1993

# A descriptive study of adaptation to the role of caregiver

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## Recommended Citation

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DOI: https://doi.org/10.31979/etd.8cs5-cqdd
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# A descriptive study of adaptation to the role of caregiver

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San Jose State University, 1993

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# A Descriptive Study of Adaptation to the Role of Caregiver

A Thesis
Presented to
The Faculty of Occupational Therapy
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By
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May, 1993

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# Abstract

## A Descriptive Study of Adaptation to the Role of Caregiver

By Karen Nelson, OTR

This study involved five case studies of female caregivers in the community setting. Subjects participated in in-depth interviews regarding caregiver activity, caregivers and their multiple roles, and role adaptation. Caregivers, in this study, identified adaptive behaviors perceived to be necessary for fulfilling the role. Important skill aspects were also reported for success in this role.

Participants reported that the caregiver role dominated all other roles in which they engaged. Although many role adjustments were made to accommodate the caregiver role, participants reported being unsatisfied with these adjustments. Adaptation occurred at a level of need survival only. Adaptation for personal actualization was rarely achieved. Role balance, the integration of appropriate multiple roles, was regarded as poor among the caregiver participants.

Occupational therapists, with specialized training in educating for role adaptation, can offer a unique service to community caregivers. Treatment implications are identified.

# Acknowledgements

I would like to take this opportunity to thank the many people who assisted with the completion of this research.

To my advisor Dr. Lela Llorens, thank you for your input and patiently answering all my questions. Your leadership in the profession is an inspiration.

Thank you Dr. Gordon Burton and Professor Lorraine Pedretti for your input, encouragement, and careful editing.

Thank you to Home Health Plus, Santa Clara and to Veterans Hospital, Palo Alto for permission and assistance in subject recruitment.

Thank you to all the members of my thesis support group, Yuriko Wong, OTR, Pamela Hope Dent, OTR, and Rene′ Padilla, OTR, for holding me publicly accountable. It is your turn!

A special thank you to the Platzker family for editing, computer advice, and hugs.

I would also like to especially thank the caregivers who took time from busy schedules to share with me and assist me in this research.

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# CHAPTER 1

# INTRODUCTION

## Purpose of Study

The purpose of this study was to describe the adaptive behavior and/or skills utilized by family members or significant others during the transition to the role of caregiver and in the successful maintenance of the caregiver role.

## Statement of the Problem

A growing reliance on untrained family members to provide medical care for sick or disabled relatives has been created by the aging of the population and medical cost containment measures (Wood, 1991). The family has traditionally and will continue to provide care for ninety-five percent of the elderly in the community (Brackley, 1992). It is estimated that the average female will spend eighteen years caring for dependent relatives (Baum, 1991).

Research has shown that the caregiver experiences a number of ethical dilemmas (Hasselkus, 1991). When a family member becomes a caregiver, that individual experiences significant disruption, as roles change, and new roles are acquired. Role acquisition occurs developmentally throughout life to meet environmental demands (Llorens, 1991). Assuming the role of caregiver is frequently unplanned, and in many instances occurs traumatically, the inability to balance new roles with existing roles may lead to dysfunction in occupational behavior.

The conflict between role demands or the imbalance in time the individual allots to role performance can also result in maladaptive occupational behavior (Oakley, Kielhofner, Barris & Reichler, 1986). An unequal shift in the balance of these life roles can affect the caregiver's ability to utilize occupational therapy services. Knowledge of the caregiver's adaptation process can assist in the development of patient treatment and family training goals by the occupational therapist resulting in the integration of both the patient's and the caregiver's needs.

## Objectives and Questions

The objectives of this study were:

1. To explore the caregiver's daily existence in the individual's environment from the caregiver's perspective.
2. To explore trends and styles of adaptation utilized by a family member during the acquisition of the caregiver role.

3. To explore the process of integration of the caregiver role in relationship to current roles, changes in those roles, and the balance of these roles.
4. To explore treatment implications for occupational therapy in the home health setting in assisting the adaptation process that benefits both the client and caregiver so that care and follow through are enhanced.

This research was designed to answer the following questions:

1. What adaptive behaviors are required by the individual to be successful in the role of caregiver?
2. What is the adaptation process utilized during the acquisition of the caregiver role?
3. How is the balance between the new role and current roles achieved?
4. What are the treatment implications for occupational therapy in facilitating adaptation to role acquisition for caregivers?

## Definitions

Conceptual definitions for the terms utilized for the purpose of this research are defined as follows:

Adaptation Process: the relationship between the environment and the behavior that an individual utilizes to meet the demands of that environment. These adjustments are made by the individual to enhance personal survival and to contribute to the actualization of personal potential. The process demands that the individual actively adjust to different conditions or environments as called forth by that environment. Adaptive responses are organized by the nervous system subcortically. The adaptive process is self-reinforcing, with each successful adaptation serving to motivate the individual to achieve mastery over the next, more complex environment. An adaptive response cannot be imposed and must reflect the individual's needs or wants (King, 1978).

Adaptive Behaviors: are skills specific to each role in the life span which allow the individual to successfully explore and master the physical and social demands of that individual's environment (Llorens, 1991).

Caregiver: a non-professional worker, family member or significant other, who provides either partial or full assistance to a disabled individual in self care, home management, community management, financial management, and/or decision making.

Environment: the complete setting which includes the self, or caregiver, other people, objects, earth, space and the relationships within space (Gilfoyle, Grady, & Moore, 1981).

<u>Occupational Therapy</u>: the therapeutic use of self-care, work, and play activities designed to increase independent functioning, enhance development, and prevent disability. May include adaptation of task or environment to achieve maximum independence and to enhance the quality of life (American Occupational Therapy Association, 1986).

<u>Occupational Adaptation</u>: the interaction process between the environmental occupational challenge and the individual's perception of the internal and external expectations for occupational performance. Through this adaptation process, an occupational response is generated to master that challenge. The response is evaluated for outcome; feedback from the response is integrated for future use (Schkade & Schultz, 1992).

<u>Roles</u>: the functional positions, such as worker, parent, spouse, held by an individual in society (Llorens, 1991). Each role has expected responsibilities and privileges as defined by the society in which the individual exists. Roles provide a means for the needs of both the individual and society to be met. They define behavior through the obligations and expectations that accompany each role. Roles also organize productive behavior by placing the individual within the social structure and providing a personal identity (Kielhofner & Burke, 1985). Skills acquired through various life roles serve to assist the

individual to improve and master the environment (Reilly, 1962).

Role Acquisition: the process of achieving new roles through the course of the individual's life span. During this process, roles may be relinquished, and/or adjusted to accommodate role changes (Kielhofner & Burke, 1985).

Role Balance: is achieved through the integration of an optimal number of roles in one's life. It is maintained when integration occurs despite ongoing changes in specific roles. Through the rhythm and change, sufficient time and effort for performing tasks associated with roles is accomplished. Role balance exists when one's roles adequately structure the individual's use of time without conflict or competition for that time (Kielhofner & Burke, 1985).

Operational definitions for the terms utilized for the purposes of this research are defined as follows:

Adaptation: the adjustments made by the caregiver in response to environmental demands as measured by the responses to questions in the adaptation process section of the interview questionnaire

Caregiver: those characteristics, time usage, and expectations as measured by the responses to questions in the caregiver section of the interview questionnaire

Environment: the setting in which the caregiving takes place.

Roles: those responsibilities measured by the responses to questions in the roles section of the interview questionnaire.

## Assumptions

Assumptions made for the purpose of this research are as follows:

1. It was assumed that achievement of role balance during times of role loss and acquisition is an adaptive process.
2. It is also assumed that adaptive behaviors necessary for the acquisition of the caregiver role occur to meet the demands of the caregiver's environment and are unique to that environment.
3. It is further assumed that the role of caregiver for disabled or aging parents and spouse is a new and emerging role in the human life span and therefore expectations of this role may not be clear.
4. It is assumed that because of the knowledge base of occupational therapy in role balance and adaptation, occupational therapy can provide a valuable and unique contribution to caregiver training in the community environment.

## Limitations

Possible limitations inherent in this study are as follows:

1. As five subjects in a convenience sample only represents a small segment of the caregiver population, generalizations regarding the adaptive process and adaptive behaviors cannot be inferred to all caregivers.
2. Recruitment of participants was difficult, thereby limiting the range of possible candidates who met established criteria.
3. As subjects were interviewed in the individual's personal environment, responses may have been altered or less complete when the caregiving recipient was present. When possible, privacy during the interview was ensured.
4. As data were collected in an interview process, the subject provided information by self-report, thus concerns of the accuracy of responses must be acknowledged.
5. As the researcher conducted the interviews, it must also be acknowledged that, although precautions were taken to reduce or eliminate bias, some bias may have occurred in reporting the data.

## Significance of the Study

Successful adaptation of caregivers to a new role depends on the individual's ability to assume competent role responsibilities. Occupational therapists have training that is unique from other disciplines currently working with caregivers relative to role balance and adaptation. In addition, occupational therapists have the ability to modify the environment, if need be, during the role acquisition process to assist the caregiver to meet the needs of that environment. Despite these skills, the researcher believes occupational therapy is underutilized in the community setting. Research is needed to provide evidence to support the need for occupational therapy services to provide family training in the area of role adaptation in the home health setting. To date, previous caregiver research has not adequately explored the relationship of roles and the adaptation process in terms of becoming a caregiver.

# CHAPTER 2

# LITERATURE REVIEW

## Introduction

The literature review is organized by sections. The first section reviews the research regarding caregiver themes of burden, psychological stress, and ethical issues. The second section reviews the literature pertaining to research regarding caregiver roles. The third section reviews Frames of Reference in Occupational therapy in relationship to roles and adaptation, on which this study is based.

## Caregiver Themes

In the past, the term caregiver referred only to a health care professional. Since 1979, when data revealed that eighty percent of all caregiving for elders was provided by family members, attention to the study of nonprofessional caregivers emerged (Hasselkus, 1990). The term caregiver now also refers to any family member or friend who assumes primary responsibility for providing supportive assist to another to improve that individual's condition or lifestyle (Wood, 1991).

Research studies, primarily conducted by gerontologists and psychologists, have revolved around the burdens and the ethical dilemmas faced by caregivers, the psychological well being of the caregiver, and the meaning of caregiving. Zarit, Reever, and Bach-Peterson (1980) were the first to develop burden as a research construct. Since then, numerous burden measures have been developed that differ in theoretical frameworks and definitions of terms (Vitaliano, Russo, Young, Becker, & Maiuro, 1991). In an attempt to quickly identify distressing caregiver experiences, Vitaliano et al. (1991) developed a screen for caregiver burden. Walker, Martin, and Jones (1992) recently completed a study regarding the benefits as well as the possible costs of being a caregiver. Few studies have examined the benefits of the caregiver experience.

Callahan (1988) questioned the ethical limits of a family's obligation to provide care to ill or disabled members in the face of social isolation and the lack of a supportive culture. He points out that while caregiving may be mutually rewarding for the family and patient, the experience may also trap a caregiver in an undesired lifestyle. Additional research by Hasselkus (1991) identified two ethical themes, justice and benefice, which guide caregivers' decision making regarding lifestyle and use of professional and community services.

The caregiver's psychological well being has been studied from the perspective of coping abilities (Barusch, 1988), counseling needs and intervention (Smith, Smith, & Toseland, 1991), and stressors and the relationship to depression (Lawton, Moss, Kleban, Glisksman & Rovine, 1991). Common psychological issues facing caregivers center around feelings of guilt, impatience, frustration, stress, changes in relationships, lack of coping skills and communication.

In an ethnographic study by Hasselkus (1988), meaning in family caregiving was examined. Six themes of meaning were identified: "sense of self, sense of managing, sense of future, sense of fear and risk, sense of change in role and responsibility, and tensions" (p. 687). Further analysis of data collected by Hasselkus (1989) revealed three broad activity categories in the daily life of the caregiver: "getting things done, achieving a sense of health and well-being for the care receiver, and achieving a sense of health and well-being for the caregiver" (p. 650).

In a critique of the caregiver literature, Malonebeach and Zarit (1991) pointed out several gaps in the knowledge base. Issues that these leading scholars identified as warranting increased attention include: the definition of caregiving, more representative research samples, socio-demographic variables, the family context of caregiving, and longitudinal research. It is this researcher's finding that most studies regarding caregiving have focused more on distressed caregivers rather than on caregivers who are adequately coping. While caregiving studies have looked at related demographics, such as gender, and relationship to patient, few have looked at caregiving in terms of life roles, and position or status in the family structure held by the caregiver or the care receiver. Although the research of Callahan (1988), Hasselkus (1988), Smith et al. (1991), and Wood (1991) mention roles and the possible effect that roles may have on caregiving, few in depth studies have been published to date.

## Research of Caregiver Roles

Since 1979, the literature has supported the concept of caregiving as an emerging new role in society. A recent survey conducted by a major insurance company showed that twenty percent of their workers aged thirty years or older were providing some form of care to an older adult. National estimates indicate at least eleven percent of caregivers quit their jobs to become full time caregivers. At this time, it is estimated that the average female will spend eighteen years of her life caring for dependent parents (Baum, 1991).

Roles may be defined as either developed or undeveloped. A developed role has clearly established expectations of the individual engaging in that role. These expectations are normative, shared, and reasonably consensual within a significant reference group (Rosow, 1985). An undeveloped role exhibits vague, limited, and unpatterned expectations. Consensus and normative elements within the significant reference group are negligible (Rosow, 1985). The caregiver role, as it is an emerging role, is undeveloped. As there is only a vague pattern of activity intrinsic to the position of caregiver, clearly defined behavior may not exist. Little research has been conducted into the complexity of the caregiver role regarding the needs and expectations associated with that role (Wood, 1991).

Stoller and Pugliesi (1989) conducted one of the first studies which looked at the effect of multiple roles in relationship to a caregiver's burden and well-being. The study examined multiple roles only in terms of occupancy. This study found support that other roles in the caregiver's life may contribute to burden, especially when the care receiver required a lot of physical assistance. However, this study also supported the concept that involvement in multiple roles could lead to the caregiver's well-being if these roles reduced or buffered the caregiver's stress, provided additional support, or increased the caregiver's self-esteem.

Skaff and Pearlin (1992) studied the caregiver role in terms of role engulfment and the resulting loss of self. The study found that the greater number of roles in which the caregiver engaged, the more the caregiver was insulated from self-loss. Of the three roles examined--spouse, worker, and parent--it was the caregiver's loss of the worker role which significantly contributed to self-loss. Employment outside of the home, as it was further removed from the caregiving setting, gave the caregiver more protection against role engulfment. In addition, the age of the caregiver was also significant for self-loss. The younger the caregiver, the greater the cost or self-loss.

The purpose of the study conducted by Franks and Stephens (1992) was to explore the caregiving experience of women in relationship to other family roles. The study found that stressors in the roles of wife, parent, and caregiver, were related to decreased feelings of adequacy in these roles. However, the study found that only in the roles of wife and caregiver were feelings of adequacy consistently related to well-being. Guberman, Maheu, and Maille (1992) looked at reasons women became caregivers despite other role responsibilities. This group found that feelings of love, family ties and duty, the belief that institutional settings are inadequate, and family traditions served as reasons why women became caregivers.

Brackley (1992) studied the effect of a transition support group for women prior to becoming caregivers. Brackley proposed that support for the caregiver through the transition process and assistance in redefining life roles could lead to successful functional role adaptations. Results from this study, however, only suggest that participation in a support group of this type effectively increased communication and understanding regarding the concerns of aging between the potential caregiver and care receiver.

## Frames of References in Occupational Therapy

In the Model of Human Occupation, roles are described as functioning to meet the needs for both society and the individual (Kielhofner & Burke, 1985). The role of the family caregiver serves society by providing care for relatives or friends in times of an aging population and diminishing public financial resources. The role of caregiver meets the individual's needs of caring, duty, and responsibility toward the family member. Roles in society define behavior through the obligations and expectations that accompany each role. Roles organize the individual productive behavior by placing the individual within the social structure and by providing a personal identity (Kielhofner & Burke, 1985).

Developmentally, role change occurs through either the acquisition of new roles or the loss of old roles. It is a dynamic process that occurs throughout the human life span (Llorens, 1991). When an individual chooses to become a caregiver, that individual chooses to acquire a new role. This new role must be integrated with current roles to form a balance, despite ongoing changes. Role balance is necessary to provide each individual some rhythm and change between different modes of doing tasks and with sufficient time and effort for performing those tasks associated with each role (Kielhofner & Burke, 1985).

The caregiver may experience difficulty in role balance because of the stress of the new role, if the individual gives up important roles to meet the needs of the care receiver, and or loss of time for self. The loss of important roles can result in role imbalance, bringing about disorientation as the role, a source of identity and a format for guiding behavior, diminishes (Kielhofner & Burke).

The process of developing adaptive behaviors specific to a life role results in adaptation (Reilly, 1962). Adaptation is the relationship between the environment and the process or behavior that an individual utilizes to meet the demands of that environment. These adjustments are made by the individual to enhance personal survival and to contribute to the actualization of personal potential. The process demands that the individual actively adjust to different conditions or environments, as called forth by that environment. Adaptive responses are organized by the nervous system subcortically. The adaptive process is self-reinforcing, with each successful adaptation serving to motivate the individual to achieve mastery over the next, more complex environment. An adaptive response can not be imposed and must reflect the individual's needs or wants (King, 1978). Skills acquired through various life roles serve to assist the individual to improve and to master the environment (Reilly, 1962).

Successful performance for an individual in the role of caregiver will require the ability to meet the demands of the environment, to achieve consistency with cultural and societal requirements specific to the life span stage, and to achieve balance of life roles. An adaptive behavior can not be truly said to have occurred until the individual consistently carries it out in the course of ordinary activity (King, 1978). As roles provide a recognized structure for individual interaction with the environment, balance and variety of roles are necessary to the adaptive system (Elliott & Barris, 1987).

Recently, a newly articulated frame of reference, Occupational Adaptation, has been proposed. In this context, adaptation is viewed as a change in a person's functional state as one moves toward mastery over occupational challenges. Occupation or activity is utilized as the method to adapt to changes and conditions. As an intrinsic motivational force, the desire to be engaged in occupation leads to adaptation (Schkade & Schultz, 1992).

## Summary of Literature Review

The literature review encompassed caregiver themes of burden and well-being, research regarding the caregiver role, and the occupational therapy frames of references on which this study was based. The majority of research in this area has been conducted by psychologists and gerontologists, thus the emphasis on well-being and burden. Although more attention has recently been focused on the role of the caregiver, these studies again primarily reflected concern regarding the caregiver's state of being. To date there have been few, if any, studies regarding the caregiver's adaptation to the role of caregiver or role balance between the caregiver's multiple roles. Successful caregiving in the community setting has not been described.

Occupational therapy frames of reference were presented to demonstrate a theoretical base in role adaptation and role balance. Occupational therapists were described as having the training, unique from other disciplines currently working with caregivers, to assist caregivers in role adaptation and role balance.

## CHAPTER 3

## DESIGN AND METHODOLOGY

### Purpose

The purpose of the study was to describe the adaptive behavior and/or skills utilized by family members or significant others during the transition to the role of caregiver and in the successful maintenance of the caregiver role.

### Questions

This research was designed to answer the following questions:

1. What adaptive behaviors are required by the individual to be successful in the role of caregiver?
2. What is the adaptation process utilized during the acquisition of the caregiver role?
3. How is the balance between the new role, and current roles achieved?
4. What are the treatment implications for occupational therapy in facilitating adaptation to role acquisition for caregivers?

## Design and Sample

The research was designed as a descriptive, qualitative study utilizing case study methodology. It is a preliminary, exploratory study.

The sample for this study consisted of five adult female caregivers who met the established criteria. The criteria for participation were as follows:

1. have the role of caregiver as previously defined for no less than three months
2. provide care for a person with a neurological disability
3. be between the ages of 25 and 65

The age range of the caregivers in the sample was 41 to 61 with a mean age of 53 years and 4 months. Of the five caregivers, three were caring for a spouse, one was caring for an adult child, and one was caring for a parent. Of the five care receivers, three required care as a result of cerebral vascular accidents, one required care as a result of a brain tumor, and one required care as a result of a traumatic brain injury. All five of the caregivers provided care for their family members who lived in their residence.

## Instrument

A semi-structured questionnaire, based on the principles of adaptation, and developed by the researcher guided the interview process for data collection (Appendix A). The semidirective nature of the questionnaire gave participants freedom to respond as they wished while focusing on data collection in the areas of research interest. The questionnaire was divided into four sections: demographics, roles, caregiver role, and adaptation process. Additional questions were asked for clarification only.

## Procedure

The subjects for this study were recruited from the community. Resources from Santa Clara County home health agencies, and the Palo Alto Veterans Administration Hospital Occupational Therapy department were utilized. Professionals who assisted in the recruitment process were provided with a letter containing information regarding the study and the desired subject criteria (Appendix B). Caregivers who were identified as potential participants were then sent a recruitment letter describing the study, the criteria for involvement and who to contact if interested in participating in the study (Appendix B).

Qualified caregivers who expressed interest in participating in the study were contacted by telephone to set up appointments.

Upon arrival at the caregiver's home, the interview process was explained and the caregiver was informed that the interview would be tape recorded with permission. Written authorization for the study to be undertaken was obtained from the subjects involved (Appendix C). Caregivers participated in an in-depth interview in the caregiving environment. The interviews required three to five hours each, with a mean time of 3.8 hours. Each caregiver was interviewed in one session.

Data were collected over a three month period from November 1992 through January 1993. Data collected during the interview process were documented, utilizing two different methods to facilitate accuracy. The entire interview was tape recorded and later transcribed. In addition, answers reported by the caregiver during the interview were noted for each question by the interviewer on the questionnaire.

Data are initially presented by categories of demographics, roles, caregiver activity, and adaptation, as structured in the questionnaire design. The data content were analyzed for the emergence of trends or patterns in adaptive behaviors, role changes, and role balance to answer the research questions.

# CHAPTER 4

# DATA AND RESULTS

## Presentation of Data

Data collected are presented in order of length of time from the shortest to longest caregiving experience. The data presented represents a summary of information obtained in the interview process.

## Case A

### Demographics

Case A, a 61 year old female, had been a caregiver for six months at the time of the interview. Case A cares for her husband who suffered a cerebral vascular accident. Case A is the sole caregiver.

### Roles

Case A's roles as stated during the interview were as follows: caregiver, wife of 43 years, mother of two children who live out of state, grandmother of three, and worker until onset of husband's disability .

When asked to list her roles in order of value, Case A listed caregiver as first, followed by worker, wife, and friend. Case A expressed that her husband had always been number one, and that people were more important than anything else. When describing her role as a worker, Case A stated that her job was never looked upon as family support but as extra income. She valued the job enough, however, to state that while quitting was not a big loss, it was big enough.

When asked to list the roles in order of necessity, Case A listed caregiver as first, followed by homemaker, friend and wife. The role which requires most of Case A's time is that of caregiver. Providing care is her number one concern. As a homemaker, Case A's second most demanding role, time is spent in housework, laundry, shopping, yard work, bill paying and meal preparation. Case A next described the role of friend. Case A stated that she has a few friends with whom she occasionally speaks but that she has lost touch with most of them. She described her existence as isolated.

Case A reported that at least nine hours a day are spent in the caregiver role. Case A describes the day as hitting the floor running at eight o'clock in the morning and staying busy until her husband takes an afternoon nap at one o'clock. While her husband is napping, Case A is involved in homemaking tasks until time to prepare the evening meal.

From six o'clock in the evening on, Case A exercises by walking for one hour, then sews or reads. Reading is described as the main form of recreation.

When asked if an opportunity to change how time was spent in each role, what would be changed, Case A stated it would be wonderful to renegotiate responsibilities. Case A's primary change would be to return to work as it was something she enjoyed. Case A also talked about spending more time with friends but that a whole new set of friends would need to be found.

### Caregiver Role

During the interview, Case A stated that she had no choice in becoming a caregiver. Placing her husband into a nursing home was something that, in her opinion, could not be done. Being a caregiver is important to Case A as she loves her husband and believes in the marriage commitment. Marriage is something one stays with, not something one gives up on. Case A stated that she could not see her husband suffer in a nursing home.

To Case A, the important aspects of being a caregiver are numerous. Caregiving should be done as cheerfully as possible, and not as a "whiner." Case A does not want her husband to be burdened with what it costs. It is also important for Case A to "do it right", providing the best care possible and keeping her husband comfortable.

In general, as a caregiver, Case A spends her day bathing her husband, preparing three meals a day, monitoring his blood sugar level and giving insulin shots as well as other medications, and walking with him for exercise. Case A stated that it has gotten better as her husband can now take care of his own personal needs, such as dressing and hygiene. Initially, Case A also helped with the above. In addition to the daily tasks, Case A has also become responsible for the bill paying, yard work, and housework on a weekly basis, tasks for which her husband was previously responsible.

Case A's caregiver role model is a good friend who had taken care of her mother and husband, both of whom have died. Case A calls her friend for support and encouragement. Case A stated that her friend reassures her that she is doing a fine job and that she can make it. Case A also admires her 78 year old neighbor, who has had two knee replacements and is currently taking care of her husband. Case A is inspired by this neighbor expressing that if her neighbor can do it then so can she.

When asked about the expectations that she had and others have of the caregiver role, Case A stated that was a hard question for her. Case A expressed that she did not think anyone expected her to do more than she already has. People have been very encouraging of her efforts and complimenting Case A on "holding up" real well. Case A's own expectation is that her health will hold out, as she does not know who would take care of her husband if she was unable.

Case A described her life now as not being the "pits." She stated that, believe it or not, she is relatively content. She also stated that it does not pay to think about it too much as the simpler one is, the better off one is. Case A enjoys the "little things" such as reading, sewing, and gardening which she did not have time for in the past.

At this point in life, Case A thought she and her husband would be traveling. She also thought that they would have moved to be closer to their children in Oregon. In reading about diabetes, Case A had anticipated possible complications such as heart trouble or skin problems. She stated that she never anticipated her husband having a stroke with these results.

### Adaptation Process

When asked what steps Case A had taken to be a good caregiver, she stated that by being prudent in the past and in anticipating living off retirement income, ensured that the house was paid off. She also believes that not enough attention was given to anticipating health issues. Case A took steps to learn about her husband's therapy in the home setting for exercises, positioning, and how to help him dress. She also had to learn about testing blood sugar and giving insulin shots.

Case A reported that important skills to have as a caregiver are good health; ability to be self-contained; mental, emotional, and physical stamina; and homemaker skills. She explained that being self-contained was important since as a caregiver she must spend more time at home entertaining herself. The homemaker skills are important in terms of learning to juggle time and jobs in order to get everything done in a certain amount of time.

Case A stated that, in her opinion, she learned most of her skills as a caregiver in the home setting. At that time, she participated in her husband's therapy and nursing needs.

The events or factors, as a caregiver, that Case A reported feeling good about, is the satisfaction of knowing one is doing the right thing, that her husband is receiving good care and that she has no doubts about God's will in her life. Case A again stated that it did not pay to think too much about it. She stated that she has no regrets about taking care of her husband.

In describing how becoming a caregiver has affected other role areas in her life, Case A primarily discussed the loss of her role as a worker and as a wife. As a worker, Case A stated that she was no longer a wage earner. She described the loss of the wife role to being "widowed." It is not the physical aspects of her husband's condition but his cognitive changes that accentuate the loss. She no longer has a helpmate with whom she can share problems or "dump" on. She emphasized that life changes. Neither she nor her husband have much of a social life at this time. She described her social life as isolated because people were afraid to come by and see her "blubber." Case A used the analogy of having an infant in the house and it being a devastating time as one is locked in after previously having had freedom.

When asked what adjustments Case A has made in her other roles in relationship to being caregiver, she stated that the whole thing has been one big adjustment. She further described the situation by listing the things she must do, but she does not enjoy, such as all of the driving, the bill paying, all of the decision making, and all of the yard work. These are areas for which her husband was previously responsible. She stated that the biggest adjustment was in dealing with the isolation. She has found ways to entertain herself at home such as reading, sewing and gardening.

In response to being asked if she was satisfied with the adjustments and what changes would be made, if possible, Case A initially stated that she could not change anything. Therefore, one had to learn to like it. One must like the situation one is in. Case A emphasized that she counted her blessings. Case A later stated that if she could make changes she would have her husband one hundred percent well again.

When asked where Case A saw herself five years from now, she thought she would be alone. She stated her belief that her husband probably did not have years to live. It was her opinion that this was one reason she could be a caregiver. Case A anticipates that if she is alone it will be another whole adjustment in having no one for whom to care.

## Case B

### Demographics

Case B, a 56 year old female, had been a caregiver for seven and a half months at the time of the interview. Case B was caring for her husband who suffered a cerebral vascular accident. Case B initially had additional twenty-four hour help from a son who now continues to assist up to one hour daily.

## Roles

Case B's roles as stated during the interview were as follows: caregiver; wife of 40 years; mother of five children, four of whom life in the area; grandmother of five; and worker.

When asked to list the roles in order of value, Case B listed mother first, followed by wife and worker. Case B stressed that she always considered being a good mother and good wife as important duties for her since she was sixteen years old. Her home life has always come first. When describing her role as a worker, Case B stated it was not for the money but for the different outlook it gave her in life. She considers her job as something to look forward to besides cooking and cleaning.

When asked to list the roles in order of necessity, Case B listed caregiver first, followed by homemaker, then worker. The role which requires most of Case B's time is that of caregiver. Case B's second most demanding role is that of homemaker. Case B stated that the combined demand of the caregiver and homemaker roles now prevents her from spending more time at work. She initially quit work when her husband became ill. She has since returned on a part-time basis within the last month.

Case B reported that she spends at least a full day in the caregiver role. The only time she is not available to assist her husband is during the three hours in the afternoon when she is at work. Case B's day starts between seven-thirty and eight o'clock with preparing breakfast and seeing to her husband's morning medications. She stated that she is "up and down" enough to lose ten pounds with the things with which her husband needs help. As a wife, Case B stated that before she leaves for work and the majority of the evening time is spent with her husband. Case B's homemaking tasks are scheduled around her time at work and helping her husband. As a mother, Case B reported that she tries to be available to her children as needed, but that time has decreased significantly as her children recognize how busy she is. As a grandmother, Case B no longer has her youngest grandchild stay overnight. She reported that she does not have the time.

When Case B was asked how she would change the time that is spent in roles, she stated that she would like to spend more time at her job. Case B believes that spending more time at work would decrease her mental stress as she would be at home less. She would also like to spend less time as a caregiver. She stated that she can handle her husband's physical needs but that he demands too much of her time. She described mental stress as dealing with all of the things about which her husband worries and wants done immediately around the house or yard. She talked about his not "letting up" once he gets an idea into his head.

Caregiver Role

During the interview, Case B stated that being a caregiver was her duty as a wife. Marriage is for better or worse so one does not give up the worse but keeps "hanging in there" and surviving, if possible. Being a caregiver is important to Case B as taking care of her husband is her first duty and because she loves him. A marriage oath means, to Case B, that one stands by rather than just decide not to "fool with" the other person. Case B also stated that she would expect her husband to do the same for her if she was disabled.

To Case B the important aspects of being a caregiver are numerous. It is important to primarily give her husband love and attention. In addition, to see that he is bathed, has his meals and takes his medications.

In general, as a caregiver, Case B spends her day assisting her husband with his bathing, dressing, preparing his meals, administering his medications, teaching her husband household tasks that he is attempting to perform, and trying to motivate him to go to therapy. In addition to the daily tasks, Case B now handles the family checkbook with help from her daughter, and arranges for transportation for her husband's outpatient therapy and doctor visits and for herself when she needs to go shopping. Case B has never driven. She previously relied on her husband to meet her transportation needs.

Case B, when asked, stated that she did not have a caregiver role model to whom she looked to or from whom she sought help. She knew of no one who had gone through this, but wished she did.

When asked about the expectations that she has or others have of the caregiver role, Case B stated that it was up to each person as an individual to decide what duty was. Case B's expectation of herself was to do her duty to her husband and family.

Case B described her life now as full of pressure, tension and sometimes depression. There are times when at work that she feels relieved to be out of the house but at other times she feels nervous worrying that something might happen to her husband while she is gone. She is now also concerned with medical issues regarding her husband's progress, conflicts with her husband's physician and her husband's declining motivation. She described herself as holding on to her faith in "the man upstairs" to carry her through, just as she has all of her life.

At this point in her life, Case B thought she would be working full time, and spending more time with her youngest grandchild. She had planned on things being pretty much as always, taking care of the house, visiting with her friends and working on her craft projects.

### Adaptation Process

When asked what steps Case B had taken to be a good caregiver, she stated that she has had to do a lot of things. She has had to learn about her husband's medications, make up a schedule to assist her in remembering to give all the medications, and to find different ways to get him to take the medications such as putting the muscle relaxant into his tea. Case B says that she has had to also learn how to deal with her husband's "tantrums" by distracting him or reassuring him. She has learned to set limits regarding her husband's time frame in order to get her tasks completed. Case B also expressed that she has had to learn to motivate her husband to keep improving by "sticking" with his therapy.

Case B feels that important skills to have as a caregiver are the ability to learn new ways to handle things, to be able to recognize when one needs a break from being a caregiver and taking it, and when to let the person take risks and when not.

Case B stated that, in her opinion, she learned most of her skills as a caregiver in the home setting. She believes that having the therapists and nurses coming to the home was the most effective, as once her husband was home they had no choice but to learn it. She stated that in the hospital she and her family did not do that much because the staff did it all.

There are several events or factors as a caregiver that Case B feels good about. One is knowing that she has done a pretty good job of it despite not knowing how to be a caregiver in the beginning. Another is that her husband thanks her for all of her efforts. The last factor she mentioned is that it gives her satisfaction to know that she is handling the new changes.

In describing how becoming a caregiver has affected other role areas in her life, Case B primarily discussed the changes in her role of wife and worker, and the stress involved in caring for her husband. As a wife, she stated that there is now more stress from arguing, and dealing with her husband's "tantrums." She described the stress as a heavy load that she is enduring. Case B also stated that she has less time for herself for reading and for craft work. She also goes to bed much later at night to know that the day has past and that the morning will be here soon. As a worker, Case B regrets having to initially stop work altogether, and then having to change her hours from full time to part-time. She misses the children and the teachers with whom she works.

Case B describes the adjustments she has made, as numerous. She has learned to "let things go" such as housework if she is not up to it. She has given up her housework routines, such as always doing laundry on a certain day. Now she does tasks on the spur of the moment, telling her husband that she will be busy for the next hour or so. She has given up all of her crafts except crocheting, as crocheting is something that can be put down and picked up again if her husband needs anything. She has developed a record system for keeping track of when she needs to give her husband a medication. She is teaching her husband how to do some simple housework tasks to keep him busy and to lighten her load. She has also delegated the yard work responsibilities to her son and the checkbook responsibilities to her daughter. She also now finds ways to keep herself busy, to keep her feelings of self-pity under control.

In response to being asked if she was satisfied with the adjustments she had made, Case B stated, "not really." She wishes things were a little bit better. The primary area in which she would like to make changes is what she described as her husband's "mental state." She feels that it is his tantrums, his impatience to get things done immediately, and his inability to let go of a topic that contributes directly to her stress.

When asked where case B saw herself five years from now, she stated that one cannot predict the future. She does wonder, though, if she will go first as a result of the stress or if she will still be where she is today. She also worries if she will be able to handle the situation when she is older if things get worse. She stated that one knows things like getting sick can happen to anyone, so one must be content and not take life for granted. She now recognizes the value of the life she and her husband had before the stroke. She says her husband does not talk about moving to Oregon upon retirement like he did previously. Case B says she was never the one to plan ahead like her husband. She always told him that she would try living in Oregon and see if she liked it. Case B stated she is still not planning ahead, just looking to God everyday to give her the strength and patience to "hang in there."

## Case C

### Demographics

Case C, a 41 year old female, had been a caregiver for two years at the time of the interview. Case C is caring for her mother who suffered a cerebral vascular accident. She is the sole caregiver except for occasional supervision needs provided by her husband or teenage son.

## Roles

Case C's roles as stated during the interview were as follows: wife of eighteen years, mother of three children ages sixteen, fourteen, and twelve years, caregiver, homemaker, sister and friend.

When asked to list the roles in order of value, Case C listed mother, caretaker of the animals, wife, and caregiver. Case C stated that she was listing her roles in order of what was supporting her most at this time. She expressed that at this time wife is the role that probably looses out, but that she valued her role as wife over that of caregiver.

When asked to list the roles in order of necessity, Case C listed caregiver as first, followed by mother, homemaker, animal caretaker, wife, and friend. She stated that at this time, her relationship with her husband was not real strong or supportive, secondary to the difficulty of the caregiver role. The role which requires most of Case C's time is that of mother, followed by caregiver, homemaker and wife. She explained that because she was caring for her mother she spent more time at home than she would otherwise.

Case C reported that at least nine hours a day are spent in the role of mother. Case C explained that from the time her youngest daughter gets home it is "mommy, mommy" for everything. The role of homemaker consumes about five hours a day. Caring for her mother can take up to four hours daily for direct hands on help, and then her mother requires supervision. Case C stated that she will occasionally leave her mother for brief periods if she is laying down or if her son is home. Care of the animals takes up to one hour a day. Case C estimates she spends about three hours a week in her role as wife.

Case C stated that if she could change how her time is spent in her roles she would like more time for herself. She would like to finish her college degree, exercise more to get into shape, vacation with her family, and catch up on her sleep. She would also like to spend more time with her husband.

## Caregiver Role

During the interview, Case C stated that she did not feel like there was any option about being a caregiver. There was not enough money to have her mother's care given in any other way. Case C's sister is a single working parent and was not in a position to help. Case C also felt that her mother would not make it if she was in a nursing home. As her mother had taken care of Case C's aunt when she was ill, Case C believed that her mother deserved the same consideration. Being a caregiver is important to Case C as she wanted her mother to have a successful ending to her life. In addition, Case C knew her mother was very much against nursing homes. Case C stated that caring for her mother was also important as a continuation of their relationship.

To Case C the important aspects of being a caregiver included: giving her mother emotional support, learning skills to assist her mother's self care, adaptability, flexibility, patience, and self-control. The hardest aspect of caregiving for Case C is the emotional support required. She says that even though she gives it, she is also learning that this is not really her responsibility. It is hard to know when to take control or when not to for her mother's sake. Case C also believes that people skills are important as so often she is the middle person in so many situations for her mother. Case C felt that being in good health was another important aspect.

In general, as a caregiver Case C spends her day bathing her mother, helping her dress and assisting with toileting. She also prepares her meals and gives her medications. On a weekly basis Case C washes her mother's laundry, and cleans her bedroom. Case C is also responsible for all of her mother's finances, and dealing with her New Hampshire home. Up until the last year, Case C also drove her mother to the senior center twice a week as well as to all appointments. As her mother is now unable to get in and out of the car, Case C arranges her mother's transportation through Outreach and Escort services.

Case C's caregiver role model is her mother. Her mother took care of her own sister, Case C's aunt, at home when she was dying. Even though this event occurred on the east coast while Case C was living on the west coast, she believes that this created a mental picture for her of how her mother's family takes care of their own. In addition, Case C has a friend who has had a little taste of what it is like to be a caregiver. Case C feels that this friend understands the emotional aspect of this type of situation. Case C talks with her friend regarding this component of caregiving.

When asked about the expectations that she has and others have of the caregiver role, Case C thought that if all a caregiver had to do was to take care of the physical needs then that would be more than enough. Case C believes that when one takes on the role of caregiver that people expect you to be everything. Sometimes taking care of a dependent person means helping the care receiver to do things he or she does not want to do. Case C cites as an example her husband's new health plan which will provide financial compensation to help in caring for a parent if one works outside the home. Case C stated that she is angry about the assumption that if one does not work outside of the home then that person must not have anything else to do. She says that because she does not work outside of the home, the expectation by others is that she has plenty of time to take care of her mother. This attitude "bothers" her to put it mildly. Case C stated that other people have no idea what a great impact caregiving has on one's life.

Case C described her life now as that of being trapped. She says that being a caregiver is not necessarily obviously awful or no one would do it. On the other hand, Case C explained that she has mixed emotions about it. The situation definitely ties one down in a whole different way. She reported that it is like having an infant in the house, a stage with which she believes she did not deal well in regard to her children. Case C also described her life as being dutiful. She explained that she is now continuously tied to duty at a time when she had hoped to have more options.

At this point in her life, Case C anticipated having more free time during the week as her youngest daughter was now in junior high. Case C hoped that at this time she would be able to go back to school. She had thought that this would be a time that she and her family would be traveling during the summers. Case C anticipated having more fun, more time for herself, and more direction in her life with her children being older.

## Adaptation Process

When asked what steps Case C had taken to be a good caregiver, she stated that she participated as often as she could while her mother was in rehabilitation. She had also taken a caregiving support class and is a continuing participant in a caregiver discussion group. Case C and her mother attended stroke support meetings off and on during the last two years. In addition, Case C has read numerous books on strokes and caregiving.

Case C believes that important skills to have as a caregiver are patience, ability to set priorities, to set and know one's own limits, to communicate, and to have a sense of the care receiver's life perspective. In communicating, Case C believes that during communication with her mother, she needs to take the bulk of the responsibility for that communication, as one would with a child. It is also important to know how to help someone to dress, bathe, and transfer to and from a wheelchair when caring for a physically dependent person. Nursing skills are also helpful.

Case C stated that, in her opinion, she learned her skills as a caregiver in a variety of settings. Initially she was exposed to techniques while observing and participating in her mother's therapy at the hospital. Case C then participated in her mother's outpatient and home health treatment. Case C believes that she learned how to move and handle her mother's self-care needs through home health services. Case C also stated that a lot of her caregiver knowledge has come from the college of hard knocks.

The events or factors as a caregiver about which Case C feels good are, when her mother has accomplished something new, either physically or emotionally, the satisfaction of handling a situation well, when people appreciate or recognize her efforts as a caregiver, and when her mother expresses her appreciation. Case C again stated that there is a lot of ambivalence about being a caregiver and that sometimes just the feeling of following through on her commitment is good.

In describing how becoming a caregiver has affected other role areas in her life, Case C stated that it has dominated them. The experience has taken something away from every other area. Everything else has been put on the back seat because everything is conditional on how her mother is doing. Case C says that just the mental and emotional energy as well as the physical time it takes, impacts her and her family's life.

In discussing the adjustments she has made in relationship to being a caregiver and other roles, Case C stated that she puts less into and cuts back in all of her roles. Instead of encouraging her children to get involved in numerous activities she insists they choose only the activities very important to them. Case C also spends more time in what she calls resting. She says that if she has a little time she weighs how tired she will be if she spends time at a task against the opportunity to rest and build her reserves, as she never knows when she will have to expend energy to assist her mother. In relationship roles, Case C now spends less time trying to work out problems. Rather than take total responsibility to keep things running smoothly, she expects more reaching out from the other party involved. She cites her relationship with her sister as an example. She says she has also become more selective with which friends she spends time.

In response to being asked if she was satisfied with the adjustments and what changes would be made if possible, Case C was pleased with part of the adjustments she had made in her relationships. She has had to focus on trying to have healthier relationships, part of which has been not taking as much responsibility for other people's feelings. She says if this was not occurring at this time, her family would not be surviving at all. The family is currently going through counseling to deal with the stress now in the home. They are trying to achieve more balance in their relationships. She feels that being a caregiver has forced her to look at how she relates with people. She wonders if she would have had the motivation to pursue the changes if not in her current situation. Now it is survival. In some aspects, Case C believes that being a caregiver has simplified things through giving her a focus. It has eliminated some of the deciding on what one is going to do because caregiving has come first.

When asked where Case C saw herself five years from now, she felt she would probably be right where she is now as her mother's condition is not terminal. She recognizes that although her children will be older, potentially they could all still be living at home while in college. Case C stated that she has to take into consideration that she may still be in "limbo" for the next five years. If she does not keep this in mind she worries about having expectations which are too high. To handle this, she feels it is better not to have any expectations. Case C also says that she does not want to perform caregiving for five more years or the whole family will "go crazy."

## Case D

### Demographics

Case D, a 49 year old female, had been a caregiver for five years at the time of the interview. Case D is caring for her 26 year old son who suffered a traumatic brain injury. Case D's husband assists her with caregiving for an hour every evening.

### Roles

Case D's roles as stated during the interview were as follows: mother of four children ages 22, 26, 28, and seven; wife of thirty years, homemaker, and volunteer. She worked full time until her son's accident. Case D's seven year old is her adopted granddaughter whom she has raised since infancy.

When asked to list the roles in order of value, Case D listed mother to her youngest daughter as first, followed by caregiver and wife. Case D expressed that caregiving for her son was like having another child in the house.

When asked to list the roles in order of necessity, Case D listed caregiver as first, followed by mother, and wife. The role which requires most of Case D's time is that of caregiver. Providing care is her number one priority at this time. Case D's second most demanding role is that of mother.

She sets aside ninety minutes a day solely for her daughter. That time is used to help with homework and to spend time together. Case D also spends one morning a week as a volunteer at her daughter's school.

Case D reported that at least three hours a day is spent with her son directly meeting his basic needs, bathing, and dressing. It can take another couple of hours just to help him to eat. She stated that he really can never be left alone. However, within the last year, she has begun to leave him occasionally for up to two hours at a time. Case D explained that her time as a wife is not much at all.

When asked if given an opportunity to change how time was spent in each role what would be changed, Case D stated that she would like to go back to work. She believes that all of her time is now spent in the home. She would also like to spend more time in her role of wife. She says that because her husband can be spontaneous and just get up and go that it is difficult to spend time together as someone must stay with the son. She would like to have the flexibility to go with him instead of being tied to the house.

### Caregiver Role

During the interview, Case D said that she had no choice, as she saw it, in becoming a caregiver. She could not put her son in a nursing home with old people. Being a caregiver is important to Case D as she is in control. She knows what kind of care that her son is receiving with her. She knows that she can give him the loving care that he needs. She also feels that because he is really set in his ways and can not talk, it is important for him to be with someone who knows what he wants, when to leave him alone, and when not to leave him alone. With Case D, she knows that her son is getting the best care that can be given. She gives him the attention he needs which is something that Case D believes a nursing home would not be able to provide.

In general, as a caregiver, Case D spends her day helping her son bathe and dress, fixing his meals and helping him eat. Although he still receives a tube feeding sometimes, she likes to prepare his food as it feels more like a normal role for her. She likes to prepare his favorite foods. His eating, however, is very slow and difficult for him. If time is short, the gastrointestinal tube feedings are utilized. Case D stated, that with her son, the tube feedings are a habit because it is easier for him versus eating. Case D also spends her day supervising her son as he is rarely left alone. Her weekly tasks as a caregiver are washing his laundry, tending to his bowel program, and cleaning his room and fish aquarium.

Case D's caregiver role model is her mother. Her mother took care of Case D's grandmother the last year of her life. However, Case D says she has never asked her mother for advice in helping with her son.

When asked about the expectations that she has and others have of the caregiver role, Case D said one cannot do it alone. If one is the sole caregiver it is total chaos both mentally and physically. One would burn out. Case D says it is important to expect help if it is available. No one can do it all. She stated that having respite help available through the Veterans Administration Hospital lets her take a breather. She uses that week to recharge her batteries. She feels it is just as important for her son to also get a break from her. A caregiver should expect some time for himself or herself.

Case D described her life now as very routine. To her, it is like having a baby in the house. One must get up every morning and feed the baby, dress the baby, and bathe the baby. Although she says her son is not a baby, he does have his routines that he sticks to no matter what.

At this point in life, Case D was looking forward to the children getting older and leaving the house. She thought she would be doing more things with her husband, traveling for instance. She use to think that with the children out of the house, she and her husband would be more economically set as both would be working. She wanted to take it easy and spoil the grandchildren. Case D and her husband had just reached this stage as her daughter was fifteen when her son had his accident. Case D stated that she previously fantasized about getting old. Now she worries about it. She worries about not being able to be her son's caregiver.

## Adaptation Process

When asked what steps Case D had taken to be a good caregiver, she stated that she learned how the hard way. The caregiver role, in her opinion, was thrust upon her. She had anticipated maybe having to care for her mother some day, but never imagined having to care for her adult son. Her son had already been out of the house for two years at the time of the accident. When he first came back home, Case D says that he required total care. She had to learn how to lift, dress, bathe, shave, and change him. She was working full time day and night. Compared to the beginning, it is now easy. Her son has just now reached the stage where she can occasionally leave him alone for two hours without worrying very much. Another important step she had to take in being a good caregiver was to learn to deal with her anger and frustration. For this she went through professional counseling. Case D has also taken steps to improve her health so that she can be a caregiver as long as she can. This includes dieting and losing sixty-four pounds, and exercising five days a week. She started exercising while dieting but now it is something she does for herself. She says that her blood pressure and health are better than ever before.

Case D believes that important skills to have as a caregiver are good health, some nursing skills, patience and loving. The nursing skills that are important include lifting, changing and handling tubes, and moving people in bed. One has to be patient and loving because there is a lot of anger and resentment on the part of the care receiver and caregiver.

Case D stated that, in her opinion, she learned most of her skills as a caregiver at home on her own the hard way. One must. She also believes that she has learned in support groups by listening and sharing with others who have the same difficulties. Some of the nursing skills such as dealing with the feeding tube, Case D learned in the hospital.

The events or factors as a caregiver that Case D feels good about are seeing progress in her son, and having people tell her how well he looks and is doing. She also cites the care and love that she gets receives from her son as another important component.

In describing how becoming a caregiver has affected other role areas in her life, Case D stated that it has affected everything. It has impacted Case D's relationship in her role as daughter, as she will now be unable to care for her mother. Last year when Case D's mother was ill, Case D felt that she was going through a most terrible time as she was unable to help her mother or invite her mother to move in with her. Case D felt that she could not be a caregiver for two people. As a caregiver, Case D believes that she has less time to spend with her other children and her husband. She is unable to do things together with her husband, like visit relatives out of town, or go to the movies as there is no one to stay with her son. She stated that she does not seek help from her 22 year old daughter. Case D believes that she cannot ask her daughter to give up her normal life just so Case D can go out.

Case D has made several adjustments in her roles in relationship to her caregiver role. One is that she is no longer involved in the schools anymore. She previously was active in the Parent Teachers Association (PTA). She feels that this took away time from her son as a caregiver and as a mother to her youngest daughter. Instead, she tries to have direct, quality time with her daughter. She also helps one morning a week in her daughter's classroom. In her role as wife, she and her husband now try to plan to have more time together even if it is just to the movies. She and her husband also plan time together around her son's respite weeks, two to three times a year. However, she quietly stated that her and her husband's roles are totally different now. In some respects they have drifted apart, but Case D says that this could have happened even if her son had not been hurt. She thinks that a lot of couples go their separate ways as they get older. Case D has also adjusted her plans regarding leaving the house to her children if anything happened to her or her husband. Rather than sell the house and divide the proceeds, she believes it is now necessary to leave the house to her disabled son. This will insure that he always has a place to stay.

In response to being asked if she was satisfied with the adjustments, Case D stated that she is now. She says that three years ago her answer would have been no. At that time she was pretty emotionally burned out. Now she feels that she is better at coping even though she still sometimes goes "off the wall." Seeking counseling assisted her in this change. If she could change things, the major change would be that her son was never hurt. There are many times when she thinks about this area. Things would be a lot better. Not so much for her but for her son. He would have had a chance to marry and have children. She believes that her son would have been a good husband and father as he is a very loving and gentle person. The heartache for Case D is that so many of her son's hopes and plans for the future are gone.

When asked where Case D saw herself five years from now, she thought she would probably be doing the same thing. She has hopes that it will be better than it is now. She hopes that her caregiving responsibilities will change from full time to part time. She would like to be able to work outside the home part time if her son could be independent enough for her to leave him at home alone for four hours a day. She would like to receive pay for something that she likes even if it is just a play job.

## Case E

### Demographics

Case E, a 60 year old female, had been a caregiver for seven years at the time of the interview. Case E was caring for her husband who suffers from a brain tumor. During the last seven years her husband has had three craniotomies, radiation twice, and chemotherapy several times according to Case E. His level of care has increased over this period. Case E has children in the area who will stay with their father occasionally for short periods of time. Other than these few and brief episodes, Case E is the sole caregiver.

## Roles

Case E's roles as stated during the interview were as follows: caregiver, wife of 44 years, mother of eight, grandmother of fifteen, and worker.

When asked to list the roles in order of value, Case E listed grandmother as first, followed by mother, wife, and worker. Case E explained that her role of wife is not the same as she and her husband no longer have an intimate relationship. In her worker role, Case E paints and makes crafts to sell. She also worked one day a week at the shop which sold her work. She gave up painting and working at the shop six months ago.

When asked to list the roles in order of necessity, Case E listed caregiver as first, followed by homemaker, and grandmother. Up until six months ago, Case E had her elementary school aged grandson living with her. He is now with his other grandmother. The role which requires most of Case E's time is that of caregiver.

Case E reported that she is involved in caregiver activities day and night. She must help her husband in and out of bed and to the bathroom several times a night. In the last few months her husband has required full time supervision. Case E stated that she spends little time in her mother and grandmother roles. She feels that she needs to be available just for her husband. Within the last week, Case E started painting again. She stated that normally at this time of the year she would be painting and working on her crafts four to five hours a day in preparation for selling at Christmas.

When asked if she had an opportunity to change how time was spent in each role what would be changed, Case E stated that she would rather not be the caregiver. She would like more autonomy, to be able to go shopping, or to be able to paint when she wanted, for example. She would also like to spend more time with her family.

### Caregiver Role

During the interview, Case E stated that she became a caregiver as she felt it was something she needed to do for her husband. She also feels that she is a born caregiver. She explained that she has been a caregiver type all of her life. Being a caregiver is important to Case E, as in her opinion, God expects people to take care of each other.

To Case E the important aspects of being a caregiver are numerous. Initially, she felt that it was important to help her husband in areas in which he had trouble such as bill paying, decision making, self-care, and with his medical needs. As he has declined considerably in the past three months, Case E believes it is important to keep her husband comfortable and to "get through this".

In general, as a caregiver Case E spends her day helping her husband get out of bed, go to the bathroom, bathe, and go for a walk. In addition, she prepares all of his meals and gives him his medications. Case E also pays all of the bills, serves as an advocate for her husband to the doctors, and drives her husband to and from doctor's appointments, when needed.

Case E's caregiver role model is the husband of her friend. Her friend died of cancer and heart problems. Case E admired her friend's husband because he would take his wife every place he went or she wanted to go even when using a wheelchair. Despite her friend's illness, Case E states that the two of them continued to have a good relationship up until the end.

When asked about the expectations that she has and others have of the caregiver role, Case E expressed concern over the concept that she has and others have of the caregiver having to do it all. Because of this, it is hard for her to take time for herself. As a wife, Case E believes that being the caregiver is expected of her. Case E worries about the time when she will not be able to care for her husband and what others will think if she places him in a nursing home.

Case E described her life now as being very boring and stressful. She feels tired all of the time. Another word she uses to describe her life is trapped. She explained that she cannot leave the house when she wants or needs to. If she does leave briefly, she must return by a certain time. Her husband becomes upset when she leaves and insists on knowing when she will be back. Case E says that there are many times when she felt like running away. She also says that she could never do that to him. Case E says she just takes is all a day at a time.

At this point in her life Case E thought that she would be traveling all over, doing fun things, and visiting with the children. She though she would have more time to devote to her painting. She wanted to be active, taking classes, and participating in art groups.

### Adaptation Process

When asked what steps Case E had taken to be a good caregiver, she stated that she has tried to use her nursing skills. She had gone back to school after her eighth child. She worked as a licensed vocational nurse for four years until she hurt her back. Another step Case E has taken is to make sure that she is acting as an advocate for her husband. She described this as keeping the doctors informed, as her husband never tells them anything. She tries to keep well informed of her husband's medical needs and potential symptoms. She also tries to be empathetic in dealing with her husband, although he does not always like her to be.

Case E believes that important skills to have as a caregiver are a good back, some nursing skills, patience, empathy, and a good memory. The nursing skills she feels are important are knowing signs and symptoms, safety, medications, and lifting. It is important to have a good memory as one must remember everything for two people.

Case E stated that, in her opinion, she learned how to be a caregiver in several settings. In the hospital, Case E feels she learned about signs and symptoms of a brain tumor and therapy. In the home setting, she feels she has learned a lot about safety, lifting, and her husband's self-care needs. She has also been involved in outpatient services and support groups.

The events or factors as a caregiver that Case E feels good about, are knowing that she is capable of taking care of her husband, and knowing that her husband appreciates her efforts. She also feels that it is through her efforts that he has lived as long as he has. She credits herself with having kept up on his symptoms and with keeping the doctors informed of her husband's changes and needs.

In describing how becoming a caregiver has affected other role areas in her life, Case E stated that it has just about taken everything away. She very rarely paints anymore. She gave up her job at the shop. Case E does not see as much of her grandchildren, her children, or her friends. Case E says she has to put aside her household tasks so everything is a mess. She has to make all of the financial decisions because her husband does not have the capacity. He, however, does not recognize his decrease in abilities and fights all of her decisions. There has been a significant impact on her role as wife. With the onset of her husband's tumor, their intimate relationship ended. Initially, she thought that her husband no longer loved her. As her husband had always been "macho" he was unable to adjust to the idea of intimacy being something besides sex. In addition, Case E says her husband blames everything that happens to him on her. If he stumbles, or has difficulty getting dressed he asks Case E why she did that to him. He never blames what is happening to him on the tumor. It is very hard to always be blamed for things stated Case E.

Case E has made several adjustments in relationship to being a caregiver and her other roles. She has quit working at the crafts shop. She has stopped painting and working on her crafts which she sells. She stopped spending time on paper work associated with her husband's medical bills. She worries about this piling up. She also has stopped spending time on the house. She has put off appointments and doctor visits concerning her own needs. Her grandson is no longer living with them. She spends less time with her children and grandchildren.

In response to being asked if she was satisfied with the adjustments she had made, Case E stated, "not really." If she could change her roles she would like to have more free time just to get needed things done. She would also like to be in full control of the finances enabling her to make decisions without involvement from her husband. She says it is just too hard trying to communicate when he really does not understand. She gave as an example the selling of their house to buy a condominium. She wanted to pay off the entire new mortgage to secure their future. Case E would also like to paint more and go back to working at the crafts shop. In addition, she would like to spend more time with her children, grandchildren, and friends.

When asked where Case E saw herself five years from now, she stated that she was not worried about it. She feels confident that she will be hard to find. If her health holds up she plans to travel and visit her children who live out of state. She has worked with one of her daughters to develop a financial plan for her retirement income. She says that she has the advantage of knowing that her days as a caregiver are winding down. She plans to also work hard at her painting and crafts to earn money for traveling to places that she has not seen yet.

## Results and Discussion

The data content from five case studies was analyzed for the emergence of trends or patterns in adaptive behaviors, role changes, role balance, and implications for treatment as determined by research questions. The results and discussion are presented for each research question.

### Adaptive Behaviors of the Caregiver Role

Question One: What adaptive behaviors are perceived by the individual to be successful in the role of caregiver?

Adaptive behaviors are skills or activities specific to a role. These skills allow the individual to successfully explore and master the physical and social demands of that individual's environment (Llorens, 1991). Activities of the caregivers interviewed are divided into direct care and indirect care. These activities, as well as the number of participants performing each activity, can be found in Table 1. These findings are consistent with previous studies as reported by Baum (1991).

Table 1

*Caregiver Occupations* (N = 5)

| Activity | # of participants |
|---|---|
| Direct Care | |
| bathing | 5 |
| meal preparation | 5 |
| dressing | 4 |
| toileting | 4 |
| medications | 4 |
| bed mobility | 3 |
| transfers | 3 |
| Indirect Care | |
| laundry | 5 |
| cleaning receiver's room | 5 |
| scheduling appointments | 5 |
| finances | 5 |
| decision making | 5 |
| driving | 4 |
| advocate | 3 |

All five caregivers were asked to state which skills they felt were important to have as a good caregiver. The list consisted of eleven skills. The list and number of caregivers who perceived the skill as important can be found in Table 2. The most important skills reported were self-care skills, the caregiver's good physical health, nursing skills, knowing own limits, the ability to set limits, patience, and empathy.

The important aspects of being a caregiver reported can be grouped into three areas: providing good care, having a good attitude towards caregiving, and being an advocate for the care receiver. Hasselkus (1991) documented similar findings. In providing good care, four of the five caregivers felt one should give the best care, make sure their family member was comfortable, and do it right. Having a good attitude towards caregiving for three of the five caregivers consisted of being loving and attentive, and doing it cheerfully and patiently. Four of the five caregivers felt that being an advocate for their family member was an important aspect. This consisted of getting appropriate health care services, keeping the doctors informed of medical signs and symptoms, dealing with health insurance agencies, and making informed decisions regarding care for their family member.

Table 2

Important Caregiver Skills Reported (N = 5)

| Skill | # of participants |
|---|---|
| self care skills* | 5 |
| good physical health | 4 |
| nursing skills** | 4 |
| know own limits | 3 |
| ability to set priorities | 3 |
| patience | 3 |
| empathy | 3 |
| mental and emotional stamina | 2 |
| ability to learn new techniques | 2 |
| set limits and boundaries | 2 |
| good communicator | 1 |
| self contained | 1 |

*self care skills defined as transfers, dressing, bathing, toileting, bed mobility tasks

**nursing skills defined as medical needs, medications, procedures

In order to be successful in the caregiver role, each caregiver reported the steps taken to improve her skills. (see Table 3) By actively learning new skills, each caregiver responded to the environmental demand of the role. Two of the five caregivers are in the middle adult stage of the life span continuum. Appropriate adaptive behaviors for this age group, as described by Llorens (1991), are attaining civic and social responsibility, maintaining financial responsibility, helping family members, children, and aging parents, and developing friendships, all of which are evidenced in the skills learned and steps taken described in Tables 2 and 3, respectively. Three of the caregivers fall into the later adult life span with ages 56, 60, and 61. Appropriate adaptive behavior for this age group involves the continued growth towards the individual's potential. All five of the caregivers sought out skills each considered important to the success of the caregiver role. This process of developing adaptive behaviors specific to the role of caregiver is called adaptation (Reilly, 1962). The five caregivers studied utilized a variety of settings in which to learn new adaptive behaviors. Four of the five caregivers stated that they learned safety issues, therapy exercise programs, some self-care techniques, medical needs, and medications regarding their family members in the hospital setting. Only two of the five care receivers

Table 3

Steps Taken to Learn New Skills (N = 5)

| Steps Taken | # of participants |
|---|---|
| learned self care skills* | 5 |
| began active exercise programs | 4 |
| learned nursing skills* | 4 |
| arranged/learned finances | 4 |
| learned to deal with emotional aspects of caregiving | 4 |
| learned to set priorities/limits | 3 |
| learned to motivate family member | 2 |

*self care skills defined as transfers, dressing, bathing, toileting, bed mobility tasks

**nursing skills defined as medical needs, medications, procedures participated in outpatient services. In this setting, exercise programs were emphasized according to the caregiver participants.

All five of the caregivers interviewed reported having learned skills in the home setting through home health services. These skills consisted of self-care techniques for dressing, toileting, bathing, and bed mobility, home modifications and adaptive equipment needs, safety, and nursing skills such as medications and monitoring signs and symptoms. Discussion of skills learned in the home setting elicited comments such as "at home it is the old college of hard knocks," "learned a lot on my own, you just have to when the person is home," "it really counts when they come home, you have to learn," and "what was learned at home was better internalized."

Three of the five caregivers had participated in support groups. The support groups were described as "informational." Four of the five caregivers had participated in individual counseling sessions in the community after the family member returned home. In this setting, the caregivers report learning to deal with feelings of anger, how to know own limits, and how to deal with the care receiver's behavioral problems and changes.

## Adaptation Process Utilized in Caregiver Role Acquisition

Question two: What is the adaptation process utilized during the acquisition of the caregiver role?

The adaptation process is the relationship between the environment and the behavior that an individual utilizes to meet the demands of that environment. The process demands that the individual actively adjust to different environments to enhance personal survival. Participation in life roles organizes productive behavior. Mastery of the environment occurs through the occupations of roles. The process is self-reinforcing and reflects the individual's needs or wants.

Data, to answer question two, are presented in terms of the participants' environment which included multiple roles, the role expectancies of a caregiver from the individual's and societal perception, the changes made in their multiple roles to become a caregiver, and the reinforcers available to help in maintaining the caregiver role.

As appropriate to the position on the developmental life span continuum, the research participants were engaged in multiple roles. Two of the five participants were in the middle adult stage, ages 41 and 49. Roles which predominate this stage can be those of spouse, worker, parent, grandparent, and daughter or son (Llorens, 1991). Three of the five participants were in the later adult stage, ages 56, 60, and 61. Roles at this stage may be comprised of parent, grandparent, spouse, worker, and daughter or son (Llorens, 1991). The roles in which each of the participants were engaged can be found in Table 4. All of the participants were engaged in age appropriate roles.

The multiple roles of the participants in this research supports previous studies regarding caregivers and their responsibilities (Franks & Stephens, 1992; Stoller & Pugliesi, 1989). Occupying multiple roles can bring about competition among these roles for time and energy. Despite this, all five of the caregiver participants continued to engage in numerous roles.

Management of multiple roles may require one to set priorities. Each participant was asked to delineate her roles by value and necessity in order of most important to least important. Four of the five participants listed mother as the most valued role. One participant valued the role of caregiver as most important. The second most valued role was that of wife for three of the five participants. One participant listed caregiver as second, one listed grandmother as second in value. The third role listed by value was wife for two of the participants and worker for three of the participants.

Table 4

Multiple Roles of Caregivers (N = 5)

| Roles Engaged In | # of participants |
|---|---|
| mother | 5 |
| caregiver | 5 |
| wife | 5 |
| homemaker | 5 |
| grandmother | 4 |
| worker | 4 |
| friend | 2 |
| sister | 1 |

All five participants listed the role of caregiver as the most important role by necessity. Fcr two of the five participants, mother was listed next. One participant listed worker as second, while one listed homemaker as second. The role of wife was listed as third most necessary by three of the participants. One listed homemaker as third, while another listed worker. The role of caregiver as a necessity comes into conflict with the valued role of mother.

A role is a functional position held by an individual in society (Llorens, 1991). Each role has expected responsibilities and privileges as defined by the society in which the individual exists (Kielhofner & Burke, 1985). Perceived societal expectations of the caregiver role as described by the research participants were: to provide good care for the members of the family (5 of 5); it is one's duty to care for the family (5 of 5); and if one becomes a caregiver then one is able to do it all (4 of 5). The expectation that bothered the caregivers most was the last one, that of being able to do it all. As one caregiver stated, "the expectation that one has nothing else to do than to take care of your parent and that it is not impacting on one's life '<u>bothers</u>' me to put it mildly." Another example of societal expectations can be derived from the following data: four of the five participants reported having a caregiver role model to whom they looked up to; two of the four participants had both family and friends as role models; one participant had only a family role model and one participant had a only friend role model.

Expectations that the participants had of themselves in the caregiver role included: providing the best care one could; carrying out individual conception's of duty; and helping in the caregiver role was important. As one caregiver stated, "it is physical and mental chaos for one person to do all the caregiving." These expectations reflect the influence of the society and family culture in which the participants live. There is, however, one conflict between the perceived social and individual expectations reported. Society expects a caregiver to do it all, and the individual expectation is to have help.

Developmentally, role acquisition occurs as a dynamic process throughout the life span to meet environmental demand (Llorens, 1991). Becoming a caregiver requires integration between the caregiver role and other life span roles. In this process, roles may be relinquished and/or adjusted to accommodate changes (Kielhofner & Burke, 1985). To explore the role acquisition process each participant was asked during the interview process, to describe what each thought her life would be like at this point in time, what changes in roles were made to accommodate the caregiver role, and what events or factors reinforced each in maintaining the caregiver role.

The two caregivers who fell into the middle adult life stage were appropriately looking forward to having more time to themselves as the children for one the caregivers were now in high school and gone during the day, and for the other, her children were now in college. Case C, at 41 years of age, had been anticipating going back to college at this stage. She had also planned to travel in the summers with her children. This was to be a time of doing things Case C wanted to do for herself. Case D, at 49 years of age, was looking forward to traveling and spending time with her husband. She looked forward to being on her own and more financially secure as her children reached adulthood. The three caregivers who fell into the later adulthood stage, ages 56, 60, and 61, were appropriately looking forward to traveling and visiting with children, as each was moving toward winding down their work pace.

In becoming caregivers, all five of the participants relinquished the opportunities to which they had looked forward in this stage of their lives. In describing life now, terms such as stressful, boring, routine, and trapped were used. All participants felt isolated and restricted in their homes. Each participant reported a significant loss of personal time as a result of having become a caregiver.

These findings are consistent with previous studies as reported by Walker et al. (1992).

The two roles reported by all five participants which were affected most by the acquisition of the caregiver role were those of wife and worker. All five participants reported changes in their role of wife. Three of the five participants who are caring for husbands reported the most change. Two of the three who were caring for their husbands reported loss of the wife role, while one reported changes in the role. In describing the loss of the wife role, one participant stated that for all intents and purposes she was "widowed." Both participants stated that their husbands were no longer helpmates or partners. An intimate relationship no longer existed. The third participant reported the changes in her relationship with her husband as being increased arguing, and less time talking.

Two participants, although caring for an adult child, and parent still reported changes in their roles as wives. These included less time spent together, less emotional support, and increased conflict.

Four of the five participants reported loss of the worker role as a result of becoming a caregiver. All four had been employed outside of the home. All four also stated that if possible they would like to return to work. Work provided each of them with personal challenge and satisfaction. As one stated, work was something to look forward to in her life. Only one of the four above has returned to work part-time. One participant who was a full time homemaker and mother, reported giving up outside volunteer work upon becoming a caregiver. She would like to return to college. The above data demonstrates the impact of the worker role loss in relationship to self-esteem and the juggling of multiple roles as previously documented by Baruch and Barnett (1986).

In addition, all participants reported making changes in homemaker tasks in regarding "letting things go," and changing routines. Participants also spend less time in leisure pursuits, and less time in friendships.

Four of the five participants also reported gaining role responsibilities previously handled by the care receiver. Examples of these included: doing all of the driving and all of the yard work, taking over all the finances, and making all decisions.

An important component in the adaptation process is that it cannot be imposed but must reflect the individual's needs or wants (King, 1978). Each participant was asked why she became a caregiver. Four of the five participants stated that they had no choice in becoming a caregiver. One participant reported that she had considered herself a born caregiver. All five of the participants felt that they could not place their family member into a nursing home. Each of the caregivers responded to a need to care for her family member out of duty and to care for that person in a more desirable setting than a nursing home. The three participants who were caring for husbands felt that it was their duty as a wife. However, the participant caring for her mother felt it was her duty, but as a daughter. She wanted her mother to have a successful ending to her life. The participant caring for her adult child felt it was her duty as a mother. She wanted to be in control of seeing that her son received good care. These feelings of love, family ties and duty, the belief that institutional settings are inadequate, and family tradition as reasons these women became caregivers supports earlier work by Guberman, et al. (1992).

The second important component in the adaptation process is that it is self-reinforcing. Each participant was asked what events or factors made her feel good about being a caregiver. All five participants stated that appreciation, thanks, and receiving love from her family member made each caregiver feel good about their role. Three of the five participants listed getting appreciation and recognition from people outside of the home was an important reinforcer. Three of the five participants also stated that they derived pride in themselves from knowing that they can handle new situations, and also when their family member has made improvement either physically or mentally. Two participants reported satisfaction from knowing they were doing the right thing.

In summary, adaptation while acquiring the new role of caregiver occurred. The adaptation process utilized by the caregivers was consistent with King's (1978) description found in occupational therapy literature. Each caregiver actively acquired new occupations or adaptive behaviors that she felt met a need relative to the environmental challenge. Each caregiver, in an attempt at mastery of the role, sought knowledge in areas determined necessary to be a good caregiver. All of the participants in the study experienced changes in other roles in relationship to being a caregiver, thus enhancing personal survival. All participants received reinforcement to maintain the role of caregiver.

While there appears to be evidence of adaptation on a survival level, adjustments to facilitate contribution to the actualization of personal potential is lacking in relationship to other roles. All five of the participants relinquished the opportunities to which they had looked forward in this stage of their lives. Four of the five also reported giving up the worker role which had provided them with personal challenge and satisfaction outside of the home setting.

## Role Balance

Question Three: How is the balance between the new role of caregiver, and current roles achieved?

As roles provide a recognized structure for the individual's interaction with the environment, balance and variety of roles are necessary to the adaptive system (Elliot & Barris, 1987). A new role, such as that of becoming a caregiver, requires integration with current roles and balance between these multiple roles. Role balance provides the individual with the rhythm to change between different modes of doing tasks with sufficient time and effort for performing the tasks associated with each role (Kielhofner & Burke, 1985).

To determine if role balance existed in this research sample, each participant was asked how much time was spent in each of her roles. All five participants considered the role of caregiver as the most time consuming role. Time spent in this role ranged from four to ten hours a day in direct care with a mean of 7.2 hours for each caregiver. All but one of the care receivers required twenty-four hour supervision. Participants reported occasionally leaving their family member alone if in bed for up to two hours.

In the role of homemaker, hours per day ranged from two to five hours a day with a mean of 3.2 hours for each participant. Three of the five participants reported spending time in the role of mother. This time spent ranged from one to nine hours a day with a mean of 4.3 hours per day. For all five participants in the role of wife, time spent on a daily basis ranged from zero to four hours with a mean of 1.2 hours per day. Only one participant spent time in her worker role, three hours a day. Table 5 presents hours spent daily in each reported role for all participants. Case A and Case E spent more than fifty percent of the day in caregiver roles. Case A was the caregiver with the least amount of experience in that role. Case E, who was a caregiver for the longest time of the sample group is now dealing with her husband's declining health. Three of the participants spent just under fifty percent of their total time in the caregiver role. When asked if each could change how much time they spent in roles, all five stated that they would like to spend less time in the caregiver role. Three of the participants stated that they would have liked to return to work, one would have liked to increase her work hours. All five also stated that they would have liked more time to themselves for leisure, more time with family and with friends.

Table 5

<u>Time Participation in Roles by Caregivers in Hours per Day</u>
(N = 5)

|  | Case |  |  |  |  |
|---|---|---|---|---|---|
| Role | A | B | C | D | E |
| Caregiver | 9 | 8 | 4 | 5 | 10 |
| Homemaker | 3 | 3 | 5 | 3 | 2 |
| Mother | 0 | 1 | 9 | 3 | 0 |
| Wife | 0 | 4 | 1 | 1 | 0 |
| Worker | 0 | 3 | 0 | 0 | 0 |
| Total | 12 | 19 | 19 | 12 | 12 |
| % of total time in caregiver role | 75% | 42% | 21% | 42% | 83% |

Becoming caregivers significantly affected each participant's involvement in other roles. Four of the five caregivers stated that the caregiver role dominated or took something away from everything else. One caregiver stated that her caregiver role made everything stressful. Other areas in each of the caregiver's lives depended on how their family member was doing. Caregiving activities or needs served as the primary guideline in time allotment for other role tasks.

In an attempt to manage the daily requirements of the participants' multiple roles, several adjustments were made by each. The common adjustments amongst the sample include four of the five caregivers "let more things go," have "cut back in all areas," "cut back in outside activities," and quitting work outside the home. Four of the five stated that they now spent significantly less time socializing. One described the isolation as the biggest of all the adjustments.

When each participant was asked if she was satisfied with the adjustments made, four of the five said no. One stated she was now but if she had been asked three years ago she would have said no. She described herself as having been emotionally "burned out" at that time. The difference for her at this point was a better ability to deal with both her and her son's emotions.

When asked what changes one would make in their adjustments, if possible, three common areas were mentioned. Three of the five participants stated that she would have liked to see their family member healthy and returned to normal. Two of the five stated that they would have liked to decrease the stress of the caregiver role, and two of the five would have liked to increase the amount of time they spend for themselves. One caregiver would have liked to improve and balance her relationships with family and friends. One caregiver would have liked to have more financial control.

As all participants reported that the caregiver role dominated and took away from everything, integration between roles was lacking. The caregiver role impacted on all the other roles to the point of interfering with the participants' ability to actualize personal potential appropriate to the life span stage. The participants evidenced making adjustments but were not satisfied.

Role balance also appeared to be poor as the time allocated between roles was disproportionate enough to require that "things are let go," or that some role tasks were left incomplete. The rhythm in changing between one mode of doing to another was disrupted. Case A for example spent seventy-five percent of her time in the caregiver role. That does not allow her time to participate adequately in roles she may find more satisfying. Although Case C spent only twenty-one percent of her total time as a caregiver, her demands of the mother and homemaker roles, combined with that of caregiver prevents her from participating in roles she would like to pursue. The participants, in order to succeed at meeting the demands of the caregiver environment, may be jeopardizing success in other roles.

## Treatment Implications

Question Four: What are the treatment implications for occupational therapy in facilitating adaptation to role acquisition for caregivers?

The first step in role acquisition is to incorporate new adaptive behaviors needed to perform the role. Occupational therapists can train both the caregiver and the care receiver in the important area of self-care skills. Self-care skills consisting of personal hygiene, bathing, dressing, transfers to and from the wheelchair, and bed mobility are areas of expertise for the occupational therapist. This would involve training the care receiver to be as independent as possible in this area, potentially relieving the caregiver in this aspect of direct care. The second component would be to assist the caregiver in acquiring techniques that maintain the care receiver's independence, and/or assisting the caregiver in learning the most effective method for performing the self-care tasks themselves if necessary. The evaluation and modification of the caregivers' routines to allow more time outside the caregiver role may also add to the development of adaptive behaviors. The occupational therapist would also incorporate the adaptive behaviors appropriate to the caregiver's life span stage already being utilized.

The next treatment area would occur during role acquisition in the adaptation process. This would entail assisting the caregiver in learning to evaluate current roles and to set priorities on aspects of the roles which should be kept and those which may be relinquished in view of value and necessity. In this manner, self-actualization aspects may be preserved, thus potentially increasing the caregiver's satisfaction with adjustments made. Occupational therapists could also be aware of the behaviors or occupations that reinforce caregiver activity and utilize this in the adjustment process. In addition, the therapist may assist the caregiver in exploring new opportunities for mastery within the home setting as opportunities outside the home setting decrease.

Another treatment area to consider is that of role balance. To assist the caregiver in learning to integrate roles held with that of the caregiver role, the therapist may need to assist the caregiver in educating others in the demands of the caregiver role, thus hopefully gaining more assistance from family or friends. The caregiver may also need to learn how to delegate and which tasks may be delegated from not only the caregiver role but all roles held. Educating the caregiver in use of available community resources may also assist in decreasing the demands of the caregiver role. Furthermore, the therapist may assist the caregiver in learning to evaluate and modify time spent in roles to achieve better flow in moving from one task to another in a way that has meaning to the participant.

Occupational therapy intervention can occur during the transition to caregiver, in maintaining the caregiver role, and when changes in the care receiver's health require modification in the caregiver's occupations or role balance. The goals of occupational therapy, therefore, consist of assisting the caregiver to acquire appropriate adaptive behaviors to meet the demands of the caregiver role, to evaluate and intervene as needed in the adaptation process during role acquisition to meet both survival and personal needs, and to assist the caregiver in achieving successful role balance. The therapist should always be aware of the cultural environment in which caregiving occurs.

# CHAPTER 5

# DISCUSSION, PROFESSIONAL IMPLICATIONS, AND RECOMMENDATIONS

## Introduction

Organization of this chapter occurs by sections. The first section discusses support of the findings as reported in the literature as well as the findings discovered in this research. The next section describes the study in relation to practice implications for occupational therapy. Implications for further research are presented next. The last section summarizes the study's findings.

## Discussion

Previous studies, primarily conducted by gerontologists and psychologists, only focused on the burdens and ethical dilemmas faced by caregivers, the psychological well being of the caregiver, and the meaning of caregiving. The limited research conducted on the role of caregivers centered around the number of roles in which caregivers engaged and the effect on well-being, role engulfment and the resulting loss of self, and the relationship of female caregivers' family roles and stressors which affected feelings of adequacy.

While it is not possible to generalize the results of this research to all caregivers due to the small sample size, this study, however, looked at the caregiver role from a new perspective of adaptation and role acquisition. The study also looked at the caregiver role in relationship to other occupied roles and the effect on those roles.

This study demonstrated the successes and the difficulties that caregivers encountered in role acquisition and role balance. As expected, participants acquired new adaptive behaviors to be successful in the role of caregiver. The activities that caregivers in this study performed in relationship to the role was consistent with previous studies reported by Baum (1991). The important skills and aspects of being a successful caregiver reported by the participants supported earlier findings documented by Hasselkus (1991).

The study participants reported utilizing a variety of settings, such as hospital, outpatient, support groups and home to learn new adaptive behaviors. As expected by the researcher, learning new skills in the home setting was reported as having had the biggest impact on the study participants. The researcher would like to point out that skills may have been taught in all of the above settings.

However, the information reported above reflects the caregivers' perceived learning setting. The results may also be biased towards the home setting as participants were recruited through community services.

During the successful acquisition of the caregiver role, adaptation, on a survival level, occurred. Each caregiver actively acquired new occupations to meet needs presented in her environment. Adjustments, while not always satisfactory, were made in relationship with other roles and responsibilities. The adaptation process utilized by the caregivers was consistent with King's (1978) description found in occupational therapy literature.

Difficulties faced by caregivers in this study occurred in the higher level of adaptation, actualization of personal potential, and in role balance. Becoming caregivers had a significant impact in all roles in which participants engaged. All five of the participants relinquished opportunities of personal challenge and satisfaction that each had looked forward to in her later life stage. Adjustments to facilitate contribution to the actualization of personal potential was lacking. While adaptation at the survival level was anticipated in regard to the two new caregivers of less than one year, finding that the three caregivers who had been in the role for more than two years still remained at the survival level was not.

The second difficulty, role balance, regardless of the caregiver's length of experience in the role, was found to be poor. All participants reported that the caregiver role dominated and took away from all roles. Integration between roles was lacking. This was anticipated by the researcher as experience had demonstrated that caregivers in the community can become overwhelmed by the responsibilities of the role. Research by Skaff and Pearlin (1992) found that domination of a role led to role engulfment and role loss as experienced by this study's participants.

## Implications for the Practice of Occupational Therapy

The above discussion indicates that there is a role for occupational therapy in the training of caregivers for management of family members in the home setting. This study demonstrated the difficulties and the successes that caregivers have had in adapting in the areas of role acquisition and role balance. Occupational therapists, because of their training in adaptation and role balance, can offer a unique and useful service that is different from other disciplines which are currently working with this population.

As a profession, the challenge is then to advocate for services of occupational therapy to meet the treatment needs of the caregiver population. To achieve this, the members of the profession must educate other disciplines which work with caregivers regarding the unique abilities and skills that members of the profession can offer in this area. Expansion of the home health occupational therapist's role could assist in meeting the caregiver's needs in adaptation and role development in his or her own environment. Caregiver training could be incorporated within the patient treatment in the home setting.

## Implications for Further Research

Results of this study generated additional needs for research in the areas of caregiver activity and occupational therapy theory. The most obvious need is to study additional caregivers in the community setting to enhance this sample. This may allow generalizations to be made regarding caregivers' multiple roles and adaptations in the caregiver role. There is a need to further compare the societal expectations of the caregiver role to the individual's expectations. The results may benefit the establishment of health policy for this growing population. Effectiveness of caregiver training in a variety of settings may enhance provision of caregiver services. Further studies which document the results and cost effectiveness of occupational therapy in treating this population may enhance reimbursement for the service. It would also be beneficial to further look at successful caregivers in various stages, comparing new caregivers to those with more experience. In this manner, further information may be gathered regarding how to succeed in this demanding and difficult role.

Studies of this nature can further contribute to the knowledge base of occupational therapy in roles and adaptation. It is recommended that further studies of the adaptation process in role development be undertaken with caregivers of people with a variety of diagnoses. The adaptation process should be studied relative to both personal survival and personal actualization and how it may differ for each level. Studies should also be undertaken to determine if stages of adaptation other than those found in this study can be identified. And finally, the profession of occupational therapy should clarify the importance of adaptation relative to theory. Does adaptation occur as a result of good performance or does good performance result from good adaptation? Both of these concepts can be found in occupational therapy literature. It appears from this research that balanced role performance, the highest level of human occupation, may result from successful adaptation. Adaptation is the process by which humans interact and master their environment.

## Recommendations

There are several recommendations to improve upon the current study. As the sample population was small and one of convenience, results from this study cannot be generalized. Study of a much larger group of caregivers would be beneficial. The sample group should also be expanded to include caregivers of non family members and caregivers of both genders.

The questionnaire was designed based on the assumption by the researcher that becoming a caregiver required adaptation. This may have affected the results of the study. Improvements in the design of the questionnaire may elicit a truer picture of becoming a caregiver. As the interview process occurred in one session, answers given to questions asked may not be consistent over time. Therefore, it may have been beneficial to have spent more time interacting with the caregivers.

## Summary

This study involved five case studies of female caregivers in the community setting.  Subjects participated in in-depth interviews regarding caregiver activity, caregivers and their multiple roles, and role adaptation.

Common adaptive behaviors utilized and valued by the participants were identified. The most common adaptive behaviors listed for the caregiver role were self-care skills, nursing skills, and coping skills to deal with the emotional aspects. The adaptive behaviors described in the caregiver role were age appropriate.

Acquiring the role of caregiver required adaptation. The adaptation process utilized was described in terms of societal, and personal expectations, role adjustments or role loss, reasons for becoming a caregiver, and those factors which reinforced the role. Adaptation on a survival level occurred as caregivers were successful in the role. Acquired adaptive behaviors were incorporated. Reinforcers for the caregiver role existed. Adaptation on an actualization level, however, was insufficient. Caregivers reported giving up roles or occupations of roles they considered valuable to self. The caregivers studied also reported being dissatisfied with the adjustments made during the adaptation process.

Role balance, the integration of new roles with current roles, and sufficient time to perform tasks associated with multiple roles was poor in the sample population. The caregiver role competed with the participants' other roles for time and energy. The caregiver role was considered to dominate all roles. The mean percentage of daily time spent in the role of caregiver was 52.6 percent. All participants reported wanting to spend less time in the caregiver role and more time in roles that met personal needs.

Results from this study indicate that there is a role for occupational therapy in the training of caregivers for management of family members in the home setting. To facilitate the adaptation process in acquiring the caregiver role, goals of occupational therapy could center around three stages. The first stage may involve assisting the caregiver to acquire appropriate adaptive behaviors to meet the demands of the caregiver role. The second stage may involve evaluation and intervention in the adaptation process during role acquisition to assist the caregiver in meeting both survival and personal needs. The third stage may involve assisting the caregiver to achieve successful role balance. The therapist would take into account all cultural environmental factors in the caregiving situation.

As a profession, occupational therapy can make a contribution to this population by advocating for services to meet the needs of the caregiver. Education of other disciplines working with caregivers regarding adaptation and role balance would also benefit this population.

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# APPENDIX A

# INTERVIEW QUESTIONNAIRE

# INTERVIEW QUESTIONS

## DEMOGRAPHICS

age
sex
dx of patient
length of time as caregiver
relationship to pt.
others involved in the caregiving

setting/environments caregiving occurs

## ROLES

Overall, what are your current responsibilities?

List in order of importance the roles you value

List the roles in order of importance by necessity

Which roles do you devote most of your time to?

Estimate the amount of time you spend involved in each of these roles (hrs. per day/week/or month)

If you could change, how you spend your time in these roles, how much time would you like to spend in these roles?

CAREGIVER ROLE (role loss/aquisition)

Explain why you chose to become a caregiver

Why is being a caregiver important to you?

What are the important aspects of being a caregiver?

In general, as a caregiver, how is your time spent each day?

What are your daily tasks?

Is that typical?

What did you think this time in your life would be like?

How would you describe your life now?

Do you have a caregiver role model whom you can seek help from or that you look up to?

What do you see as the expectations you or others have of the caregiver role?

## ADAPTATION PROCESS

What steps have you taken to be a good caregiver?

What skills do you feel are important to have as a caregiver?

In what setting do you feel you learned how to become a caregiver? i.e. hospital, home, outpatient, support group

What factors or events make you feel good about being a caregiver?

How has becoming a caregiver affected your participation in other role areas of your life?

What adjustments have you made in relationship to being a caregiver and your other roles/responsibilities?

Are you satisfied with these adjustments? What changes would you make if you could?

Where do your see yourself in five years from now?

Karen Nelson, OTR
Nov. 1991

# APPENDIX B

# RECRUITMENT LETTERS

DEAR PROFESSIONAL,

I am looking for caregivers who may be interested in participating in a research project. The research is designed to study how family members or significant others adapt to the role of caregiver.

Criteria for participation in the research is as follows:

1. The caregiver must be between the ages of 25 and 65
2. The caregiver must have been engaged in this role for at least three months
3. Provide care for a family member or friend with a neurological disability.

If you know of a potential volunteer, please inform him or her the following:

1. Participants will be randomly selected from a group of qualified caregivers
2. Participation involves a four hour interview in the caregiver's own environment and at their convenience
3. The interview questions will center around the caregiver's role and responsibilities.
4. The caregiver's answers will be tape recorded
5. Data collected and analyzed will be confidential.

After having explained the above with the caregiver, please inform the caregiver that you will give their name and telephone number to the researcher. The researcher will then contact the caregiver for follow up and possible selection. If preferred, please feel free to provide my name and telephone number so that the caregiver may contact me at his or her convenience.

Thank your for your assistance in this matter.

Sincerely,

Karen Nelson, OTR
(408) 292-1641

DEAR CAREGIVER,

Volunteers willing to participate in a research project are now being sought. This research project is designed to look at how family members or significant others adapt to the role of caregiver.

The criteria for participation is as follows:

1. The caregiver must be between the ages of 25 through 65.
2. The caregiver must have been engaged in this role for at least three months
3. Provide care for a family member or friend with a neurological disability

Participants will be randomly selected from the group of qualified caregivers.

Caregivers selected to participate will be involved in a four hour interview process. During this time you will be asked questions regarding the caregiver role and responsibilities. The interview will take place in the caregiver's own environment at his or her convenience. The interview will be tape recorded.

Data collected and analyzed will be confidential.

If you are interested in volunteering to participate in this research, please contact:

KAREN NELSON, OTR
(408) 295-4285

Thank you for your time and assistance.

# APPENDIX C

## SUBJECT CONSENT FORMS

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

**College of Applied Sciences and Arts • *Department of Occupational Therapy***
One Washington Square • San José, California 95192-0059
Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078 • FAX: 408/924-3088

# INFORMED CONSENT

I have been asked to participate in a study of how caregivers of family members or friends learn this new role. The results of this study will should further our understanding of how family caregivers learn to take care of their loved one.

I understand that:

1. I will be asked to participate in a two to four hour interview in my home. The interview can take place all at once or in two parts, whichever is most convenient for me.
2. The possible risks of this study are that I may find it difficult to talk about some of my experiences as a caregiver if the questions remind me of emotional issues.
3. The possible benefit of this study is that this time may also provide me an opportunity to express my feelings. However, no promise is made that I will receive any benefits from this study.
4. The results of this study may be published, but any information from this study that may identify me will remain confidential and will be disclosed only with my permission.
5. Any questions about my participation will be answered by Karen Nelson, OTR at (408) 292-1641. Complaints about the procedures may be presented to Lela Llorens, Ph.D., OTR at (408) 924-3070. For questions or complaints about research subjects rights, or in the event of research related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies and Research) at (408) 924-2480.
6. My consent is given voluntarily without being coerced. I may refuse to participate, or withdraw at any time by notifying the researcher. Refusal to participate in the study or withdrawal from the study will not affect your current or any future relationship with SJSU.
7. I have received a copy of this consent form for my file.

MY SIGNATURE BELOW INDICATES THAT I HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT I HAVE DISCUSSED THIS STUDY WITH THE RESEARCHER, AND THAT I HAVE VOLUNTARILY AGREED TO PARTICIPATE.

Signature of study participant Date

Signature of investigator Date

Veterans Administration Hospital

## INFORMED CONSENT

### A Descriptive Study of Adaptation to the Role of Caregiver

I have been asked to participate in a study of how caregivers of family members or friends learn this new role. The results of this study will should further our understanding of how family caregivers learn to take care of their loved one.

I understand that:

1. I will be asked to participate in a two to four hour interview in my home. The interview can take place all at once or in two parts, whichever is most convenient for me.
2. I understand that there is no anticipated risk to me. However, I may find it difficult to talk about some of my experiences as a caregiver if the questions remind me of emotional issues.
3. The possible benefit of this study is that this time may also provide me an opportunity to express my feelings.

WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY

4. The results of this study may be published in scientific journals, but any information from this study that may identify me will remain confidential and will be disclosed only with my permission.
5. I understand that no payment will be provided for this project. There will be no additional cost to me for participation in this study.
6. Any questions, about my participation will be answered by Karen Nelson, OTR at (408) 292-1641. Complaints about any procedures may be addressed to Lela Llorens, PHD OTR at (408) 924-3070 or Dr. Elaine Date at (415) 493-5000, ext. 4039.

Signature of study participant Date

Signature of investigator Date

A Descriptive Study of Adaptation to the Role of Caregiver
Informed Consent Cont.

7. My consent is given voluntarily without being coerced. I may refuse to participate, or withdraw at any time by notifying the researcher. Refusal to participate in the study or withdrawal from the study will not affect my current or any future relationship with SJSU, or my relation and medical treatment with the VA Hospital Palo Alto, or Stanford Hospital.
8. All forms of medical diagnosis and treatment--whether routine or experimental may involve some risk of injury. In spite of all precautions,, you might develop medical complications from participating in this study. If such complications arise, the researcher will assist you in obtaining appropriate medical treatment but this study does not provide financial assistance for additional medical or other costs. [Additionally, Stanford is not responsible for research and medical care by other institutions or personnel participating in this study] I do not waive any liability rights for personal injury by signing this form. For further information, please call (415) 723-5244 or write the Administrative Panel on Human Subjects in Medical Research at Medical School Office Building, Room c-051, Stanford, California, 94305. In addition, if you are not satisfied with the manner in which this study is being conducted or if you have any questions concerning your rights as a study participant, please contact the Human Subjects Office at the same address and telephone number.
9. In the unlikely event that you are injured as a result of participation in this study, Palo Alto Veterans Affairs Medical Center will furnish humanitarian emergency medical care(for non-veteran participants) or medical care (for veteran participants) as provided by federal statute. Compensation for such injury may be available to you under the provision of the Federal Tort Claims Act and/or 38 U.S.C. section 1151(formally section 351) (for veteran participants only) For further information, contact the V.A. District Counsel at (415) 744-7676

MY SIGNATURE BELOW INDICATES THAT I HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT I HAVE DISCUSSED THIS STUDY WITH THE RESEARCHER, AND THAT I HAVE VOLUNTARILY AGREED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO ME.

Signature of study participant Date

Signature of investigator Date

A Descriptive Study of Adaptation to the Role of Caregiver

## EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

Persons who participate in a medical experiment are entitled to certain rights. These rights include but are not limited to subjects right to:

- be informed of the nature and purpose of the experiment;
- be given an explanation of the procedures to be followed in the medical experiment, and any drug of device to be utilized;
- be given a description of any attendant discomforts and risks reasonably to be expected;
- be given an explanation of any benefits to the subject reasonably to be expected if applicable;
- be given a disclosure of any appropriate alternatives, drugs or devices that might be advantageous to the subject, their relative risks and benefits;
- be informed of the avenues of medical treatment, if any available to the subject after the experiment if complications should arise;
- be given an opportunity to ask questions concerning the experiment or the procedures involved;
- be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice;
- be given a copy of the signed and dated consent form;
- and be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

Signature of study participant Date

Signature of investigator Date