpers.

Three major areas must be assessed before a caregiver project such as this could be started. Initially, the needs of the community must be assessed. Questions to ask might include whether there are caregiving families in the community and whether they might be receptive to help from nonfamily members. Second, church leaders must be persuaded to offer their support to the project. This support might take many forms, but certainly should include a commitment to endorse the project to the congregation. Spiritual and monetary support also would be welcome and needed. Third, the congregation of people would need to indicate a willingness to offer their time, talents, and even money to a project such as this. The most valuable commitment of these people would involve their time to participate.

Planning the project would include a compilation of materials to use in training volunteer workers. These volunteers might be trained in everything from actual technical skills to communication skills to preparation of special diets.

Implementation of the project could be accomplished through the use of volunteers to offer respite services in the home to allow caregivers a well-deserved break. These relief services might be provided on the basis of a few hours or several days. Teams of volunteers might be used to provide a wide range of services to several caregiving families.

Evaluation of an undertaking such as this should involve feedback from the caregivers and their dependent family members as well as from the volunteer caregivers, church congregation, and church staff. It would be crucial to evaluate every aspect of this project to assess its perceived effectiveness by all involved; these evaluations would serve as the basis for program changes.

Although a project such as this would be time-consuming, one nurse might be able to coordinate this as a fulfillment of his or her commitment to community service. The participation by a team of nurses who pooled their talents would possibly be even more effective.

This proposed project is not intended to take the place of formalized home health services or efforts by other community agencies. It is envisioned as one way to fill the gap that sometimes exists when the needs of caregivers for help go unmet. It is one way of assisting family caregivers to connect with help.

Nurse educators have a responsibility to assist novice nurses in learning how to offer help to caregiving families. Because of the increasing scope of the family caregivers' roles, professional nursing students need experience in dealing with these community concerns. A curriculum using the connecting process as an organizing concept could provide nursing students with the theoretical content that would be valuable in dealing with families who care for dependent members in the home. Experiential learning that enabled students to become involved with family caregivers in an ongoing relationship over an entire quarter or semester of coursework would provide a valuable opportunity for learning. An assessment tool organized according to the framework of help, hope, and happiness could be used to identify individual family caregiver needs and could serve as the basis for nursing diagnosis and care planning.

The teaching role of nurses must be emphasized to student nurses. Involvement in community outreach projects for caregivers through local churches, businesses, or civic groups would allow students the opportunity to meet one of the most important help needs identified by caregivers--the need for education. By their participation in education projects as well as task-oriented care in the homes, students can strengthen the coping abilities of caregivers.

Connections with Hope. As recognized members of a health care profession, nurses are frequently asked questions by family, friends, and acquaintances in their communities. Many people seek information or advice, but some individuals are searching for hope. These are the people who ask the tough questions about statistics and life expectancy with certain diagnoses. When individuals pose these questions, the nurse should know that the individual has a personal concern related to the subject. Sometimes they are asking questions about their own health or a person they love.

As the caregivers in this study related, people desire hope, but they also desire honesty. False reassurance for cures and positive outcomes are not wanted. The opportunity to face reality with an open-minded attitude is preferred. Mallison (1988) has stated, "While others seek cures, nurses seek the compromises that infuse daily life with possibility" (p. 1459). Nurses can offer caregivers hope in the form of sharing possibilities, not statistics.

The caregivers' unstated promises to cure their family members through love has some basis in reality. Human love shared between individuals has been responsible for empowering others to live against all odds. In some situations, however, human love is not sufficient in preventing deterioration and death. When a caregiver promises a cure and the promise is not fulfilled, a devastating sense of failure may engulf that caregiver's mind and heart. Nurses often have opportunities to assist these caregivers to find a more realistic way to approach their mission.

It will never be an appropriate nursing response to destroy another person's hopes, even if those hopes seem unrealistic. The hope for something better may serve as an ego defense mechanism for the individual. Stripping a person of hope makes this person vulnerable to total collapse. A more moderate and humane approach might be to introduce other ideas that also indicate hope without judging or negating the hopes that already exist. Supporting the caregiver in his or her efforts to care for and protect their loved one while offering the idea of hope for a peaceful life can be an appropriate nursing intervention.

As nurses have the opportunity to interact with caregivers, it is important that the individual's spiritual faith be encouraged. Faith in God was a common theme in this study of caregiver needs, and this faith was the basis for hope. Connecting with this hope through prayer, scripture reading, and interactions with friends on a spiritual level was a meaningful process for caregivers. These same spiritual resources are available to the nurse who interacts with caregivers and potentially can offer the nurse a similar degree of hope for the situation. Ideally, the nurse's level of hope should be equal to or exceed that of the caregiver if an effort is being made to offer that caregiver supportive hope.

Students of nursing should be taught how to facilitate hope in caregivers. Because hope is such an intangible concept, it may be difficult for nursing educators to teach to students. Possibly the most important idea to convey to students is that they should not offer false hope to caregivers. Student nurses often respond to their own insecurities and discomforts when dealing with despondent families by tending to make trite comments that reflect superficial reassurances. These types of responses from novice nurses may be perceived as insensitivity by families who are hurting. Nurse educators can strengthen students' abilities to respond appropriately to these families by coaching students in basic helping skills which focus on tuning in to another person's feelings. Listening to and identifying the feelings being expressed by family caregivers, rather than the words being spoken, will enable the student to develop a sensitivity that will enhance the ability to offer realistic hope to others. Teaching the student to focus on the feelings of the other individual rather than the student's own feelings will facilitate a realistic interaction with caregivers who are struggling to maintain levels of hope.

Connections with Happiness. One person cannot make another person happy. Although other people certainly influence an individual's degree of happiness, each person is responsible for his or her own levels of contentment. For this reason, nurses must not involve themselves with caregivers for the purpose of making that individual happier.

Stressful and painful life experiences have the potential for robbing people of happiness. It is difficult for an individual to connect with that internal sense of peace when negative situations abound. For the caring nurse who desires to intervene with unhappy caregivers, promoting a sense of control over the situation for these caregivers may be helpful. Exploring and encouraging strategies that facilitate control such as self-care activities, asking for additional help from other family members or friends, or other means might afford the caregiver an opportunity to reduce stress levels and feel calmer about the situation. A feeling of calmness in many circumstances is prerequisite to contentment.

Self-care is an important aspect to happiness. The ability to love and accept oneself is inherent in the ability to find contentment amidst trying life circumstances. Nurses possibly can intervene with caregivers in a way to help them value themselves for who they are and for what they have accomplished. Offering deserved praise and a realistic survey of how well caregivers have functioned despite hardships is one way sensitive nurses can bolster the sagging self-esteem of tired caregivers.

Caregivers who have time for self are able to renew their energies to face their tasks again. The nurse offering himself or herself as a relief worker or facilitating respite care by other individuals is another way to assist caregivers with reconnecting with their own inner strengths and with happiness.

Caregivers in this study described one facet of their happiness as that of being loved and accepted by others. The physical presence of other people who genuinely cared for the caregiver was a source of energy that lifted the spirits. Nurses, too, can promote happiness in caregivers by simply conveying a genuine love and concern. If an authentic concern for a caregiving family is not present, the nurse does not need to voluntarily become involved in trying to be a helper. This lack of concern certainly will inhibit the achievement of a significant degree of happiness in the caregivers through a depletion of positive energy levels.

Promoting happiness in others is a difficult process to teach to student nurses. As an external influence on caregivers' lives, a student nurse is limited in the ability to facilitate conditions that make others happy. However, the need for love and acceptance expressed by caregivers is a need students may begin to meet.

The most effective way for nursing educators to teach affective skills to student nurses is to role model those skills. An educator who sincerely loves and cares for the feelings and well being of others will demonstrate these feelings in interactions with families. Novice student nurses who witness the verbal and nonverbal exchanges of this concern between the caring nurse educator and the family members will not only see the technique, but will also see the results. Nurses who grant themselves the freedom to openly share their caring attitudes with others enhance the potential for the development of happiness in those other individuals.

There are definite interventions that nurses may use to assist caregivers to connect with help, hope, and happiness. The majority of these interventions can be carried out by caring nurses who simply choose to become involved in the lives of people in their communities. The scope of involvement of nurses can range from a short visit to the family to offer support and encouragement of a personal nature, to the design and implementation of a well-organized caregiver support system using volunteers and established community resources such as churches or businesses. The possibilities are endless. However, the most important aspect of this involvement of nurses is that connections are facilitated. As the nurse extends a part of himself or herself to make connections with caregiving families, those families can then know they have a concerned professional who will assist them in connecting with needed sources of help, hope, and happiness.

Nursing Research

Nursing involvement with caregivers cannot be limited to the emotional or instrumental realm. A distinguishing attribute of the professional nurse is a desire to promote the development of nursing science for the ultimate purpose of improving the nursing services to humanity. Research is important in order to improve care for caregivers.

As nurses interact with caregiving families in the community, there is a continued need to evaluate that interaction and to search for ways to make nurses' involvement more effective and meaningful. Clark and Rakowski (1983) proposed that research should encompass a search for the types of programs that would be helpful to develop caregiver skills. Stages of caregiving and persons likely to benefit from caregiver support groups were also suggested areas for future study. The needs expressed by family caregivers and the identified processes by which these needs were met can be influenced by nursing intervention. Utilization of the findings of this study as a framework would enable professional nurses to engage in more in-depth research into holistic care for caregiving families.

Recommendations for Further Research

This study of the needs of family caregivers has raised several questions for future research. The basic study of the caregivers' connecting processes deserves continued development to add depth to the suggested conceptual relationships. A focused exploration of the nontangible and nonverbal connecting processes on the emotional, spiritual, and interpersonal levels also would expand the basic study.

Because this study involved only American, Caucasian families, the same approach should be applied to family caregivers with more diverse cultural and racial backgrounds to look for similarities to and differences from the findings in this study. Different needs or processes may be applicable to other groups because of these differences.

Literature reviews have suggested that the interactional and relationship patterns that exist within family systems are the most significant contributors to a family's coping ability. An entire series of studies could be devoted to analysis of family dynamics and the relationship of these dynamics to perceived caregiver needs. An exploration of the relationship of existing family dynamics to the major processes used by caregivers to meet their needs would provide valuable information related to the influence of the family of origin on life processes.

A follow-up study more directly related to this current study might investigate how meeting caregiver needs for help, hope, and happiness affects the quality of care offered to dependent family members. A research question might be, "Does the establishment of caregiver support networks lead to better holistic care offered to the family member who is being cared for in the home?"

Each of the needs for help, hope, and happiness could be the focus of an individual research project. The individual needs could be explored in depth to determine whether additional facets of these needs were not discovered in this current study.

As nurses are involved on individual or group bases with family caregivers, these interactions need to be recorded. Descriptive studies of formal and informal caregiver projects are needed to serve as the basis for additional qualitative and quantitative research. Submission of these research reports for publication is a must in order to disseminate the findings in an effective manner.

Additional questions of interest which might stem from this initial research are the following.

1. How does the nurse's need for help, hope, and happiness affect his or her ability to meet these needs in caregiving families?

2. Do the processes of misconnecting, disconnecting, and connecting apply to meeting needs of clients in other health care settings such as tertiary care centers?

3. Are there methods of assisting family caregivers to connect with helpful resources that are more effective than those suggested in this study?

4. How might ineffective communication patterns within a family affect the ability to connect with helpful resources?

Summary

This study has provided an initial look at one process that is useful in meeting caregiver needs. Relationships between needs and processes have been suggested, and the resulting discussion has given rise to several additional questions that are conducive to research. Further expansion of the scope of these ideas and the application of these concepts may offer nurses a greater sensitivity to caregiver needs and greater insight into effective processes for need satisfaction.

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APPENDIX A

Letter to Family Members

Dear Friend,

As a doctoral student in nursing, I am interested in studying the family system and how the individual members are helped by their families to maintain their health.

It is a well-established fact that when one member of a family becomes ill or disabled, all members of that family are affected in some way. Some family members take on extra responsibilities that involve caregiving to meet the needs of the ill individual as well as those of other family members. It is quite common for those people who become caregivers to others to develop special needs of their own which they may have difficulty getting met.

Because your family has had to undergo certain changes with some members assuming this caregiving role, I would like to invite you to participate in research related to this issue. Specifically, I would like to invite the adult family members (age 14 or older) living in your household as well as any close "extended" family who also may be involved in the caregiving role to participate. I would like to conduct an informal family interview for the purpose of letting you share with me your family experiences and feelings. In order to enable me to compile the information into a usable form, I would also like to tape record the session. No names will be used in the tapes or in any written documents related to the research. The information you share will be analyzed and pulled together in the form of a descriptive research report which will be shared both in written and verbal form with my professional colleagues. The primary purpose of this project is for my professional learning. However, I would also anticipate the data to provide a basis for allowing nursing professionals to be more sensitive to the emotional, physical, and spiritual needs of families. This knowledge would enable nurses to better provide those services to families to help meet the needs expressed.

If your family would be willing to devote approximately one to one and one-half hours of time to participate in this type of interview, then I would be pleased to include you in my study.

After talking this over with your other family members, if you decide to participate, I would request that you sign a statement of agreement for this participation. On the next page is a simple statement of understanding for all adult members of your household to sign. This signature assures me that you understand the purpose of the study and are willing to be interviewed.

If your family chooses to participate and the agreement is signed, you may return it to me in the envelope provided or give it to me in person. There is no obligation whatsoever for you to participate. Your family's involvement is purely voluntary. If you choose not to participate, no explanation is necessary--simply discard this letter.

If I can clarify for you any questions you or your family members might have about the study, please call me at one of the numbers listed below. I will be happy to discuss this further with you.

Thank you for your time and consideration of this request.

APPENDIX B

Participant Agreement

After reading a description of this proposed study, and after discussing its purpose, our family would like to accept the invitation to participate in this project related to caregiver needs.

We understand that our participation is voluntary, and any family member who so desires can ask to be excused from the interview.

We understand that the interview will be tape-recorded for the purpose of data analysis and that our names will not be used in any way. We further understand that confidentiality of all participants will be maintained by the researcher.

We agree to the researcher's sharing the interview information in both written and verbal form with her professional colleagues for the purpose of student learning and for the development of nursing theory.

Signature of adult family representatives:

Date: _______________ ________________________________

____

____

Signature of researcher: _______________ Date_______________

APPENDIX C

Sample Interview Questions

1. Describe your current family group as they live together in your home.
2. Tell me what a typical day is like in your family group.
3. Tell me about the illness (or disability) of your family member.
4. Who helps take care of this ill person?
5. How has his or her illness affected the family group?
6. What special needs do you perceive your family has in relation to the illness of this member?
7. Do you have a way you can get these needs met? Please describe.
8. What ways do you see that others might assist you in getting these needs met?

APPENDIX D

Family Demographic Data

Family No.	Caregivers (Ages)	Occupation	Person Receiving Care (age)	Disability
1	husband (35)	attorney	wife (34)	back pain
2	father (50)	salesperson	daughter (14)	retarded
	mother (49)	community service worker		
3	wife (58)	retired secretary	husband (65)	disabled amputee
4	wife (57)	real estate agent	husband (62)	Alzheimer's
	son (36)	corporate executive	father	
5	grandmother (66)	retired nurse	grandson (4)	retarded
6	daughter (60)	unemployed clerk	mother (88)	frail elderly
7	niece (73)	retired secretary	aunt (101)	frail elderly
	niece (76)	retired teacher		

APPENDIX E

Validation Survey

February 26, 1989

Dear

As a follow-up to the interview I had with you several weeks ago related to my "Study of the Needs of Family Caregivers," I would like to ask your additional help.

Enclosed is a summary of the major ideas that I have gleaned from a compilation of information from all my family interviews thus far. I have taken the situations and information everyone has shared with me and extracted the most important themes that I think have been discussed.

I need your help in evaluating whether or not the ideas I have compiled represent reality to you. In other words, does my interpretation of the information seem truthful and correct? This feedback from you is an important part of validating my findings and making my report as accurate as possible.

I would appreciate your reading the enclosed material at your convenience and responding by offering your comments. A section for your comments has been provided at the end of each major section--you can simply indicate whether you think the information is accurate and write in your ideas in that space if you choose to do so. I need to know whether you agree or disagree with my findings as they relate to your situation. Feel free to offer me any additional ideas you might have or any corrections if you think my interpretation is incorrect.

I would like to receive your feedback as soon as possible. A self-addressed, stamped envelope is provided for your convenience in returning the form. Please call me if I can answer any questions for you.

Thank you, again, for your help.

Sincerely,

A Study of the Needs of Family Caregivers

Summary

The interviews with family caregivers were conducted to discover what were the major needs common to all family caregivers, and what were the processes or ways used by caregivers to have their needs met. Three basic needs were expressed by all family caregivers: the needs for help, hope, and happiness.

Caregiver Needs for Help

Family caregivers expressed the need to have help in several areas. Some caregivers needed other family to help with care of the ill or disabled person. This necessitated a shifting of family and personal schedules in order for others to be able to help. One of the top needs was respite or relief from caregiver duties. This periodic break from the burdens of caring for another person was viewed as vital to the mental and physical health of the caregivers.

Friends were also needed to help. They were seen to be able to offer something different to the ill or disabled person in the form of distraction and relief from boredom. Visits and interaction with friends also offered support to the caregiver.

Help was needed from health professionals, especially in the area of educating the family. Frequently, as a family began their caregiving tasks, they felt they were not given enough information or education to be able to manage caregiving tasks efficiently. Physicians were sometimes perceived as too busy or too insensitive to take the time to explain things adequately to caregivers. Most caregivers wanted to learn and were interested in doing things correctly at home, but felt they could not control the situation well at home because there were so many unanswered questions.

A third area in which caregivers needed help was with decision making, especially in the initial stages of their caregiving roles. In their efforts to adjust to new roles and learn new ways of doing things, caregivers voiced some confusion as to what was the right thing to do. A caring, competent person who helped with initial decisionmaking was seen to be a needed resource. As time passed, caregivers learned better how to manage situations at home and were more capable of making efficient decisions without help.

Caregiver comments:

Caregiver Needs for Hope

A second need for family caregivers was that of hope. Hope was seen to originate from two sources: from God and from other people.

Caregivers expressed a belief that there was a purpose in everything that happened and that God used these human situations to build spiritual faith. Although it was hard to see why these trying situations occurred, caregivers believed that God would not require of them more than they could handle. Their hope for a better future and a way to cope was founded in a faith in God.

Secondly, caregivers expressed a need to be offered hope from other people. Health care providers were in a position to offer hope and encouragement to these families. Sometimes these providers offered hope and sometimes they did not. Friends and family were important in that they, too, could offer honesty and realistic hope to these caregivers. Caregivers needed to know that they could make a difference and that their efforts could keep hope alive for positive changes.

Caregiver comments:

Caregiver Needs for Happiness

Happiness was the third need expressed by family caregivers. The burdens of constant caregiving made it difficult to maintain happiness, and caregivers experienced periods of emotional highs and lows.

Family activities, especially vacations, were hard to plan and carry out. In situations in which caregivers were spouses, the maritial relationship faced additional strain. There was little or no time for enjoying couple activities and for fulfilling special relationship needs.

When one individual was caring for his or her spouse, there was also a struggle to maintain that level of activities that married couples found enjoyable.

It was also difficult for caregivers to find time to spend with friends. The nourishment of long-time friendships was very difficult when a person was burdened with caregiving tasks.

The fulfillment of plans and dreams for the future was often postponed or abandoned by caregivers. There was frustration and sadness expressed by those who could not find time to enjoy life's pleasures such as going out to eat or pursuing hobbies.

Caregivers expressed a need to enjoy happiness through experiencing the love, attention, and acceptance of other people. When this involvement by others was lacking, caregivers were unhappy.

Caregiver comments:

The Meeting of Caregiver Needs

Family caregivers recognized that making connections with realistic, helpful resources was crucial to having needs met. This basic social process of connecting was identified as a major behavior common to all family caregiving situations. The processes of misconnecting and disconnecting also occurred and were related to the connecting process. These processes of misconnecting, disconnecting, and connecting occured continually throughout the family members' experiences as caregivers.

In the process of trying to learn their new roles, caregivers frequently tried to find sources of help, hope, and happiness that would be beneficial to them. Sometimes these caregivers misconnected with people or agencies that did not meet their needs. They may have interacted with physicians, ministers, therapists, or families that were not very effective in offering them help. They sometimes misconnected with people who offered them false hope and shallow, meaningless words of encouragement. They also occasionally misconnected with activities or thoughts that made them unhappy.

As caregivers experienced these misconnections and came to realize their needs were not being met, some were assertive in making a disconnection with those resources that were not helpful. Some caregivers made decisions to change physicians, to discontinue a certain type of therapy, or to drop out of a social group. Thus they sought different ways to better equip themselves as caregivers to obtain more positive social support.

The connecting process enabled family caregivers to interact with sources that were perceived as more helpful. Many caregivers eventually were able to create bonds or relationships with individuals, groups, and agencies that enabled them to realize a more complete fulfillment of their needs. They were able to get more help with caregiving tasks so that their burdens were lessened. They were able to interact with honest, sensitive people who helped them evaluate their situation effectively and foster realistic hope. They were able to deepen their spiritual roots to find sustenance and hope through God's help. They were able to recognize the negative thoughts, behaviors, and interactions that created unhappiness and then make a deliberate choice to select more positive activities that would bring them happiness.

Making proper and helpful connections occurred over time and was a state all caregivers worked for, although it was not something every caregiver accomplished. Some people were not able to make those positive connections that enabled them to meet their needs for help, hope, and happiness.

Caregiver comments:

Thank you again for your contributions to this study. Your input has been indispensable and I appreciate your willingness to share an important chapter of your life with me. S.R.R.

APPENDIX F

Summary of Needs and Processes

BASIC CAREGIVER NEEDS:

HELP HOPE HAPPINESS

BASIC PROCESS FOR NEED SATISFACTION:

CONNECTING

(SUBPROCESSES: MISCONNECTING AND DISCONNECTING)

GRADUATE SCHOOL
UNIVERSITY OF ALABAMA AT BIRMINGHAM
DISSERTATION APPROVAL FORM

Name of Candidate Shirley R. Rawlins

Major Subject Adult Health Nursing

Title of Dissertation Connecting: Meeting the Needs of Family Caregivers

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