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An exploration of the needs of family caregivers of older persons after a cerebral vascular accident

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AN EXPLORATION OF THE NEEDS OF FAMILY CAREGIVERS OF OLDER PERSONS AFTER A CEREBRAL VASCULAR ACCIDENT

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

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

by
Sonja Marie Johnson-Egertson and Jean S. Koketsu
May, 1994

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ABSTRACT

AN EXPLORATION OF THE NEEDS OF FAMILY CAREGIVERS OF OLDER PERSONS AFTER A CEREBRAL VASCULAR ACCIDENT

by Sonja Marie Johnson-Egertson and Jean S. Koketsu

In this qualitative research study, nine family caregivers of older persons who have had a stroke were interviewed regarding their needs and experiences as caregivers. Indepth interviews of the subjects yielded 22.5 hours of interview data.

In this study, eight common themes were identified regarding caregiver needs. The themes of needs were: loss of time to perform activities of daily living, value of social support and interpersonal relationships, lack of wheelchair accessibility in the home and community, valuable aspects of interactions with health care professionals, challenges of role changes within relationships, importance of living at home: use of resources, stages/phases in caregiving, and adapting to new life changes.

The findings suggest that occupational therapists can play an important role in helping caregivers by educating them, by effectively communicating with them, and by including the caregiver in treatment planning.

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Last, but certainly not least, we want to thank our wonderful husbands, who supported and encouraged us during the whole research process. We would also like to thank God for his strength, wisdom and guidance. Without His love, we couldn't have done it!!

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CHAPTER 1

INTRODUCTION

Purpose

The purpose of this study was to explore the needs of family caregivers of older people who have previously experienced a cerebral vascular accident. This study attempts to identify ways that occupational therapists can better meet the needs of family caregivers of older persons who have had a stroke.

Statement of the Problem

Statistics have shown that elders account for an increasing percentage of the U.S. total population. In 1980 11% of the U.S. population was 65 years or older. By 1990 (U.S. Bureau of the Census, 1990), the population of individuals 65 years and older made up 12.6% of the population. It is predicted by the year 2000 that those over 65 years old will reach almost 15% (Huston, 1990). In addition to the rapid growth in the number of elders in the U.S. population, life expectancy has also increased dramatically. At the beginning of the 20th century, life expectancy was 50 years. Currently, life expectancy is about 75 years of age and many Americans can expect to live beyond 85 years.

Research has shown that up to one out of seven older persons who live in the community require some type of supportive services to maintain independent living (Lewis, 1979). Over five million persons aged 65 years or older were estimated to need assistance to remain at home in 1985. This number is predicted to increase to 7.2 million in the year 2000 and this figure is expected to double by the year 2050 (Jacob, 1991).

Today, 80% of primary caregivers are family members (Huston, 1990) who usually have not had the benefit of formal training (Jacob, 1991). Caregivers are predominantly women, one-third are over 65 years of age, most family incomes are below the poverty level and one in three caregivers are in poor health (U.S. Bipartisan Commission on Comprehensive Health Care, 1990).

The ever increasing health care costs will undoubtedly result in the numbers of elders requiring care at home to rise. Demands on family caregivers will also increase as older patients are released sooner from hospitals while still requiring assistance in daily activities.

The needs of family caregivers can be numerous. Literature on frail elders identifies a multitude of daily stresses on family caregivers including physical strain of assisting the older person in activities of daily living, isolation and loneliness, loss of privacy and personal control of time, lack of sleep, emotional reaction to the physical decline and anticipated death of a loved one, expense and family distress (Jacob, 1991).

Although caregivers have been the subject of numerous studies (Malonebeach & Zarit, 1991), a paucity of research on the subject exists in the occupational therapy literature. Most of the research done on this subject appears to have been done in gerontology and in nursing. In reviewing the occupational therapy literature from 1947 to the present, only a few articles directly addressed the subject of caregivers. Furthermore, the American Occupational Therapy Association's (AOTA) treatment guidelines for home health care do not include education and support for caregivers (Kunstaetter, 1988). Given the documented importance of caregivers and family in the outcomes of home care treatment (Hill & Matthews, 1985; Kunstaetter, 1988; Levine, 1978; Marjoribanks, 1982; Meeske & Jacoby, 1952), this exclusion needs to be addressed.

Research Objectives

The objectives of this study were to:

1. Explore the needs of family caregivers caring for older family members who have experienced a cerebral vascular accident.
2. Discover the role that occupational therapists can play in assisting family caregivers.

Research Questions

The questions to be answered in this study were the following:

1. What are the needs of family caregivers caring for older persons who have experienced a cerebral vascular accident?
2. What role can occupational therapists play in assisting family caregivers of older persons who have experienced a cerebral vascular accident?

Definitions

The definitions used in this study were:

Activities of Daily Living (ADL): For the purposes of this study ADL include but are not limited to whatever the caregiver identified as "the typical life tasks required for self-care and self-maintenance, such as grooming, bathing, eating, cleaning the house and doing laundry" (Christiansen & Baum, 1991, p. 847).

Adaptation: "the satisfactory adjustment of individuals within their environment over time. Successful adaptation equates with quality of life" (Christiansen & Baum, 1991, p. 847).

Caregiver training: Includes any training that the family caregiver perceived as receiving from health care providers (such as occupational, physical and speech and language therapists) in assisting the care receiver.

Cerebral Vascular Accident (CVA): A medical diagnosis or disease process characterized by an interruption of the blood supply to the brain and leads to secondary brain abnormality. It is abbreviated as "CVA" and also referred to as "stroke." For the purposes of this study the caregiver identified CVA as a diagnosis made by a physician regardless of the resultant amount of disability.

Family caregiver: In this study a family caregiver is a person who provides services, assistance or care to a relative (either by legal or familial relation) in the home which enables the person to remain in the community and avoid institutionalization. The caregiver has had no professional training.

Life Tasks: Occupation or active participation in self-care, work, leisure, and play.

Needs: "the perception of a discrepancy between the resources available and those required" (Hinds, 1985, p. 576). In this study "needs" includes any areas in which the caregiver feels that they are self-described as lacking, especially in relation to their role as caregiver.

Occupational Therapists (O.T.): People who have been educated and have graduated from an accredited program in occupational therapy or have certificates in occupational therapy. In this study "occupational therapist" describes an individual that the caregiver identified as the person providing occupational therapy services during a hospital stay, during rehabilitation or while receiving home health therapy.

Older Persons: For the purposes of this study, describes people who are 60 years of age or older.

Play/Leisure: "choosing, performing, and engaging in activities for amusement, relaxation, enjoyment, and/or self-expression" (Christiansen & Baum, 1991, p. 856). Includes any activity that the caregiver considered as "play/leisure."

Purposeful Activity: "goal-directed behaviors or tasks that comprise occupations. An activity is purposeful if the individual is an active, voluntary participant and if the activity is directed toward a goal that the individual considers meaningful" (American Occupational Therapy Association, 1993, p. 1081).

Rehabilitative Health Care Professional: Health care professional who evaluates, treats, and educates disabled individuals in attaining maximal functioning. In this study "rehabilitative health care professional" included any healthcare provider that the caregiver considered to provide rehabilitative services to the care receiver. The professionals include but are not limited to medical doctors, nurses, occupational therapists, physical therapists, speech and language pathologists, recreational therapists, psychologists, dieticians, social workers and neuropsychologists.

Roles: "a set of behaviors that have some socially agreed upon functions and for which there is an accepted code of norms" (Christiansen & Baum, 1991, p. 857). For the purposes of this study "roles" is self-defined by the caregiver and includes but is not limited to the role of wife, husband, caregiver, father, mother, grandmother, worker and daughter-in-law.

Social Environment: "those social systems or networks within which a given person operates; the collective human relationships of individuals, whether familial, community, or organizational in nature, constitute the social environment of that individual" (Christiansen & Baum, 1991, p. 858).

Social Support: "the social relatedness and interactions with others that are perceived by the individual as providing emotional, physical and social resources" (Christiansen & Baum, 1991, p. 858). "Social support" is self-identified by the caregivers in this study and describes a situation where the caregiver feels encouraged in their role as caregiver.

Transient Ischemic Attack (TIA): A temporary interference with the blood supply to the brain. The symptoms of neurological deficit may last for only a few moments or several hours. After the attack, no residual brain damage remains (Thomas, 1989). For the purposes of this study, the caregivers self-identified TIA as a medical diagnosis that the care receiver received from his/her doctor.

Work: "skill and performance in purposeful and productive activities in the home, in employment, in school, and in the community" (Christiansen & Baum, 1991, p. 860). In this study, "work" was self-defined by the caregivers and included any area of their life that the caregiver did not consider to be self-care or leisure/play.

Assumptions

The assumptions of this study were as follows:

1. It is assumed that subjects in this study gave honest responses when the data were collected;
2. audiotapes were accurately transcribed;
3. interviews were reliably conducted.

Limitations

The limitations of this study were identified as:

1. The research findings cannot be generalized to other populations that are similar to the subjects of this study. The aim of this study was to explore the needs of a small group of family caregivers of individuals who have had a CVA and to describe their experiences. Further research needs to be conducted to further support or refute the findings.

2. The results of this study may have been affected by researcher bias during interpretation of the data. The researchers made every effort to interpret the data accurately by cross-checking each other's interpretations to ensure objectivity.
3. The researchers relied on the subjects' verbal statements and the subjects' perceptions of reality.

Significance of the Study

The purpose of occupational therapy is to help "people cope with the challenges of everyday living imposed by congenital anomalies, physical and emotional illness, accidents, the aging process or environmental restrictions" (Christiansen, 1991, p. 2). Therefore, the tremendous increase in the number of elders and the aging of the population are not concerns in themselves for occupational therapists. Occupational therapists are concerned that research has shown that advanced age positively correlates with chronic illness (Brummel-Smith, 1990).

For example, most dementias occur in the general population in persons aged 65 and older (Baum, 1991). By the year 2000, it is estimated that persons over 65 will account for 50% of all health care costs (Davis, 1988). Health care statistics also reveal that most older people receive medical care mostly for acute exacerbations of a chronic illness (Davis, 1988). The care received between those acute exacerbations is usually fragmented and uncoordinated. Elders are also the primary receivers of long term care because of their high risk of chronic conditions which may result in difficulties in independent living (Somers, 1991). One of the most commonly experienced chronic physical conditions in the older population is hemiplegia (Levy, 1990; U.S. Senate Special Committee on Aging, 1986). Cerebral vascular accidents, in particular, are the most common of neurologic disorders (Pedretti, 1990). Occupational therapists frequently treat patients who have suffered from the effects of this relatively common neurological disorder.

Since the majority of primary caregivers of older people are family members (Huston, 1990) who have not had any formal training in caregiving (Jacob, 1991), occupational therapists can provide assistance and support to instruct caregivers in how best to care for frail older family members (Hasselkus & Brown, 1983). Since very little research has been conducted in occupational therapy on the topic of family caregivers, this study will add to this developing body of knowledge.

CHAPTER 2

LITERATURE REVIEW

In this chapter a literature review will be conducted which will include a theoretical framework, a description of older people, caregivers, home health care, CVA, and CVA and caregiving.

Theoretical Framework

The field of occupational therapy stresses a commitment to holistic care, and its professionals must consider their commitment to the well-being of their patients with this in mind (Kunstaetter, 1988). According to Taber's Medical Dictionary (Thomas, 1989), holistic medicine is comprehensive, and it includes the needs of the patient in physical, emotional, social, spiritual and economical areas. All of these areas must be considered when caring for a patient to ensure that patients receive optimal care. Occupational therapy is an ideal profession to meet the needs of older persons and their caregivers because of its holistic basis.

Occupational therapy personnel "possess unique attitudes and skills for addressing dysfunction in daily living at the level of adaptation to environmental challenges in chosen activities" (Davis, 1988, p. 743). The promotion of environments that support independent living skills is important in minimizing the effects of physical disabilities (McClain, Beringer, Kuhnert, Priest, Wilkes, Wilkinson & Wyrick, 1993).

Occupational performance is the frame of reference that provides the best context for this study. Occupational performance is based on an important concept in occupational therapy as it is defined as the accomplishment of tasks related to the performance skills of self-care, work/education, play/leisure and rest/relaxation (Llorens, 1991). The environment demands successful performance in these areas which depends on developmental stage and life roles (Llorens, 1991). Occupational performance is crucial to the assumption of life roles which change during the life span from infancy to old-old age (Llorens, 1991).

Decline in some areas of functioning may occur due to advanced age. However, individuals adapt as they age (Llorens, 1991). The importance of adaptation in occupational therapy is evident in the American Occupational Therapy Association's (AOTA) definition of occupational therapy. The AOTA defined occupational therapy as, "therapeutic use of self-care, work, and play activities to increase independent function, 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, p. 852). Because the elders may experience an increasing number of physical changes as they age, they must be especially ready to make adaptations, adaptations that occupational therapists can skillfully help to facilitate.

People who have experienced a stroke, as well as those who are caring for them in the home may encounter new challenges and demands of living. These can require an adjustment or change of behavior. For adaptation to occur, one must be successful in coping with situational demands (Christiansen, 1991).

The Older Population

As stated earlier, the population of seniors in the United States increased rapidly between 1980 and 1990 (U.S. Bureau of the Census, 1990). From 1980 to 1990, the population of those over 75 years of age increased approximately 31% (U.S. Bureau of the Census, 1990). The growth in the numbers of older persons in the U.S. will continue as baby boomers will become 65 years of age between the years 2010 and 2030.

Research has shown that 95% of this country's older people live in the community and that one in seven of these require some type of supportive service to maintain independence (Lewis, 1979). The majority of frail elders in the community are cared for by family caregivers (Shanas, 1979). Statistics indicate that three-quarters of disabled older persons who live in the community rely entirely on family and friends and most of the remaining one-quarter rely on a combination of family members and hired assistants (Soldo, 1983).

Research has shown that many occupational therapists and assistants work with older persons. In a survey conducted by the American Occupational Therapy Association, it was found that half of the 40,000 registered occupational therapists and certified occupational therapy assistants (COTAs) work with the older adult populations (Davis, 1988). Because many of these older persons are cared for by family members, it is important for occupational therapists and occupational therapy assistants to be aware of caregivers' needs.

The Caregivers

An abundance of research on family caregivers exists in the nursing and gerontology literature. Family caregivers supply a wide range of services including medical care, household assistance and psychological support for the care receiver. Family caregivers have helped to fill the need created by budget cuts by offering these services in the home as an alternative to institutional care (White-Mean & Thornton, 1990). Research has shown that the majority of caregivers are women, one-third are over 65 years of age, most have incomes below the poverty level and one in three are in poor health (U.S. Bipartisan

Commission on Comprehensive Health Care, 1990). It was reported in one study that 75% of caregivers live with the care recipient, adult daughters comprise 28.9% of the group and wives, 22.7% (Stone, Cafferata, & Sangl, 1987). In another study conducted by Horowitz (1982), it was found that women were more likely to be cared for by their children and other relatives while men needing assistance were more commonly cared for by their wives.

Becoming a family caregiver or receiver changes the family structure, patterns, and roles (Jacob, 1991). The most commonly reported problems from caregivers result from the alteration in lifestyle (Evans, Griffith, Kaselkorn, Hendricks, Baldwin & Bishop, 1992). This change can produce feelings of guilt, anger and resentment and often results in numerous daily stresses for the family caregiver. These stresses may include the physical strain of assisting the patient in activities of daily living, loss of sleep, loss of privacy and personal control of time, isolation and loneliness, increased expenses, family distress and an emotional reaction to the physical decline and possible anticipated death of a loved one (Jacob, 1991). In another study, Corcoran and Gitlin (1992) found through an extensive literature search that the consequences of caregiving are different depending on gender, familial relationships and culture.

These stresses are compounded for the older adult caregiver who may be facing their own physical disabilities and financial burdens. In a study by Horowitz (1982), it was found that when the caregiver was the spouse of the care receiver, the caregiver reported that their own health was either fair or poor in 74% of the cases. This was also true for 40% of adult children caregivers and 43% of other relatives who provided the caregiving. Studies have shown that functional disability of care receivers is not what determines the well-being of a caregiver.

Diminished social functioning and inappropriate behavior of the care receiver and the relationship of the caregiver and the care receiver may be more important determinants of caregiver well-being (Silliman, 1989; Silliman, Fletcher, Earp, & Wagner, 1984).

Often, support for family caregivers is minimal or nonexistent (Ebersule & Hess, 1985). According to a study conducted by White-Mean and Thornton (1990), if several caregivers are available for one care receiver, thus making a substitute caregiver readily available, the limitations on the caregiver's leisure time decreases. They suggest that this type of situation may limit the amount of stress a caregiver perceives. Past studies have also shown that the precipitator of placement of an elder care receiver into a facility is more often caused by exhaustion of family resources and excessive burden of family members than a change in the older person's health status (Brody, 1966; Isaacs, 1971; Silverstone, 1978; Teresi, Bennett & Wilder, 1978).

There are a limited number of studies conducted on the needs of caregivers (Hinds, 1985; McLean, Roper-Hall, Mayer & Main, 1991; Wood, 1991). One study on the needs of cancer patient caregivers indicates family caregiver stress levels are high, yet ways of alleviating stress have not been studied (Hinds, 1985). In another study Wood (1991) emphasized the complexity of the caregiver role suggesting that further research is, therefore, needed to ascertain the needs and expectations associated with that role.

Studies have also been conducted on the ways in which professionals may intervene to assist caregivers by educating them and offering support group programs (Green & Monahan, 1989). Green and Monahan (1989) found that eight-week professionally guided interventions were successful in reducing anxiety, depression and a sense of burden in the short term and continued on later but with weaker effects. However, research by Evans and associates (1992) and Oktay and Volland (1990) has suggested that programs should be further evaluated because they are not reducing perceived burdens or providing practical assistance.

Jacob (1991), in her paper, has suggested that the primary needs of family caregivers are in the forms of education and support. Family caregivers need information on ways to promote optimal level of functioning, and they need guidance in preventive techniques. They require information on medication and possible side effects, how to obtain equipment and assistive devices, resources in the community and on how to recruit extended family, friends and neighbors for support. In addition, a pilot study found that caregivers listed one of their top 20 education needs as interactions with medical and other service providers (Matthis, 1991).

Family caregivers need support because their role is both physically and emotionally challenging. The stresses involved in caregiving can lead to burnout and even elder abuse. Offering support about care decisions, reassurance about feelings, and allowing the caregiver to ventilate feelings are all beneficial ways of supporting the caregiver (Jacob, 1991).

Although an abundance of research exists on the topic of family caregivers in the gerontology and nursing literature, a paucity of research exists on the topic in occupational therapy. Hasselkus (1988, 1989, 1991) has provided rich information from her ethnographic study of caregivers. The researcher analyzed the data on three levels: (a) the meaning of daily activity, (b) goals of caregiving activity, and (c) the ethical dilemmas in family caregiving. The researcher conducted 60 ethnographic interviews with 15 family caregivers in four one-hour sessions to yield the data.

Hasselkus (1988) found five themes of meaning in caregiving which include (a) sense of self, (b) sense of managing, (c) sense of future, (d) sense of fear of risk, and (e) a sense of change in role and responsibility. The broad goals of caregiving were found to be (a) achieving a sense of getting things done, (b) achieving a sense of health and well-being for the care receiver, and (c) achieving a sense of health and well-being for the caregiver (Hasselkus, 1989).

In addition to the themes of meaning in caregiving five themes of ethical dilemmas were generated from the data (Hasselkus, 1991). These themes included (a) fear of violating an ethical principle, (b) a sense of current violation of an ethical principle, (c) negotiation within a principle, (d) negotiation between principles and (e) one principle overruling another. The ethical principle that was most important not to violate was the principle of providing care to the care receiver. The sense of current violation of an ethical principle was primarily the violation of the principle of justice while the negotiation within a principle regarded the principle of beneficence toward the care receiver. The negotiation between ethical principles, occurred primarily between the principles of beneficence and caring for the older person and autonomy of the caregiver. The theme of one principle overruling another principle primarily saw the principle of beneficence overruling the principle of autonomy.

Home Health Care

Because this research addresses the needs of people who are living in their homes, it is important to look at the literature on home health care providers and their involvement with family caregivers. The importance of caregivers and family in the outcome of home care treatment is stressed in occupational therapy literature (Hill & Matthews, 1985; Humphry, Gonzalez & Taylor, 1993; Kunstaetter, 1988; Levine, 1978; Marjoribanks, 1982) but not necessarily documented (Kunstaetter, 1988). Kunstaetter (1988) conducted a study in which she reviewed home care records and interviewed those therapists who provided the care. Kunstaetter (1988) wanted to determine the differences between the services occupational therapists were documenting as compared to the services they perceived as actually providing when talking to them informally. According to the study, home health care occupational therapists reported that they addressed the following areas in their treatment: (a) sensory-motor, (b) independence in daily living skills, (c) prevention, (d) therapeutic adaptation, (e) caregiver education and (f) cognitive skills. When reviewing occupational therapists' records, patient and family support along with leisure and recreational activities, and activities that encourage positive and independent attitudes were not documented. The finding that time is spent on caregiver and family education in this study is consistent with Loisch's (1985) findings. Furthermore, the American Occupational Therapy Association (1992) includes caregivers and family education in its standards of practice.

Cerebral Vascular Accidents

A cerebral vascular accident (CVA) is a neurological disease that is caused by a lesion in the brain. CVAs account for at least half of the patients hospitalized for a neurological disease, and it is estimated that 400,000 to 500,000 new strokes occur every year in the United States (Pedretti, 1990).

A CVA results in upper motor neuron paralysis which involves musculature on one side of the body, usually of the trunk and limbs, and sometimes the face and mouth (Pedretti, 1990). Spasticity or flaccidity are usually characteristic of the paralysis. Also disturbed are postural reflex mechanisms on the hemiplegic side and selective discriminative and isolated movement patterns (Pedretti, 1990).

The rehabilitation process often emphasizes treating the motor dysfunctions. However, sensory, psychosocial, perceptual and cognitive dysfunctions are often present and should not be overlooked. The perceptual processes that may be effected are numerous including the ability to recognize, localize, and make discriminations about touch stimuli; the knowledge of body construction and spatial relationships; and the ability to plan motor acts (Pedretti, 1990). Cognitive abilities such as memory, judgement, and abstract thinking may be impaired because of the integrative processes of the brain (Pedretti, 1990). The loss or impairment of any of these abilities can affect one's ability to function in his activities of daily living skills.

CVA and Caregiving

Though no studies could be found that indicate research by occupational therapists about family caregivers and older persons who have experienced a stroke, the literature indicates that research on this topic has been conducted in other disciplines. One group of researchers (Korner-Bitensky, Mayo, Cabot, Becker & Coppersmith, 1989) reports that family reactions to stroke deficits are most severe 1 to 4 weeks after diagnosis. Evans, Bishop and Haselkorn (1991) investigated factors that predict optimal post-stroke home care. Both first occurrence stroke patients and their primary support persons were evaluated. Their results indicate that families who have satisfactory home care situations at one year post-stroke include a caregiver who: (a) is less likely to be depressed initially, (b) has more knowledge about stroke by the time the patient is discharged from the hospital, (c) is married to the patient, and (d) reports healthy family function. A healthy family function refers to having a suitable environment, financial resources, and not being reliant on social agencies. According to this study, it may be assumed that informed families may be better able to adhere to rehabilitation principles or are better able to cope with the rehabilitation process itself than those who are less knowledgeable about stroke and its effects on someone's abilities. This supports the opinion that education regarding a disability is an effective method for improving home care situations both for patients and their support systems. According to this study, minimizing family dysfunction, reducing caregiver depression and increasing the family's knowledge about stroke care could provide for optimal treatment and would have a positive collective effect on rehabilitation outcomes (Evans et al., 1991).

McLean and colleagues (1991) performed a pilot study on the service needs of stroke survivors and their caregivers. They investigated 20 stroke survivors who required regular assistance with personal activities and 20 of their main family caregivers. The study found that the perceived needs of these people were in the following areas: (a) physical care, (b) affective needs (emotional and communication), (c) physical health, (d) respite needs, (e) health education, and (f) hospital aftercare (McLean et al., 1991). They found that it is important that family caregivers receive preparation to better equip them both mentally and physically in order for them to provide the best care for the stroke survivor and to meet their own needs.

Family caregiver needs are vital to the well-being of the care receiver. Health care professionals must evaluate the strengths and weaknesses of both the care receiver and the family caregivers when the initial assessment is conducted. In this way, professionals can better guide the caregiver in their intervention in the rehabilitation process. The caregiver must be included as part of the rehabilitation team in order to enable him or her to better support the patient and work toward mutual goals (Evans et al., 1992; Jacob, 1991).

Summary

In summary, the rising number of older persons requiring caregiving at home is notable. Family caregivers undergo varying degrees of alterations in lifestyle as they take on the role of caregiver. Family caregiver needs have been briefly explored in the literature, and a lack of support for family caregivers has been identified (Ebersule & Hess, 1985).

Occupational therapy personnel possess the attitudes and skills necessary to address caregiver needs (Davis, 1988). Because this literature review identifies a paucity of research on family caregiver needs, especially in the discipline of occupational therapy, this topic needs to be explored further.

CHAPTER 3

DESIGN AND METHODOLOGY

Purpose

The purpose of this study was to explore the needs of family caregivers of older people who have previously experienced a cerebral vascular accident. This study attempts to identify ways that occupational therapists can better meet the needs of family caregivers of older persons who have had a stroke.

Questions

The questions to be answered in this study were:

1. What are the needs of family caregivers for older persons who have experienced a cerebral vascular accident?
2. What role can occupational therapists play in assisting family caregivers of older persons who have experienced a cerebral vascular accident?

Sample

The research sample consisted of seven women and two men who were family caregivers of older persons (60 years of age or older) who had previously experienced a cerebral vascular accident. The caregivers lived with the care receivers and provided services on a daily basis in the home. The caregiving was provided to enable the person to remain in the community and avoid institutionalization.

Letters were sent and phone calls were made to numerous Santa Clara County senior day centers and caregiver support groups that were listed in the Nineteen-Ninety-Three Santa Clara County Senior Handbook (1992) to obtain subjects. A letter (see Appendix A) describing this study was sent to the directors of the centers as well as a text to be read to potential subjects (see Appendix B). The directors approached caregivers and asked them if they were willing to be interviewed. The caregivers wrote their names and phone numbers on the same form as the "Text to be read to potential subjects" if they agreed to be called for an interview. The researchers then called potential subjects and arranged the interviews.

Four of the subjects were obtained through a community college day treatment program for stroke survivors and families. Three of the subjects were obtained through a senior day center and two subjects were chosen through personal contacts of the researchers.

Selection of subjects were based on whether they met the following criteria:

1. A subject is a relative whether of blood relation or legal formality (marriage, adoption, etc.) to the care receiver.
2. The person being cared for has as their primary diagnosis a cerebral vascular accident and is 60 years of age or older.
3. The subject lives in the San Francisco Bay Area of California.
4. The older person requires daily care from the family caregiver.
5. The caregiver has been caregiving for the person who has had the stroke for at least 2 months and lives with them.
6. The caregiver is 21 years of age or older.

Design

The design used was qualitative research employing ethnographic methodology. The aim of this study was to provide in-depth exploration of a few family caregivers to identify their needs.

Procedure and Instrument

Each participant was asked to sign a consent form (Appendix C) to participate in the study. The data were collected by the two authors through in-depth interviews at the homes of the nine participants. One researcher interviewed four of the subjects, and the other interviewed five. The subjects were assigned to the researchers based on proximity of the subjects' homes to the researchers' homes. Demographic information was obtained either orally or in writing at the beginning of the interviews (Appendix D).

An interview guideline of open-ended general questions designed by the researchers (Appendix E) was used to obtain information. The interview guideline was formulated by the researchers after informal discussions with caregivers and with occupational therapists who work with family caregivers. The personal caregiving experiences of one of the researchers also served to assist in the formulation of interview questions. The interview guideline consisted of questions in five areas including life tasks, perceptions of self as caregiver, perceptions of relationship, caregiver needs and rehabilitative therapy and training. The five areas were determined from discussions with other occupational therapists as well as those between the two researchers. An informal pilot test was conducted with a family caregiver of a person who experienced a CVA as well as with an occupational therapist.

The interviews took place between April 9, 1993 and May 29, 1993. There were a total of 14 interview sessions. The average length of total interview time for each participant was one and a half hours, with the longest interview lasting 3.5 hours and the shortest lasting one hour. The total number of hours that the subjects were interviewed was 22.5 hours. All interviews were tape-recorded and later transcribed by a transcriptionist. After the interviews were transcribed, the researchers listened to the audio tapes while reading the transcripts to ensure accuracy of transcription.

Procedure for Data Analysis

Both researchers read all of the transcriptions and listened to all of the audio tapes at least two times. The researchers introduced and described the caregivers in the following sections that they personally interviewed. The information was then reviewed by the other researcher where a consensus was reached as to information to be presented. To synthesize the data which is organized using the interview format, the researchers were each designated different sections to review. The researchers later met several times and communicated by telephone on numerous occasions to discuss and comment on each other's analysis and to come to a consensus regarding the data.

In developing the common themes which will be described in Chapter 4, comments made by the participants that pertained to the research questions were written down by the researchers separately onto Post-It notes. The two researchers met on two separate occasions where the comments were collected and organized according to common themes that emerged. An affinity diagram (or "story board") was used where the broad themes that emerged were further organized into broader themes. A consensus was reached by the researchers when determining the themes.

The researchers met with a group of caregivers of persons who had experienced a CVA (the group included two from the sample) who validated the research findings stating they were able to relate to the situations being presented as well as the results. The social worker who leads the caregiver support group of persons who have had a CVA was also consulted regarding the data. She, too, concurred with the data and assisted in validating our findings. Direct quotes from the participants have been included in this study to support evidence of the themes that were identified throughout the interviews.

CHAPTER 4

DATA AND RESULTS

The data were collected by the two authors through in-depth interviews at the homes of the nine participants. Interviews took place between April 9 and May 29, 1993. There were a total of 14 interview sessions which ranged from one to 3.5 hours. The average length of total interview time for each participant was one and a half hours, with the longest total interview time lasting four hours and the shortest total interview time lasting one hour. Total interview time was 22.5 hours.

In this chapter, each of the participants will be described. The data which is organized using the interview format will also be presented. The common themes, which resulted from analysis of the data and will be used to answer the research questions, will also be presented in this chapter.

Description of Participants

The nine participants who participated in this study were family caregivers of persons 60 years of age or older who had previously experienced a cerebral vascular accident. All participants were Caucasian. Seven of the participants were female and two were male. All of the participants reported that they lived in the same home as the care receivers. Six of the participants were the care receivers' wives; two were their husbands; and one was a daughter-in-law. The participants ranged in age from 50 years to 85 years. The care receivers ranged in age from 64 years to 89 years. The minimum length of time since the occurrence of the stroke was 4-1/2 months; the maximum was 8 years. Eight of the care receivers were married. One was widowed.

All nine of the participants described various experiences of being a caregiver for a family member who had a stroke. The participants will be described below using pseudonyms to protect the privacy of the subjects. Some of the caregivers chose to expand and elaborate about their lives more than others. All of the care receivers had received occupational therapy at some point during the rehabilitative process and were familiar with this service.

Participant One

Participant one is Steve who is 66 years old and he reported himself to be in good general health. His wife sustained her stroke four and a half months prior to the interview when she was 79 years of age. This couple lives together in a split level home. Steve had a ramp built along the side of the house so that the entrance into the living room would be wheelchair accessible. The care receiver's bed is now located in this room so that she does not have to climb any stairs. The couple have been married 34 years and Steve recently retired. They have no children and have spent much of their married life traveling. Steve described their recent lifestyle prior to the stroke as "beginning to slow down quite a bit." He currently has an attendant to help care for his wife for 20 hours a day. This allows him to have time to run errands, prepare meals, and take care of financial matters. The attendant is mainly responsible for self-care tasks including toileting for the care receiver. The attendant also assists the care receiver with her exercises. Steve reported that the care receiver has no volitional movement on the left side of the body and to date is unable to walk. He also reported that it is difficult for her to manipulate her wheelchair for mobility because "her feet are a little bit too high off the pavement."

Participant Two

Participant two is Emily who is 85 years old and reported being in fair general health except for a hand tremor that she described as being a "nuisance." Her husband experienced his stroke two years ago when he was 87 years old. They live together in an apartment in a retirement complex. Their apartment is on the third floor which they access by elevator. They have been married 63 years and have one daughter and two adult grandchildren. They both are retired teachers and Emily reported that the care receiver "was always very active [prior to the stroke]. He had a garden and he loved to play golf." When they first retired, they managed apartments for 17 years and did some traveling. Emily and the care receiver currently live alone in their apartment and have no regular outside assistance. Emily drives locally. Their daughter and son-in-law help out with driving out of the immediate area. Her husband is currently walking with a cane. He participates in swim therapy twice a week and also attends a day treatment program at a community college two days a week. Emily reports that she helps "a little" with the care receiver's self-care tasks, but he is able to do most things by himself.

Participant Three

The third participant is Sue who is 70 years old and reported herself to be in good health except for a complaint of slight water retention. Her husband had his stroke three years ago at the age of 71. Since his stroke, the care receiver has had two heart attacks which, according to Sue, have caused little or no heart damage. This couple lives together in a one-story home and have been married 48 years. They have four children, three of whom live in the San Francisco Bay Area. They also have nine grandchildren. Sue reported that her children have been very helpful and that "they insist that we call them" if any assistance is needed. Sue is the only participant that we interviewed who is currently employed. She tutors both inside her home and at her students' homes about 14 hours a week. The care receiver stays at home alone while his wife is gone. This couple receives no outside assistance other than occasional help from their family. The care receiver has regained his independence in most self-care activities (except shaving) and is currently walking with a cane. He has been a participant in a day treatment program for two years which he attends three days a week.

Participant Four

Michelle, the fourth participant, is 79 years old and reported herself to be in good general health. Her husband, who is 80 years old, had his most recent (and most debilitating stroke) five months prior to the interview. His two previous strokes occurred in 1984 and 1987. This couple lives in a one-story home. They recently celebrated their 50th wedding anniversary. They have two children who live in the San Francisco Bay Area of California. Prior to this last stroke they both golfed one to two times a week and "did quite a bit of traveling." Michelle has household help three mornings a week to give her a chance to "get out a little bit." The care receiver has outpatient therapy (occupational and physical therapy) three times a week. Michelle reports that her husband needs help with most self-care tasks and is walking in therapy but not at home.

Participant Five

The fifth participant is Wendy who is 67 years old and cares for her husband who is 64. The couple have been married for 29 years, second marriages for both. Together, the couple have six children. The care receiver had his stroke 2-1/2 years ago shortly after the couple retired to Arizona. Prior to retiring to Arizona the couple lived in the San Francisco Bay Area for many years. The couple moved back to the San Francisco Bay Area 5 months after the stroke to be near their children and grandchildren who have offered much support. Wendy described her personal physical health as "excellent" except for being fatigued. Regarding her mental health she stated, "I am beginning to fail. I get so that when I speak about something I will tear up, and I never used to be that way. But, I think it is physical fatigue causing the mental fatigue, and the mental fatigue is causing the physical fatigue, which I feel psychologically is the same." The couple now live alone with their dog in a rented duplex. The care receiver has expressive aphasia along with right hemiparesis, and cognitive deficits. Wendy stated that the greatest loss as a result of her husband's stroke is his decreased ability to speak and think as before. She stated, "I miss him...I miss the fact that he can't speak and he can't think. He is not back 100% mentally at all." Wendy sees it as her responsibility to help her husband gain back his speech.

Participant Six

Rachel, the sixth participant, is 76 years old and cares for her husband of 56 years who is 74 years old. The couple lives in a mobile home park in San Jose. The stroke occurred 5-1/2 years ago six months after the couple retired. The couple lived in San Francisco during the time of the stroke but eventually moved to San Jose because their home was not wheelchair accessible. Rachel described her general health and well-being as "fair." She has diabetes and also arthritis in her hands. She has frequent flare-ups of pain. The couple have two children; a daughter who lives approximately 30 miles away and a son in San Diego. Rachel does not drive, and her husband is unable to drive because of the stroke.

Participant Seven

Participant seven of this study is Vivian who is 50 years old and cares for her mother-in-law who is 81 years old. Vivian and her husband have been caring for the care receiver for 4-1/2 years since her stroke. Since the stroke, the care receiver has had repeated transient ischemic attacks (TIAs). The care receiver, currently in stable health, uses a wheelchair for mobility and is incontinent at night. Vivian described her own health as "excellent" and her well-being as variable depending upon what kind of day she had with the care receiver. She stated, "She is not an easy person to deal with. If I have a day where I am being yelled at all day long, by the time I go to bed at night, my well-being may not be as good as it is on days when she is not yelling at me all day long." Vivian is a homemaker and her husband works as a teacher at a local junior college. The couple have been married for 18 years and have four grown children, who live outside the home, from prior marriages. None of the children live at home but they are "in and out all of the time and they are a great support for grandma."

Participant Eight

Amy is the eighth participant in this study and is 71 years old. She cares for her husband who is also 71. The couple have been married for 46 years and have two sons who live within 60 miles of them. They live in a large one-story home. Amy described herself to be in good general health, but she reported having back pain for the past month. The care receiver had a "slight" heart attack in 1983 and had his only stroke, which resulted in right hemiplegia, 2-1/2 years ago. Amy has been caring for him since then. According to Amy, the care receiver walks short distances with a quad cane and is independent in his transfers. The couple retired shortly after the care receiver's heart attack in 1983.

The couple had been retired for six to seven years previous to the stroke. When employed, they worked together in their warehouse business. Amy stated, "...We used to work 24 hours a day together, so I am accustomed to being with him all of the time, so that does not bother me." The couple traveled frequently when the care receiver had his pilot's license before the heart attack.

Participant Nine

The ninth participant is Keith who is 79 years old, and he cares for his wife who is 83 years old. Keith was unclear about when his wife had her stroke. He did not indicate a particular date or event when asked about the stroke. However, Keith stated that his wife's health started declining 8 years ago. The care receiver also has a diagnosis of Alzheimer's disease and diabetes. The care receiver requires only set up and cues to do her activities of daily living (ADL) and is ambulatory, but she requires 24-hour supervision because of her poor safety awareness and judgement. Keith described his own general health and well-being as poor. He has a "bad heart", inoperable prostate cancer and blocked arteries. Keith has been married to his wife for 34 years. They have no children from this marriage. However, the wife has two daughters from a previous marriage who live in close proximity. One daughter assists the caregiver by driving him to go grocery shopping and on other errands. The other daughter assists him by taking his wife on short outings during the weekends.

Findings

Based on the structure of the interview, participants described their life tasks including self-care, work and leisure activities. They also discussed their perceptions of themselves as caregivers and their perceptions of their relationships with the care receivers. Finally, the participants described their needs as caregiver, the role that rehabilitative health care professionals have played in the caregiving process, and the social support they receive.

Life Tasks

Self-Care

Caregivers were asked to describe a typical day and to describe the personal care with which they assist the care receivers. All the caregivers assist their care receivers in self-care to some extent. Some provide more care than others.

Steve, the newest caregiver, has two aides who provide a total of 20-hours a day of attendant care in two shifts assisting with his wife's hygiene, grooming, dressing, toileting and bathing. The care receiver requires constant supervision. Steve monitors his wife very closely to ensure that she takes her medications.

Emily, whose husband uses a quad cane, assists her husband with dressing, showering and shampooing. The husband attends swim therapy twice a week (his daughter drives him) where he gets a shower and shampoo which helps the caregiver.

Sue shaves her husband every morning and she described this as one of the biggest adjustments for the couple. She also stated that her husband bathes independently, but he wants her present in the room while bathing. Sue stated that although her husband does not require constant supervision and can take care of most of his own needs, she rarely leaves him alone.

Michelle's husband can do his own toileting with minimal assistance and requires her help in showering, transferring and dressing. Although her husband can do his own toileting, Michelle keeps a constant watch on his bowel movement status to ensure regularity. The couple depend on his regularity so that their day is not interrupted. Michelle stated, "It was hard to get him regulated...for awhile we would sit down to eat breakfast or dinner...and he would almost immediately want to go to the bathroom, so I would take him." Michelle stated that it is almost impossible to get non-caregiving activities done during the day because of constant interruptions to perform caregiving tasks. She has an aide come in three days a week to help her with her husband's self-care, some laundry and other chores. When Michelle first started caregiving for her husband, she had around-the-clock assistance.

Wendy stated that her husband shaves and dresses himself but needs assistance with transfers, showers, and toileting. Because her husband is susceptible to seizures, Wendy must always be present. Wendy set up a large mirror in her home so that she can see her husband from an adjoining room at all times.

Rachel stated that her husband can only perform light hygiene independently. Her husband requires her help in bed mobility, transfers, toileting, dressing and cutting his meat when dining. He requires constant supervision because of his decreased independence and cognitive status.

Vivian stated that her mother-in-law is physically capable of performing light hygiene and dressing. However, Vivian stated that her mother-in-law has lost all motivation for initiation of self-care tasks since her stroke. The care receiver requires repeated cues to perform simple tasks such as combing her hair. Vivian reported that she tried to motivate her mother-in-law to do her own self-care without success for 4 years. When asked what personal care with which she assists her mother-in-law Vivian stated, "Everything, everything. Washing her. Shampoo her hair. Cut her toenails. Cut her fingernails. Everything. The only thing she does do is brush her own teeth. Sometimes she does it without toothpaste, but at least she does do that...but that is it." However, Vivian stated that her mother-in-law can eat by herself when urged to with set up and can do her own toileting during the day. Because her mother-in-law is incontinent at night, Vivian puts a diaper on her every evening. Vivian does three loads of laundry every day to wash her mother-in-law's sheets.

Amy stated that her husband can do light hygiene with set-up, eat, and transfer to the car by himself with supervision. He requires his wife's help with dressing and bathing. Amy stated that she has her husband do his morning hygiene in the kitchen sink so she can supervise him more closely while she is preparing breakfast. Amy had ramps and bars installed in the house prior to her husband's discharge from the hospital to make it safe for him. When her husband first came home from the hospital, they had a live-in aide to assist with the caregiving tasks. Now, Amy manages all her husband's self-care without assistance.

Keith stated that his wife can independently shower, dress, and feed herself with set up and with cueing. Every day, Keith lays out all his wife's clothes including underwear and even panty liners. Keith can never leave his wife alone in the house because of his wife's poor safety awareness and judgement.

The caregivers not only assist with the self-care tasks themselves but are also concerned about the care receiver's diets, and the need to monitor cholesterol, blood sugar, and blood pressure levels. Regularity of bowel movements and the taking of proper medications are also concerns of the caregivers. Steve stated that it is a struggle to make his wife take her medications when she refuses. Managing aides and professional caregivers who assist with personal care is also of prime importance to the caregivers as is ensuring that the care receivers were keeping physically active, maintaining range of motion, and doing their exercises.

The caregivers were asked if and how their own personal care of themselves have changed since their caregiving roles began. All caregivers stated that their own self-care has changed in terms of scheduling. Amy is typical of the caregivers interviewed. Since her husband's stroke, she wakes up at 5:00 a.m. and takes care of her own self-care needs before her husband wakes up. Vivian adjusted her own showering and self-care time to make the schedule less hectic for herself. Earlier, Vivian took care of her own personal care such showering and putting on make-up, then got her mother-in-law ready to attend the day care center by 8:00 a.m. Now, she gets her mother-in-law cleaned and dressed first. Only after she drops her mother-in-law off at the day care center does she take care of the majority her own personal hygiene when it's "quiet and peaceful."

Another change in personal care for the caregivers was lack of time for self-care such as grooming, seeing a doctor and exercising. Rachel no longer keeps a standing hair dressing appointment. She now has a hairdresser come to her home to do her hair. Rachel also stated that although she feels like she needs a physical examination, especially because of the painful arthritis in her hands, she has been unable to see a doctor because of lack of time and transportation. Vivian stated that even if she did go to a doctor her husband would have to come because he cannot be home alone. She would like to have privacy from her husband when she sees a doctor.

As a group, the caregivers considered it very important to be physically healthy themselves to enable them to better care for the care receivers. Wendy takes daily walks with her dog to keep in shape. Steve said, "I have got to keep myself in good shape and I have to find the time for me...If I fail, the whole thing [caregiving] just crashes down in a big bundle of shattered cards." This caregiver goes cycling regularly and plays tennis on occasion to keep in shape mentally and physically. He said he has less time to keep in shape now since his wife's stroke. Amy wishes she had more time for exercise. Before her husband's stroke, she took walks regularly and did low impact aerobics through video tapes. Now, she is unable to exercise because of lack of time.

Work

The caregivers spent much time in caregiving tasks and activities to keep the household together. Six caregivers were employed prior to retirement and the stroke. Three were housewives. Two caregivers were retired for one year or less when the stroke occurred. One couple was retired for over 17 years, another for 6 years before the stroke. Many were looking forward to a life of leisure and traveling after retirement.

Steve was retired for about one year from his job as an aerospace engineer when his wife had her stroke. His wife was a teacher and real estate agent and was a year from retirement when she had her stroke. Emily was a housewife and her husband was a retired salesman. After retirement, the couple managed apartments for 17 years. Sue is the only caregiver in our study who continues to be employed after her husband's stroke. She tutors learning disabled children and adults part-time. Her husband was retired about a year before he had his stroke. He was a mechanical engineer. Before the stroke, Sue was working approximately 20 hours a week. Since the stroke, she works 14 hours a week but would like to work more hours as soon as her husband can be more independent. Michelle was a homemaker before the stroke. Her husband was a retired meteorologist. Wendy was also a homemaker and her husband a retired truck driver when he had his stroke. Rachel worked as a key-punch operator and her husband as an estimator for a large paint company prior to retirement. The couple were retired for 6 months before he had his stroke. Vivian is a homemaker and housewife. Her husband, who assists in caregiving for his mother, is an instructor at a local junior college. Amy and her husband owned and operated their own business for many years before his stroke. The couple were retired for six years before he had his stroke. Amy continues to consult and advise her son on the family business. Keith is a retired financial consultant and his wife was a retired auditor prior to the stroke. Keith occasionally volunteers his time to do research for various organizations when he is called upon to do so. He wants to volunteer more but cannot because of his caregiving duties, limited transportation, the need to hire a caregiver in his absence, and his decreased energy. When asked why he felt voluntering was important, Keith stated, "To get my mind occupied...A mind is like a piece of machinery. If you get a piece of machinery and shove it into the corner and you don't use it and you go to use it, it's frozen."

Four of the caregivers compared their caregiving tasks to jobs or work. Steve compared his caregiving to his job as an aerospace engineer:

> I had less than a year of retirement. I am right up to here now in stresses and thinking and working. It is tougher than going to my job at Lockheed, way tougher. There is so much responsibility and it is all on to me. It is not earning a paycheck anymore. It is really making sure that this whole thing works. It is hard.

Steve wants to return to work part-time as an aerospace engineer. He stated, "I might want to go back to work, but just half time, because that would occupy me with structure, not structure around caregiving, but structure around my job which could be a big relief." He added,

> Even though I have worked all my life to get away from work I am finding out that maybe having a job and having four hours every day very, very structured where I have to respond to others...that it might be good and it might be offsetting to the caregiving.

Rachel said, "This is a full-time job. If he is asleep I cannot stay awake. I am exhausted all of the time. It [the work] does not end."

Keith related caregiving to his experience in combat duty during World War II. He said, "I did a lot less strenuous duty in combat than I do right here in the house." He added,

> It's 24 hours, 7 days a week, 365 days a year. That's what caregiving is. It's getting up in the morning, getting her underwear out, her panty liners, her bra, putting them in the bath, seeing that she takes her shower, get her dressed, feeding her and seeing that she gets her proper food, proper rest, everything else. Getting her to bed at night. In between times, I do the laundry, do the cooking such as that, what grocery shopping there is...all these things.

Wendy felt that she hasn't been doing her "job" very well. She stated,

> I am falling down on the job, so to speak. I am not as quick as I used to be, and I love to read and I don't find time to read anymore. I should say, that if I do read, it goes right through. I don't recall anything that I have read. My mind wanders a great deal now. I keep thinking that I have got to do this, I have got to do that, and by the time I finish one job, it is time for his lunch. By the time I get him

> washed up and take him to the bathroom and tucked in, I think I'll just sit down and read for awhile, and I find that I haven't done this, or I have to wash a few more clothes, or I haven't vacuumed the floor, things that matter to a woman, it does matter to me. I want him to be in a clean house...whenever anyone comes over, I want him to feel comfortable.

Many of the caregivers considered it their work to keep the care receivers active and busy. Wendy stated: "I have him very active, because if he is sedentary he will never get well." Wendy enrolled her husband in a one-handed golf class, occupational, physical and speech therapy through one community college and physical therapy at another community college. Wendy also considered it her job to help her husband regain his speech back, so she practices speech exercises regularly with him.

All the caregivers are responsible for taking care of the tasks to run their household such as cleaning, doing the laundry, grocery shopping, cooking, doing the yard work, and paying bills. Most of the caregivers receive some source of help with the home tasks through friends, family members, or hired help.

Six of the caregivers have housekeepers who come periodically to help with the house cleaning tasks. Wendy found it a great relief "psychologically and physically" to hire a housekeeper to come to her house once every two weeks. She considered it her job to keep her house neat and clean and felt quite burdened to be unable to do so after her husband had his stroke. Amy hired a gardener after her husband's stroke. Although she enjoyed gardening, she felt she needed help because of the added caretaking tasks.

Driving and transportation is a task that most of the caregivers consider to be "work." They are busy driving to and from the doctor's office, to the different therapies, to go shopping, to run errands, etc. Amy considered having to do all of the driving her greatest burden. She wishes she could hire a driver on occasion. Keith, Rachel and Vivian use or have used the local county escort service for seniors to assist with transportation.

Cooking is another task that the caregivers perform. Rachel and Sue were looking forward to not cooking very much after retirement. Their husbands took on most of the cooking tasks after retirement and the women enjoyed not having those tasks. Sue is looking forward to the time when her husband can do the cooking again. Rachel said, "I thought when he retired I was through in the kitchen." Steve enjoyed cooking before his wife had her stroke. However, with the added caregiving tasks and because of his wife's altered mental status, cooking is no longer as enjoyable to him. His wife occasionally gets confused about the time and insists on breakfast in the evening when he has already spent time preparing a nice dinner. Occasionally, his wife flatly refuses to eat something he has carefully prepared to be low in cholesterol and fat, so he prepares foods that he considers to be less suitable for her diet. He said, "Her mental state and her well-being are probably more important than it is to be absolutely stringent about saturated fats and other things." The caregivers use various resources and strategies to lessen cooking tasks. Keith has arranged for one meal a day to be provided for himself and his wife through the Visiting Nurses Association (VNA), Steve takes his wife to a senior center every day at lunch. Emily utilizes frozen dinners to make dinner preparation easier.

Leisure

The caregivers were asked about the types of leisure activities in which they participated before and after the strokes and how their leisure times have changed since the stroke. The caregivers were also asked what types of leisure activities in which they engage with the care receivers.

First of all, the caregivers were asked how they spend their leisure time. Many of the caregivers read and like to do gardening when they can. They also like to travel, sew, golf, watch television and exercise. Amy attends an art class once a week while Steve likes to work on his bicycle.

The caregivers were also asked how their leisure times have changed. One change was the amount of time spent in leisure since the stroke. Another change was in the types of activities in which the caregivers engaged after the strokes versus before. Other changes included the need to plan and organize leisure activities more, and the need for more flexibility with leisure times.

All caregivers now spend less time engaged in leisure activities because of the time spent in caregiving and other tasks. They long for more hours in a day to be able to relax and enjoy their leisure activities. Rachel stated that as soon as she finds the time to engage in her hobbies (knitting or reading), she's so tired that she falls asleep. Amy wished for 34-hour days where the extra time could be spent reading or gardening.

Ways to engage in activities have also changed for these caregivers. Rachel and Keith now consider sleeping to be their favorite leisure activity. Steve listens to stress reduction tapes since his wife's stroke. Others now watch more television. Michelle and her husband played golf together often before his stroke. Because of his physical limitations, the care receiver can no longer golf. Michelle stated that she does not want to golf anymore because it was an activity that she and her husband did as a couple. She would like to find a hobby that she and her husband can enjoy together. Amy and her husband now find it more convenient to rent movie videos instead of going to the theater because of lack of wheelchair accessibility.

Six of the caregivers traveled extensively before the strokes occurred and are now limited in the amount of travel they can do because of the physical limitations resulting from the strokes. The caregivers stated that they do not travel very often anymore because of the difficulties in making arrangements, the cost, and problems with transfers and bathroom tasks. Emily related, "That is one of the worst things with the stroke when you have to give up traveling."

However, Sue thought she had to give up traveling with her husband because of the costs and "mechanics of it all." She was exhausted when she took her husband on a flight because she had to push his wheelchair, be responsible for all the luggage and arrangements, toileting tasks and transfers. She recently decided to order a wheelchair for herself and her husband when they travel. That way, the airport staff can assist the couple in the airport.

Rachel and Amy's husbands were recreational pilots for over 30 years before their strokes occurred. The loss of this leisure activity is especially great for these couples. Amy stated,

> We just don't get to go like we used to...Even before we retired, when he used to fly, we would just fly. Every weekend we would go...So he likes to be on the go and I think that is what is the thing we miss the most. Or we would get in the car and take it easy and go up to Chico and stop at the Coffee Tree or the Nut Tree and

> maybe that is what we missed most because he didn't have any hobbies outside of the flying. We miss the traveling more than anything.

The caregivers must do much planning to engage in some leisure activities. The caregivers are not as spontaneous as they were before the strokes. When Michelle plans to go out to dinner with her husband, she calls the restaurant to make sure that the restaurant is wheelchair accessible, that the bathrooms are wheelchair accessible, and that there is handicapped parking. She also said that she and her husband no longer visit friend's homes because their homes are not wheelchair accessible. Because of this, the couple only meets friends at wheelchair accessible restaurants. Another caregiver, Keith, must carefully plan his own leisure activities when going outside of the home. He must arrange transportation for himself (he doesn't drive) and obtain attendant care for his wife. Vivian says that it is to her advantage that she herself has always been an organized person because of the planning required to do everything she wants to do.

In addition to organization and planning flexibility is also important. Vivian says that her friends must be very flexible with their times when they plan to meet because of possible emergencies with her mother-in-law. Vivian has had to change or cancel appointments and lunch meetings with friends when her mother-in-law has had a transient ischemic attack (TIA). Vivian and other caregivers related that their leisure times are frequently interrupted by caregiving tasks. For example, Vivian related that it is almost impossible to finish sewing projects because of the constant interruptions in attending to her mother-in-law. She stated, "It takes me four times as long [to sew] because I can't sit down and do something and finish it. I am constantly up and down. Anything that I like to do and do do just takes longer." Keith stated that he cannot have any set routine with his leisure activities because of all the changes and unknowns. He said, "I cannot say I'm going to do this from 1 to 2, I'm going to do this from 2 to 3, or 3 to 4, 4 to 5. It's impossible. I cannot under these circumstances set up any type of routine, meaningful routine..."

Though they must be flexible most of the caregivers have had to set certain times for themselves to relax and engage in leisure activities. For Keith, the hours between 6:00 and 8:00 in the morning are very important for him. Those hours are the only hours during a regular day where he has time for himself when his wife is asleep. He also sets aside four hours a week to go to a park and read. A regular volunteer from a community organization attends to his wife while he goes to the park. He stated that this time away from home is what helps him more than anything else in managing his wife and the stresses of caregiving. Sue can actually leave her husband alone for short periods of time and attend weekend retreats.

The caregivers were also asked what kinds of leisure activities in which they engage with the care receivers. Some watch television with the care receivers. Others read the newspaper together. Michelle and Amy go to the airport with their husbands to watch planes take off. Many go out to eat and go to church. Steve and his wife go to the beach. Rachel said she enjoys going out to lunch but that the times are not very enjoyable anymore. She said, "I am pushing the wheelchair, or I am cutting his food. I don't mind doing it, but it is not like going out and sitting down. If I order something to eat, by the time I cut his, mine is cold, and then I push him home again." Vivian said she tried to engage in leisure activities with the care receiver but that she no longer does so because the times were usually unpleasant. For example, when Vivian took her mother-in-law window shopping or on other outings, the care receiver would immediately say that she wanted to go home.

Perceptions of Self as Caregiver

The caregivers were questioned about their perceptions of themselves as caregivers. Eight of the nine caregivers felt that they were doing the best job they could in assisting the care receivers. Vivian was typical of the caregivers when she stated, "I don't know what more I could do."

The caregivers were asked if they feel they do an adequate job as a caregiver. Overall, the caregivers interviewed felt they did an adequate job as a caregiver. For example, Rachel said, "The doctor said he is in good shape so I guess it is okay. There is no atrophy on his arms or legs or anything because he has been exercised." Vivian said, " She is immaculately clean. She is well fed. She gets her medical attention. For a lot of years she received a lot of therapy. As far as physically, again, I don't know what else one could do to get her to move more." Wendy said, "I feel I give him good care, I really do. He is number one as far as I am concerned." Emily stated, "Well we have managed. He has been able to stay at home which I think is a big plus. Even with the better nursing homes, I think they leave much to be desired."

Rachel felt she did a good job in caring for her husband but wants to take a day off. She stated, "I am just getting old and tired, that's all. I am pooped out, burned out I guess is the word." Steve, who has been caring for his wife for 4-1/2 months, felt he did an adequate job taking care of his wife's physical needs but not her psychological needs. He stated,

> I am not doing a good job psychologically. I am doing very poor. I think I am doing a good job physically, taking care of bed pans, preparing food, and so on. I have not been tutored, taught, to do the psychological thing so I am always saying things then thinking I should not have said that.

When asked about how he has succeeded as a caregiver, Steve stated,

> I do not think I am a very good caregiver. That's my own opinion. I think I have succeeded in minor things. But I do not think I have succeeded in important ways for her [his wife] which is to address her disability. I do not think I do that to be really honest with you.

Other caregivers stated that they, too, felt at earlier times in their caregiving roles that they were not doing a very good job. Amy, who has been caring for her husband for 2-1/2 years, stated that early on in her caregiving role, she felt guilty when she felt she was not doing enough for her husband. She got impatient and angry with her husband and felt guilty afterwards about those feelings. A turning point came for her when she went to a caregiver group and another caregiver said, "Well, you know you just do your best, and so be it." That has been Vivian's motto which has helped her. She now says, "Well, you do your best and don't let it make you feel guilty because you have done your best." Vivian now says that it took her four years to realize that she could do no more to motivate her cognitively impaired mother-in-law to be more independent. She spent many frustrating hours with her mother-in-law trying to help her to be more independent. Vivian said she was getting tired and was unable to spend time with her own grandchildren because of the time she spent with her mother-in-law.

After determining that she could do no more to motivate her mother-in-law, Vivian stated,

> It made it a lot easier for me to face the day for sure, because when I realized there was nothing I could do to get her any better, and that probably she was as well as she is going to get, and it would be a downhill climb from here... things got a lot better...we just approach it with a whole different attitude.

When asked about the joys of caregiving, the caregivers gave similar answers. The caregivers were encouraged to see improvement in the care receivers. Other joys included being able to keep the care receivers at home, helping them to "stay alive" and to "survive", feeling needed, and helping the care receiver to be more independent.

As far as areas for improvement as caregivers, the caregivers felt they needed to be more patient. Emily feels that she needs to allow her husband to do more for himself. Steve feels he needs to empathize more with his wife and to learn how to better communicate with his wife without getting frustrated or angry.

Perceptions of Relationship with Care Receiver

The caregivers were queried about their relationships with the care receivers and their perception of the relationship since the stroke. For the most part, the caregivers stated that they had positive relationships with the care receivers before the stroke and continue to have good relationships.

Wendy stated throughout the interview that she and her husband enjoy each other's company and that they can still often laugh together. Amy stated, "I wouldn't trade him for a million!" However, Amy admitted that although she and her husband get along very well, she gets upset at her husband when he doesn't do his exercises.

Other caregivers and care receivers, especially in those cases in which the care receiver's mental status or personality has changed since the stroke have undergone some difficulties in their relationships. For example, Steve stated that his wife's personality has changed in that she gets angry, and "there is no penetrating through...there is just a stone wall." He stated that there is no reasoning with his wife. Steve also stated that he has a difficult time separating himself from his wife and he has a difficult time balancing out his needs from his wife's. Rachel states that her relationship with her husband currently "stinks" and the couple argue more now than before the stroke. The caregiver states that her husband can now be verbally abusive and is not aware of his limitations which frustrates her. She stated that her relationship with her husband was better before the stroke when they both were independent and had their own interests. She says, "Now we are just together 24 hours a day, 7 days a week."

Vivian has learned to manage her relationship with her mother-in-law even though it has been difficult at times. According to Vivian, her mother-in-law is unreasonable, "does a lot of yelling" and can be verbally abusive. Vivian stated that she has learned to separate the effects of the stroke from her mother-in-law and has learned to not take the yelling personally. She stated, "You know, it is almost at the point now where this is not the person, and it really isn't the same person that I really knew and we had a good time together. That person is just no longer there."

Identification of Caregiver Needs

The participants were queried about what they perceived as their greatest need as a caregiver. Throughout the interview process, they also commented about other needs they had identified and they described the advice they would give a family caregiver in a situation similar to their own.

Emily reported that her greatest need was for a sense of humor and for patience as a caregiver. The remaining eight participants declared that time away from caregiving was their greatest need. They wanted more time to rest, to participate in leisure activities, and to take care of general responsibilities. Rachel commented, "I have not had time to go have a physical for so long because I have nobody...if I go I have to take him with me. We do everything together. There is no choice." Rachel also stated, "My idea of a big time on the town is to go to a motel and sleep." Steve felt he needed more time to take care of himself. He said, "I have got to keep myself in shape and I have to find time for me."

Another need that was identified by many of the caregivers was better wheelchair accessibility in the community. Most of the participants found travel to be difficult because of the inaccessibility to the bathroom on an airplane if in a wheelchair. Some of the participants discussed how many restaurants are not wheelchair accessible and that they either have to call ahead to find out if a restaurant is wheelchair accessible or they discover them by trial and error. Rachel discussed how she felt restrooms should be unisex in the community because she needs to assist her husband on and off the toilet. She does not know if she should use the women's or men's room. She also discussed how some major intersections do not have pedestrian crossing which makes it difficult for her to get to and from a shopping mall when with her husband in a wheelchair.

Amy and Rachel stated that they needed more help at home and help with driving to appointments for the care receiver. Rachel discussed how she has no privacy, not even while toileting. She stated, "I had to take the door off the bathroom to get the wheelchair through it so there is not even a door to the bathroom."

Steve and Amy expressed a need to plan for the future. Steve commented that he and his wife are isolated from their family. He was concerned about what would happen if something should happen to him and he would be no longer able to take care of his wife. Another need mentioned by Steve was for accessibility to information on support groups, conferences and anything related to caregivers and strokes. He focused on the need for a national health care system in the United States that would lessen the financial strain on caregivers and care receivers.

Three participants discussed some equipment that would better meet their needs. One was for a hospital bed to be wider so that a couple could sleep together in the same bed. Another was for a better product to help keep someone dry from urine incontinence during the night. And another was for a better and cheaper wheelchair.

The participants were asked to share what advice they would give to a family caregiver in a situation similar to their own. All nine recommended that all caregivers should get help. They also emphasized the need for them to take care of themselves in whatever ways were necessary. Amy and Michelle stated that they felt it was especially important for the caregiver to have help at home when the care receiver is first discharged from the hospital. Amy reported, "My son came home with me and that gave me a lot of stability or something because I knew he was here...you just can't feel alone when you come home with him [care receiver]." Michelle stated that it is "scary" to be alone with the care receiver when they are first discharged from the hospital. She suggested that one should get help from family, friends or even hired help, if necessary, in the initial periods after discharge from the hospital.

Vivian felt it was important for caregivers to take care of themselves and to ask for help when necessary to avoid burn out. Michelle agreed and said that a new caregiver should "get as much help as they reasonably can...get out and have time for themselves...be willing to ask for help if they need it, where they need it, and to look for what help is available."

Emily and Vivian mentioned that a good support system was valuable for caregivers. Emily suggested that caregivers be a part of a support group, for she found that to be interesting and helpful. Rachel felt it was important to begin training as a caregiver while the care receivers are in the hospital. In this way, the caregiver would have a chance to practice and get advice from health care professionals early on in the process.

Vivian felt it was important for caregivers to not take things that go wrong too personally. She commented that one should "do what they can and don't worry about what they can't do." She also suggested that in caregiving, "If one thing doesn't work try another."

Role of Rehabilitation Health Care Professionals

Respondents discussed their experiences with health care professionals, in particular, rehabilitative services. They recalled experiences with inpatient, outpatient, and home health therapy. In particular, they were questioned regarding their experiences with caregiver training and what they felt their needs were from rehabilitative health care professionals.

Experiences with Inpatient, Outpatient and Home Health Therapy

Seven of the participants stated that the care receiver had inpatient, outpatient and home health rehabilitative services (occupational, physical, and speech therapy). Steve reported that his wife had both inpatient and home health services to date but was not certain if they would begin outpatient therapy. All of the participants commented that they had at least some positive experiences with rehabilitative services. Emily described the therapy as being "very helpful" and Amy said it was a "terrific help." When talking about the therapists, three of the participants said, "They were wonderful."

Rachel and Emily discussed how they felt that the care receiver should have had more therapy. Amy felt it would be beneficial if the care receiver could be re-evaluated every year by rehabilitative services. She felt that this way if there was any new or different information that was available there would be an opportunity to work with and share this knowledge with the care receiver and caregiver.

Caregiver Training

All of the participants discussed the role of rehabilitative therapy in caregiver training. Five participants reported that they had received at least some caregiver training from rehabilitative services. Emily discussed how therapy had been helpful because "I had never been around anyone with a stroke before, and I had never been a caregiver before...so this was my first experience taking care of anyone." She described how she was taught to do transfers and was given an exercise program for her to do with her husband at home. Sue stayed over-night with her husband in an apartment-like setting in the hospital as part of the rehabilitative process. This was considered to be a "trial run" so that if they discovered any need before he was discharged home they could work that out with the rehabilitation staff. She felt this was a helpful experience. Three of the participants reported that they did not have any training and that they learned "on the job."

Caregiver Needs from Rehabilitative Health Care Professionals

The participants described various ways that rehabilitative health care professionals could better meet their needs. Three of the participants emphasized that they felt that therapists needed to be more realistic in their expectations of what both the caregiver and care receiver could do. As Michelle said, "I think that the health care professionals need to be real aware that there are just some things that do not work when one hand, and one leg, and one arm are pretty much paralyzed. I don't think they are completely realistic about what a person can be expected to do." The other participant stated when talking about health care professionals, "I think that you just have to be flexible, maybe there is a different way that will work better. Maybe it is not the way by the book, but it will get the job done."

Amy and Rachel felt they needed to be more involved in the therapy and to get more "hands on" experience while the care receiver was in the hospital. Amy said that she should be allowed to observe all therapies to better know how to handle her husband. She also said that at one facility a video tape was made of a home program for her to follow through with, and she found this to be very helpful. She felt that this would be beneficial to receive from all of the rehabilitative disciplines. Rachel expressed that she should have been able to practice while her spouse was in the hospital. She reported, "They had enough people to supervise to let me get him in and out of the bed, and in and out of the wheelchair, on and off the toilet."

Steve stated when discussing therapists, "The brightest people should be that group...that group of people caregiving [rehabilitative health care professionals] because after all, think about it, we are human beings and what is more fundamental than caring for another human being who has seen a lot of life and is suddenly deprived of a big segment...we are not devoting the cream of our people into helping other people."

Social Environment

The respondents described their experiences with those from whom they received social support. Participants described their relationships with family and friends and discussed social groups that offered help and assistance.

Family and Friends

During the interviews, participants discussed experiences they had with family and friends who were a part of their daily life. They focused on family and friends' roles as a support system for themselves and for the care receiver.

Eight of the nine participants had adult children and grandchildren who were involved in their lives to some extent. Five of these participants said that they felt their children had been a great support to them. Families provided support via running errands, such as grocery shopping, driving to appointments, staying with the caregiver during the first two weeks after hospital discharge, and staying with the care receiver to give the caregiver a break. When talking about having her son stay with her when her husband was first discharged, Amy said, "You just don't want to be alone when you take him home from the hospital. I would never want to face that without family to help you or somebody." Four participants described their families as being "close-knit," and that their children and grandchildren as a "great support."

Two of the three participants, Michelle and Rachel, who did not consider their children to be great support, felt that it was because their children lived too far away and were busy with their own lives. The other participant, Keith, felt the children were in denial in regards to their mother's condition. He commented that they considered their mother to be the "strong person" and now they cannot understand this "strong person being in this condition" so "they deny it." Because of this, he feels the children are not as supportive as they could be.

Steve, who does not have any children, reported that he was not close to his family but the care receiver's family was supportive of him. His sister-in-law and niece flew out immediately after the stroke occurred and he said, "If it hadn't been for them, I think I would have gone around the bend. Just to have them in the house was a big, big plus factor. They basically kept me sane. They really did."

Four of the participants mentioned their friends as being a primary source for support in their lives. Vivian stated, "I am very fortunate. I have a very good group of friends and most of them are very understanding and have been supportive." Michelle reported that both friends and neighbors had been very supportive when their children were not available.

Amy expressed that many of their friends had retired, some had died and some had moved away so they did not have a lot of friends around for support. Wendy reported that their friends had deserted them since the stroke because the friends felt uncomfortable. Rachel stated that she was a private person and that she did not have any friends whom she could trust and feel comfortable talking about her situation.

Support Groups and Social Interactions

Emily, Sue, Wendy and Amy regularly attended a caregiver support group while their care receivers attended sessions for themselves. This group meets once a week and all of these subjects described very positive feelings about this experience. Some comments made were: "I don't know what we would do without it. We are all one family," "We give each other ideas because we learn from each other," and "I got a lot out of it because everybody was in the same boat." Emily commented on its benefits to the care receiver. She said, "I think it has been very helpful because I think the stroke victim realizes there are so many other people that are in the same situation, and there seems to be quite a bonding. We are all concerned about each other."

Vivian, Keith and Rachel's care receivers participated in a senior day service program which was a support network for the care receiver and allowed some time off for the caregiver. Emily and Sue were involved in groups through their churches which they reported as being supportive, and Steve and his wife are active in a senior center which provided support for them. Only Michelle declared that neither she nor the care receiver was a part of any support group. Her spouse was five months post his CVA, and she felt they were not ready for a support group, yet she felt it might be a good idea in the future.

Summary

The participants described their life tasks including self-care, work and leisure activities, perceptions of themselves as caregivers, and perceptions of their relationships with the care receiver. The participants also discussed their needs as caregivers, the role that rehabilitative health care professionals have played in the caregiving process, and the social support they receive.

1. What are the needs of family caregivers of older persons who have had a CVA?

Results: Common Themes

The answer to the first research question is revealed in the common themes that were identified in the data. Each of the themes that emerged identified needs of family caregivers. The eight themes that emerged from the data analysis were: loss of time to do activities of daily living, value of social support and interpersonal relationships, lack of wheelchair accessibility in the home and community, valuable aspects of interactions with health care professionals, challenges of role changes within relationships, importance of living at home: use of resources, stages/phases in caregiving, and adapting to new life changes.

Loss of Time to do Activities of Daily Living

All nine participants in this study stated that they needed for more time for work, self-care, leisure, and rest. Participants discussed their lack of time to do work including daily responsibilities. As Michelle reported, "One thing I am finding is that I don't get a lot of time to cook. There are just a lot of interruptions, and I don't always get a lot of time to eat meals even. For awhile, it was bad." Sue wished she had more time for her paid employment as a tutor. She found her caregiving duties limited the time she had available for her profession.

Not having enough time for self-care and leisure activities was commonly mentioned. Participants reported that they did not have enough time for activities such as exercise, hobbies, haircuts and doctors appointment for themselves since they became caregivers. As Amy stated, "This is a full time job, I do not have time any more to garden [her favorite leisure activity]." It was also reported that it was difficult to get things done when one only had a few spare minutes here and there.

Three of the participants emphasized that they felt the loss of time for sleep. They stated that they felt so fatigued that whenever they did have a spare moment all they wanted to do was to sleep. Rachel said, "This is a full time job. If he is asleep, I cannot stay awake. I am exhausted all the time." Most of the participants of this study also discussed the need for respite. Wendy said, "I go through times where I need respite, I need it terribly...My son-in-law told me I could go shopping with the girls all day, but I am so tired that I would like to go some place where I could rest, just rest."

Value of Social Support and Interpersonal Relationships

Throughout the interview process, all of the participants discussed their need for social support. The participants' social networks included interactions with family, friends, neighbors, and support groups.

When asked what advice a caregiver would give to someone in a similar situation, all nine mentioned they should get some kind of help or social support. Social support from whomever was available seemed to play a key role in the coping process.

Some of the subjects reported that since the stroke occurred, they had lost some friendships which they believe was due to people not feeling comfortable around the stroke survivor anymore. This feeling was more apparent amongst caregivers of people with language difficulties. As Wendy stated, "His friends have seemed to have deserted him...they just don't know what to say anymore. They feel uncomfortable with him. I can understand that. Even our very close friends." Others too stated that both family and friends no longer visited as frequently as they had prior to the stroke. They also found it difficult to talk about their situation with people who did not have any experience of caring for a spouse or relative in their home.

The four participants who regularly attend a caregiver support group lead by a social worker described very positive feelings about this experience. When talking about the group, Emily said, "I think it has been very helpful because I think the stroke victim realizes there are so many other people that are in the same situation, and there seems to be quite a bonding. We are all concerned about each other. Wendy described the group as being "wonderful." She said, "I don't know what we would do without it. We are all one family."

Others reported that it took a long time before they were told about any kind of support group for caregivers or were told about any day treatment programs for the care receiver. Rachel had sought out a support group and was unsuccessful at finding one that was convenient for her to attend. Information was reported as being sporadic and required much research by the caregiver to find helpful programs for support.

Lack of Wheelchair Accessibility in the Home and Community

Many of the participants said that they needed better wheelchair access at various public and private facilities. Some of the participants complained that their family and friends' homes were not wheelchair accessible. As a result, they could no longer visit people unless they arranged an appropriate location. Not only did participants have difficulty helping the care receivers move around in their wheelchairs, but also in moving them into and out of their wheelchairs. For example, Rachel had difficulty in transferring her husband from his wheelchair to the dentist chair.

Also mentioned was a difficulty in traveling. Several of the participants had enjoyed traveling prior to the stroke, and they now felt it would be too difficult because of inaccessibility for wheelchairs on airplanes. In particular, people mentioned their concern regarding how the care receiver could use a toilet on a plane when in a wheelchair. These participants no longer consider traveling by plane as a possibility.

Four of the nine participants reported they were affected by some restaurants not being wheelchair accessible. Among their complaints were lack of convenient handicap parking, lack of or poor placement of ramps into the restaurants, and restrooms that were not wheelchair accessible.

Another complaint was that major street intersections were not appropriately designed for wheelchairs to cross within the time frame given by the street lights. Rachel described her frustration by stating, "The whole thing is stupid. Two or three places you have to pull the wheelchair up to get to the button and then it changes before you can get down with the wheelchair again." She also mentioned when trying to report this inconvenience, "I called the street department. Part of the street belongs to the city, part county, and part federal, and nobody wants to spend the money to fix it." Pedestrian crossings were particularly a problem for caregivers who did not drive and depended on walking to get around.

Valuable Aspects of Interactions with Health Care Professionals

Participants related that they needed to develop a good rapport with health care professionals to better understand their roles as caregivers. Throughout the interviews, the participants discussed both positive and negative interactions with health care professionals. Four of the participants emphasized that they had good experiences overall. The majority of discussion in regards to interactions with health care professionals was on their communication skills versus their technical skills. Wendy described a particular incident that she considered to be a rude and unprofessional interaction with a physician. When asking this doctor to refer to a day treatment program he replied, "What are you wasting your time and money for? He is never going to talk again, he is never going to walk again." Throughout the interview, Wendy referred back to this incident and described what a negative and lasting effect it had on her. Amy as well as others, listed courtesy, patience, listening and addressing the care receiver directly as valuable qualities for health care professionals to possess.

Steve said health care professionals need to include the caregiver throughout the medical intervention. He said that one of the best ways that health care professionals could provide for him as a caregiver is to provide "psychological help." Many participants in this study commented that they should have been more involved in the treatment program of the care receiver during the hospital course. They wanted more training and more opportunity to observe therapy sessions so that they could apply some of the techniques learned at the hospital.

Challenges of Role Changes Within Relationship

In this study, all of the caregivers said they needed to adjust to the role changes after the care receivers' stroke incidents. Initially, the caregivers in this study dealt with learning the practical skills on how to be a caregiver including learning transfers, and learning ways to assist the caregiver in dressing, showering and other activities of daily living. Eventually, the caregivers took on added tasks and roles after the strokes. The caregivers stated that assuming responsibilities previously held by the care receivers was particularly challenging.

Three caregivers discussed the role change of taking care of financial matters and paperwork that their spouses used to complete. Michelle's husband was responsible for handling all the financial matters before the stroke occurred. She stated that taking on that responsibility has been quite a burden on her especially because she does not like to do those tasks and because she does not know how to take care of those matters. She stated,

> When this [the stroke] happened, and I suddenly had to take over paying the bills and taking care of any paperwork, on top of which instead of just the normal stuff we usually had, we have stacks of things from Blue Shield/Blue Cross which is our supplemental and MEDICARE. We just get tons of paper from MEDICARE, a lot of which I do not understand, and I have found out that a lot of people do not understand it.

Wendy advises others to learn about financial matters so that they won't be in the predicament that she was in after her husband's stroke. She said, "I keep telling all of our children be careful, learn everything you can about your checking accounts...I have taken over our checking account and everything, our savings accounts, everything." She stated that she had to learn those things after her husband's stroke. She said, "It all comes easy to me now, but it wasn't easy then." Rachel was also unprepared to take care of financial matters after her husband's stroke. She stated, "I have one hell of a time balancing the checkbook." Her husband "used to do all of the paperwork and stuff. I never did any of it." She stated that she never paid bills before her husband's stroke and that she did not even know how to send a bill using an envelope with the window on it. Rachel hired an accountant to assist her with the taxes and the bills.

Rachel and Sue were regretful that after their husband's strokes they now have to take on the cooking tasks that their husbands formerly did. Amy stated, "Well, I am doing a lot of things I don't like to do like emptying the garbage, taking the car to the car wash, and seeing that the tires are rotated..."

Other caregivers stated that they now have the new duties of taking care of transportation and driving. Amy and Wendy, in particular, mentioned how they dislike their new driving responsibilities. Amy explained that driving was a new role for her and that her husband did more of the driving before the stroke. When asked if she drove, she stated:

> Yes, but I don't like to. I think that is part of the stress, too, because my husband was a good driver. He enjoyed driving and I never liked to drive, and I have heard more women at the REACH Program [caregiver support group] say that the worst part of taking care of their husband is that they have to drive.

Keith stated, "I do the laundry, do the cooking...grocery shopping. All these things. In other words, our roles are reversed." Rachel mentioned her frustration at taking on added roles as well as her husband's frustrations that he can no longer fulfill those roles. The caregiver stated, "I am doing twice as much as I ever had to do. He took care of the checkbook, big decisions, and stuff like that. He fixed things around the house. He is resentful if anybody comes in to fix anything now because he used to do it."

Rachel and Wendy discussed that their husbands were "handy men" and that they are having a difficult time completing tasks that their husbands formerly did. The caregivers must rely on professional help, friends and family to assist them with those needs.

Vivian and Steve did not mention role reversal but discussed the difficulty in taking on the role of primary caregiver. Vivian stated that her added tasks from her role as primary caregiver took away time to spend with her own children and grandchildren. However, she stated that she did not have difficulty balancing her roles as wife and mother. Steve stated that his role as caregiver was especially difficult because of his training in engineering. He reported that engineers think logically and sequentially and that the role of caregiving goes against everything that he has been taught as an engineer because of the unpredictabilities. Steve said,

> It is a difficult role. There are no right answers...I am not doing things the way I used to do them at all...I have changed and am still changing a lot. I am putting my old tools that used to work now for me, now I have to use new tools, new ideas, being far less rigid...I am a scientist and engineer and am very used to a very disciplined approach, things work or they don't work, and things like that. I am beginning to put all of that away. I don't really have to understand everything. There are a lot of things I don't understand and I don't need to get all worried about it.

Caregivers not only had a need to learn how to be a caregiver, but they felt a need to be listened to and understood by others regarding their role as caregiver. Rachel was frustrated that her husband, the care receiver, did not seem to understand her role as caregiver. She stated, "He thinks everything I do is for me, but it is really almost all for him. He doesn't think he needs any care." Vivian related that prior to taking on the caregiver role herself she did not understand the difficulty of it. Before her current caregiving role, she helped her friend, who was caregiving for her mother, by sitting with the care receiver from time to time. Vivian stated, that she used to wonder, "Gee, what is her [the friend's] problem? This old lady is so nice, she lays in bed, she does not bug anybody." Now, Vivian looks to this friend as the only one out of many friends who can relate to her challenging situation.

Importance of Living at Home: Use of Resources

The caregivers in this study mentioned throughout the interviews the importance of maintaining their loved ones at home. Many of the caregivers in this study stated that resources for caregivers were scarce and that information was not easily accessible. However, all the caregivers in this study received some source of outside help with the caregiving tasks and other tasks in the home at some point in their caregiving responsibilities. Included in this theme is the use of resources that helped the caregivers directly and indirectly maintain the care receiver at home.

Steve had attendant care 20 hours a day. Amy had full time attendant care in the beginning, but she is currently caring for her husband by herself. Caregivers reported that family support was especially valuable in the initial phases after a stroke.

Informal resources such as friends, other family members, church groups, support groups and neighbors were invaluable to the caregivers during the course of caregiving. Informal helpers assisted with transportation, grocery shopping, household chores and providing meals. They also attended to the care receiver for short periods of time so that the caregivers could do other chores and errands.

Some of the caregivers stated that the informal assistants offered to help without prompting and were available to assist when needed. At least one of the caregivers, Vivian, stated that she had to approach a family member (sister-in-law) to assist her with the caregiving tasks of her mother-in-law. According Vivian, her sister-in-law did not offer any assistance in caring for own mother even though she lived a short distance away.

Although many of the caregivers stated that family members have been helpful or have offered to help, none acted as substitutes for the caregivers themselves. There were some tasks that the other informal helpers could not or would not do such as toileting or bathing. It was not clear if the helpers were unwilling to do those tasks or whether the caregivers themselves did not feel comfortable with relinquishing those tasks. Also, the caregivers were reluctant to ask their sons and daughters for assistance because they were so busy with their own lives, work and children.

Caregivers also utilized formal services to help maintain the care receivers at home directly and indirectly by offering practical as well as emotional support. As discussed in the theme of the value of social support, four of the caregivers attended a caregiver support group during the same time as when the care receivers got therapy at a community post-stroke program. While describing the therapies as beneficial to the care receivers, these caregivers described the caregiver support group as "like a family" and "very helpful." The caregivers discussed how they learned that they can obtain help from the phone company and electric company to provide services for nominal charges or for free. According to Wendy, the caregivers in the support group also give each other handy tips to save time.

Emily took her husband to swim therapy where her husband also received his showers. Steve took his wife to a senior center for lunch to relieve him of cooking tasks for at least one meal a day. Four of the caregivers took the care receivers to a senior day service program for several hours a day a few times a week for time for themselves and time to do chores. Vivian utilizes a skilled nursing facility (SNF) for two months out of the year for respite care. She uses this time to go on vacation, to get rest, and for refreshment to continue on with the caregiving tasks for the rest of the year.

Keith also considered his doctors and medical group to be good resources. Keith utilized the services of a social worker for support when he needed to share about his experiences as a caregiver. He felt unable to talk to his wife's children about caring for her because they were in denial about their mother's level of functioning.

Six of the caregivers use some source of hired help to regularly assist with the cleaning duties, gardening tasks, and accounting and other handyman tasks. The caregivers found these resources to be especially helpful.

Rachel and Wendy used the emergency system "911" to assist them when they needed assistance in physically lifting the care receivers. Rachel stated that she has called the fire department twice to lift her husband off the ground when he had fallen. Wendy uses the skills of a golf teacher who teaches her husband to play one-handed golf.

Rachel utilized the respite services through the Veteran's Administration (VA). She underwent eye surgery and was unable to care for her husband, so her husband received respite care for two weeks. Wendy was contemplating using respite services through the VA but was ambivalent about leaving her husband with strangers, especially because he is unable to speak. She stated that she would consider using the respite care only if she knew that her daughter would visit her husband on a daily basis.

The caregivers reported using other programs that are available for elder or disabled persons. For example, the caregivers in the caregiver support group called Pacific Gas and Electric Company (PG & E) as well as Pacific Bell to assist them with any needs. Rachel, who has no transportation, has a hairdresser come to her house.

Stages and Phases in Caregiving

The caregivers described different stages and phases they went through as caregivers. The caregivers felt they needed to understand the different stages in caregiving. The newest caregivers described needing more help with the caregiving tasks. Caregivers had a need to share their experiences with other caregivers who understood the phases of their experiences.

Eight of the caregivers in this study described being under the most stress during the initial phases of the stroke occurrence. Steve related, "It was so traumatic. I really thought that I was going to lose my mind." Vivian was one caregiver who stated that she did not experience high levels of stress during the initial period. She attributes this to having had caregiving experience with three relatives prior to caring for her mother-in-law.

For the most part, caregivers utilized attendants more in the beginning of caregiving when things were new and for some, overwhelming. As Amy related, "For about the first month, I had them [attendants] around-the-clock. I had them here all of the time because I just was not used to everything yet. I felt that if anything happened, I did not want to be here alone." Wendy thought it imperative for new caregivers to have attendant care, in the early phase of caregiving. She stated:

> If someone's husband had a stroke as bad as my husband's was, I would say take your last cent for when you come home from the hospital with him and have a caregiver with you for at least one month. That saved me. I don't think I could have managed otherwise. He was too crippled and too dependent...you just can't feel alone when you come home with him.

Generally, as the caregivers became accustomed to the caregiving tasks, they used less attendant care. As Amy related, "By the end of about a month I started cutting down on that [attendant care]...I was doing about anything that needed to be done at night for him anyway..."

The newer caregivers discussed how they felt that they were doing inadequate jobs as caregivers. They often felt guilty about not doing enough. The more experienced caregivers mentioned that in the earlier phases of caregiving they too felt guilty at times. However, longer term caregivers in this study learned what this caregiver stated, "Well you do your best and don't let it make you feel guilty...because you have done your best."

The concerns of caregivers also shifted as time went on. As Steve stated, "Early on it was the physical part that was really dominant and the financial did not even cross my mind because I was so stressed out anyway. But you can see now that the thing is switching, and now I am tracing this long-term financial which I have to manage." His worries over his wife's physical condition switched to worries over their financial situation.

Goals also changed during the course of caregiving. Vivian related that it took her 4 years of frustration in trying to facilitate her mother-in-law's independence in basic self-care tasks that she finally realized that her mother-in-law did not have the cognitive ability or motivation to be more independent. She was "getting very tired" and not able to spend time with her own grandchildren when she decided that she "couldn't do this anymore." Vivian stated:

> It made it a lot easier for me to face the day for sure, because when I realized there was nothing I could do to get her any better, and that probably she was as well as she is going to get, and it would be a downhill climb from here...a lot better...we just approach it with a whole different attitude.

Interestingly, when the earliest caregivers in the study were queried about whether or not they belonged to a caregiver support group, they felt that they were not ready to join one. They felt that they needed time to adjust before attending such a group. Wendy, who is in a caregiver support group, stated that she and the other caregivers can help newer caregivers by empathizing. She stated:

> The first ones [caregivers] that come in there [to the caregiver group]...we have a session there and they introduce themselves and we all know that she [the caregiver] is going to cry as I did, as we all did, in repeating the words in a room full of strangers. We tell her who we are...we go around the circle and explain who we are...

Adapting to New Life Changes

Caregivers in this study described making many life changes since taking on their caregiving responsibilities. Because of these changes, they said they needed to learn new ways to cope.

In managing stress, caregivers developed various methods. Steve started listening to stress management tapes that his brother had given him. He stated, "I am so bound up on the inside that these tapes tend to release the knots, not all of them, but they seem to help quite a bit." Prior to receiving the tapes, Steve relied on medication to control his stress. He stated, "It [the drug] took me from this terrible heavy weight in my chest, it moderated it. It did not take it [stress] completely away, but it helped me a lot. If it wasn't for that drug I would have been insane...literally would have gone out of my mind." Keith goes to the park every week to relieve his stress. He obtains attendant care for his wife and goes to the park alone for 4 hours. He stated that the visit to the park helps him in his management of stress more than anything else. Amy takes oil painting classes to relieve her stress. There, she socializes with friends and has time to herself.

Other caregivers revealed that they did not have regular stress management techniques, especially those caregivers who had no regular time away from the care receiver. Rachel explained that she has not a minute away from her husband, who requires constant supervision. She explained that she does not even have privacy when she is in her bathroom because they took the door off to accommodate his wheelchair. When asked how she manages she stated, "Just keep going, that's all, what are you going to do? Tomorrow morning you are going to get him up, bathe him, and feed him, dress him, and you know the next morning when you get up you are going to do exactly the same thing, and the next morning, and the next morning, and so forth and so on..."

Dealing with the healthcare system itself is an adjustment for the caregivers. Doctors, specialists, physical therapists, occupational therapists, speech therapists, social workers, Medi-Cal, MEDICARE, and insurance are just some of those mentioned by the caregivers.

The emotional task of adapting to the "new person" after the stroke of the care receiver has been quite an adjustment for the caregivers in this study, especially caregivers who have had to adjust to cognitive/affective changes and communication changes. Rachel stated that her husband is "verbally abusive" while Vivian described her mother-in-law as a "different person."

Managing all the responsibility of caregiving itself has been quite a challenge for many of the caregivers. As Steve stated, "There is so much responsibility and it is all on me...It is really making sure that this whole thing works."

The caregivers have also learned how to deal with medical emergencies and how to recognize changes in the care receiver. For example, Wendy's husband has had seizures and is at risk for having more. The caregiver now recognizes the signs of a seizure and has learned what to do in its occurrence. Vivian now recognizes the signs of a TIA because her mother-in-law has had many in the past.

Many of the caregivers and the care receivers had plans for a life of leisure and traveling during retirement. However, with the advent of the stroke, many of those plans will not materialize for the caregivers. Rachel and Amy's husbands were recreational pilots before their strokes and they and their spouses were looking forward to doing much traveling during retirement. Emily and her husband were looking forward to traveling across the United States by train and getting off at whatever stop they wanted. Wendy and her husband had just retired to Arizona from the San Francisco Bay Area when he had his stroke. Vivian stated that she did not want to spend her retirement years caring for her ailing mother-in-law.

Financial changes have also been an adjustment for the caregivers. Wendy stated, "Our finances have diminished tremendously because of the medical bills...We had a great deal of money in our savings accounts, and we had it in money markets and so on, but it is diminishing." Steve stated, "Right now, I am worrying about finances. I can see all our savings being gone in maybe ten years or so, maybe five years."

Summary

Related to question one, eight themes which recurred throughout the interviews with the participants have been identified and discussed. The themes were: loss of time to do activities of daily living, value of social support and interpersonal relationships, lack of wheelchair accessibility in the home and community, valuable aspects of interactions with health care professionals, challenges of role changes within relationships, importance of living at home: use of resources, stages/phases in caregiving, and adapting to new life changes.

A review of the data and common themes demonstrate that family caregivers of older persons who have had a CVA have many needs.

2. What role can occupational therapists play in assisting family caregivers of older persons who have experienced a cerebral vascular accident?

The caregivers of this study have identified several needs, including what they need from health care professionals. They reported that occupational therapists should involve the caregiver in the rehabilitative process by providing caregiver training, offering resources and information, and practicing good communication skills.

Caregiver Training

Caregivers stated that occupational therapists can assist them by teaching them the practical "how to's" of caregiving such as transfer training, use of the wheelchair, and other activities of daily living (ADL). Emily and Amy felt they learned a great deal from therapy. Amy described how it had been helpful for her to learn how to do transfers and assist with self care. She also discussed how she had been given a video tape showing how to do upper extremity exercises with the care receiver at home. She found this to be particularly beneficial.

Three of the nine participants reported that they did not receive any caregiver training and had to learn the various tasks "on the job." Rachel stated that more "hands on" training from occupational therapists would have been beneficial. She described her hospital experience with therapy as follows: "I was there every day about 9:00 and I would go in, but they had so many therapists there that you didn't do anything, they wouldn't let you put him to bed or out of bed or anything, I guess for insurance reasons, I don't know. They bathed him and everything." Rachel also described how the lack of caregiver training led to some especially frustrating moments when the care receiver went home from the hospital for the first time. She said she did not have any idea what to do with him, and she felt like a "nervous wreck." She reported, "The first day we had him home I had a commode in the back bedroom and I took him back at 6:00 in the morning and the whole damn thing tipped over. I had to get help to get him off the floor. I think it would be helpful if they would train you, or have you go to classes and practice on nurses or other people..."

Caregiver Resources

Caregivers also reported that occupational therapists can assist them by offering resources for support and information regarding strokes. According to the caregivers in this study, community stroke programs were reported as being a valuable way of receiving social support. Four of the participants regularly attended a support group, and they all shared positive feelings about the experience. Many of the participants felt that it took a long time before they were told of any support group for caregivers. Rachel said she had sought out a support group and was unsuccessful at finding one.

Steve expressed the need to find out about what kinds of conferences and seminars are available for caregivers. He said, "I get to these things accidentally in some cases. There ought to be a much more centralized way of getting to know who is doing what conference where." Steve said he received inadequate information regarding his wife's status and about strokes in general. To better understand his wife's condition, he needed to research the subject himself. Vivian and Michelle expressed a similar frustration about not receiving enough information. When discussing health care professionals, Vivian said, "The thing that I have found when I ask questions, nobody seems to be able to give you a cut-and-dry answer. Like this is what is going to happen, this is what won't happen. It is just like it is a gray area and nobody seems to know." Michelle stated, "I get the feeling that they do not know much about it other than what has happened."

Effective Communication

Another role for occupational therapists identified by the participants is for therapists to act as communicators with themselves and with the care receivers.

The caregivers identified ways in which communication could be improved. One way is for the therapists to understand the perspective of the care receivers as well as the caregivers. Too often, participants said, their viewpoint was not considered when information was being given.

Vivian felt her opinion was oftentimes discounted by health care professionals. She said, "They think they know all the answers and you don't...they just don't listen...it is like they are preprogrammed to give you these pat answers and it doesn't make any difference." She added, "Over the years I have seen...too numerous to mention...specialists, therapists, psychologists, right on down the line and...it is like you are talking to a wall." Vivian said that to her, good interpersonal skills of the occupational therapists were more important than good technical skills.

According to Wendy, addressing the care receiver directly is also a part of being a good listener. She said she appreciated a physician who spoke to her husband face-to-face. Wendy said, "[The physician] had the courtesy to turn to him [her husband] and address him when she spoke about his condition or anything...This is respect for my husband."

In addition, Sue suggested that occupational therapists repeat the information they give to caregivers and care receivers. Repeating information could help the caregivers understand and remember the information, as well as apply the information correctly. She said, "They need to repeat nearly everything they tell the caregivers at least twice, just because there is so much to learn, so much new, that it does not always register everything." Being a teacher herself, Sue suggested that therapists ask the caregivers to repeat directions to make sure that they understood and to help them to remember what they had been taught.

According to Steve, good communication could be facilitated by the therapist's understanding of the "whole person." He felt that health care professionals should not just consider the care receiver in providing treatment, but also their environment, and the mental and emotional status of the caregiver. He stated, "When she was in her worst time, the earliest time, nobody thought to take care of me at all...I was almost insane. They just ignored me as though it was my problem." Steve said he was given little information about what he should do immediately after the stroke, which caused him a great deal of anxiety. He stated, "Nobody even told me what to do, I just got in my car, I was dazed, and I drove home...It was so hard for me, I could not believe the reality of it."

The caregivers discussed how occupational therapists need to have realistic expectations and suggestions for caregivers and care receivers. Michelle stated "I don't think they are completely realistic about what a person can be expected to do." Although a suggestion could be helpful in an ideal situation, some ideas may not be applicable in a world where there are financial and practical constraints. Rachel said, "The occupational therapists...used to want to put up bars and knock a wall out and stuff like that which is not practical. If we had knocked walls out, we would have been in the house next door." While Keith was discussing how a psychiatrist was recommending that the caregiver take more time for himself Keith said, "That's all right sitting up in a hospital telling me what to do. Their theory is a long way from my reality. Theory is a wonderful thing, but it's when you come to put the theory into play, you enter into reality."

Summary

In summary, caregivers identified functional and interpersonal roles that occupational therapists could assume to help them cope with the demands of caregiving. The major roles for occupational therapists to assist these caregivers were identified by the caregivers as (a) providers of technical information regarding techniques such as ADL and transfers; (b) resources for community programs concerning long term caregiving and social support options; and (c) as communication facilitators.

CHAPTER 5

SUMMARY AND IMPLICATIONS FOR OCCUPATIONAL THERAPY

Summary

Because of skyrocketing costs in healthcare, Congress and the current Administration are exploring options for healthcare reforms. Now, more than ever, it is important for all healthcare professionals, including occupational therapists, to consider the caregiver when treating the care receiver. Because the majority of frail elders in the community are cared for by family members (Huston, 1990), current healthcare costs are buffered. Caregiver needs should be addressed so that healthcare costs will not rise further.

The data revealed that the caregivers had many needs, several of which could be fulfilled by occupational therapists. Involving the caregiver in the rehabilitative process as stated earlier is essential. Based on an extensive literature review, Corcoran and Gitlin (1992, p. 802) found that the "emotional, physical, and social consequences of caregiving differ based on gender, familial relationship, and cultural background." The researchers stated that health services for caregivers must be "flexible to address each caregiver's specific needs, style of care, and values." Based on Corcoran and Gitlin's (1992) research, it is important that occupational therapist not generalize family caregivers into one group but rather be sensitive to differences and plan treatment based on individual differences.

All nine participants in this study stated that they experienced a loss of time to perform activities of daily living since becoming caregivers. In studies done by Wood (1991) and Jacob (1991), caregivers also reported the loss of time when discussing changes brought on by caregiving. These family caregivers reported that a lack of personal control of time was one of the new daily stresses in their role as a primary caregiver (Jacob, 1991; Wood, 1991). Participants stated that they "let a lot of things go" and they didn't have the time to care for themselves. Just as caregivers in this study discussed the need for respite, McLean and colleagues (1991) also found that stroke survivors and family caregivers identified respite as a primary need.

Throughout the interviews, all of the participants discussed their social experiences and need for social support. Receiving social support played an important role in the coping process for the caregivers in this study. The caregivers who belonged to a caregiver support group considered the experience valuable. Green and Monahan (1989) found that support groups that were professionally guided were successful in reducing anxiety, depression and a sense of burden. On the other hand, Oktay and Volland (1990) and Evans and colleagues (1992) report that general caregiver support programs have not succeeded in reducing perceived burdens or in providing practical assistance. They suggest the need to evaluate further the programs that were offered. Evans and colleagues (1992) also reported that those in most need of supportive care frequently do not participate in support programs because of practical problems such as transportation. This was found to be true of one of the caregivers in this study who did not belong to a caregiver support group because of lack of transportation.

The participants discussed their difficulties in getting around in their homes and in the community because of lack of wheelchair access. This finding is consistent with the findings of McClain and associates (1993), who completed a study in the Midwest, that found that only 53 percent of 120 restaurants provided handicap parking, 66 percent provided ramps where needed and only 60 percent had wheelchair accessible restrooms. The study also identified that a common problem in restaurants was that only one out of three provided table height that allowed for adequate knee clearance.

Throughout the interviews, the participants discussed both positive and negative interactions with health care professionals. They emphasized that communication skills, not technical skills, made a difference in how they viewed their therapist interactions. In a pilot study, caregivers listed one of their top 20 education needs as "to interact with medical and other service providers" (Matthis, 1991). This suggests that communication between caregivers and health care professionals is important in helping caregivers learn their roles.

The caregivers discussed role changes that occurred when they became caregivers. Llorens (1991) states that occupational performance which are tasks related to self-care, work, play/leisure, and rest are critical to the assumption of life roles. Within the bounds of each role, expectations are formed by society and the role occupant so that one's satisfaction with the performance of the roles is based on internal as well as external factors. An important life role that the participants in the study hold is that of caregiver. As the data revealed, the caregivers took on added tasks and roles and also experienced reversals in roles. Just as Hasselkus (1988) found sense of role change and responsibility to be one of the themes of meaning in caregiving, our study also found this to be a theme. As Jacob (1991) reports, becoming a family caregiver or receiver changes the family structure, patterns and roles. This was also found to be true for the caregivers in this study.

The caregivers utilized many resources to maintain their loved ones at home.

As Jacob (1991) points out in her article, families are the predominant health care providers for impaired older people in the community. Furthermore, according to Evans and colleagues (1992), the majority of stroke survivors reside at home with family members. However, research has shown that support for family caregivers is minimal or nonexistent (Ebersule & Hess, 1985).

The data revealed that the caregivers appeared to go through or be in different stages or phases of caregiving. As Korner-Bitensky and colleagues (1989) point out, family reactions to stroke deficits are most severe 1 to 4 weeks after diagnosis. Likewise, in this study, participants stated that the initial period following the stroke was the most stressful. However, as time passed, the caregivers adjusted to their new roles, as they found support and new ways of coping.

The participants in this study made many adaptations to their roles as primary caregivers. According to Christiansen (1991), roles are dynamic as they are acquired or replaced throughout the lifespan. She states that transition times are important because they involve the development of new skills or integration of skills previously learned. The caregivers in this study learned to adapt to their new roles, with some making smoother transitions than others.

According to Evans and associates (1992), the most often reported problems resulting from alteration in lifestyle after stroke involve emotional reactions, role changes, and communication ability. The caregivers in this study also discussed the difficulties in managing emotional reactions and adapting to role changes. As Silliman and others (1989, 1984) report, functional disability is not a determinant of the lack of well-being among caregivers. Disruptive behavior and diminished social functioning on the part of the care receiver and aspects of the caregiver-patient relationship appear to be as important, if not more important, than functional disabilities. These findings are also consistent with the data in this research.

Implications for Occupational Therapy

Occupational therapists can play an important role in assisting family caregivers of older persons who have suffered a stroke. Caregivers of this study identified several needs, including needs from health care professionals. Occupational therapists work with individuals who have disabilities to assist them in becoming as independent as possible in their daily activities. Many registered occupational therapists and certified occupational therapy assistants work with older adults who have had a stroke (Davis, 1988). The American Occupational Therapy Association includes caregiver and family education in its standards of practice (AOTA, 1992) and occupational therapy literature emphasizes the importance of caregivers and family in the outcome of treatment (Hill-Matthew, 1985; Kunstaetter, 1988; Levine, 1978; Marjoribanks, 1982). Because of occupational therapy's holistic basis and its commitment to the well-being of patients (Kunstaetter, 1988), occupational therapists can help to meet the needs of older stroke patients and their caregivers.

Caregiver needs were identified in the eight themes and occupational therapists can play a role in helping the caregiver to meet these needs. First, occupational therapists can involve the caregiver in the rehabilitative process. According to Jacob (1991), in order for the caregiver to best support the care receiver, they should be included as part of the rehabilitative team. Evans and associates (1992) reported that the family is as important as the patient in determining rehabilitative outcome. Occupational therapists can have their patients and family caregivers help in establishing realistic goals and include them in appropriate treatment sessions. Opportunities to involve the family in occupational therapy services is identified by the American Occupational Therapy Association (AOTA, 1992). However, documentation regarding the extent and manner in which occupational therapists work with families appears to be minimal at best according to Humphry and colleagues (1993). This is also noted by Kunstaetter (1988) and Loisch (1985) who report that in interviews with home health occupational therapists, including caregiver education in their treatment was common, but when reviewing records, patient and family support was not documented.

Caregivers reported that they had little time to perform their activities of daily living. Occupational therapists can assist family caregivers in balancing these functions. Working with caregivers on time management and helping them to explore interests are two ways to do this. Educating the caregiver on the needs of the care receiver and emphasizing the need for the caregivers to take care of themselves can also be valuable. In addition, therapists can help caregivers by understanding the financial and practical constraints that they must work under, and provide therapies accordingly. Participants in this study noted that they were frustrated when therapists advised therapies that were not practically feasible or when their goals seemed overly optimistic.

Occupational therapists can assist the caregivers in adjusting to the challenges in making role changes. Occupational therapist can assist the caregivers by teaching them the practical "how to's" of caregiving such as transfers and other ADL. Furthermore, because occupational therapists are trained in helping people to adjust to role changes they can evaluate the caregivers needs and provide much needed counsel. Jacob (1991) reported in her study on caregiver support that because the role of caregiving is both physically and emotionally challenging, offering support about care decisions, reassuring caregivers about feelings and allowing the caregiver to ventilate feelings are all beneficial ways of supporting the caregiver (Jacob, 1991).

The caregivers discussed difficulties in obtaining resources, so another way occupational therapists can assist the caregivers is by offering resources and helping them to organize a system to utilize resources such as family members. For example, occupational therapists can instruct the caregivers in how to set up a calendar to organize a schedule of times when family members can help.

Occupational therapists can identify the need for and refer family caregivers to support groups that offer the appropriate help and assistance. According to the caregivers in this study, community stroke programs were reported as being a valuable way of receiving social support. Occupational therapist could also include close family members and friends in caregiver training. This would be a way to get more people involved in the caregiving process. According to White-Mean and Thornton (1990) using other caregivers could decrease caregiver burnout.

Occupational therapists have the expertise to offer suggestions for better wheelchair accessibility and ideas for finding resources such as a list of wheelchair accessible restaurants. Also, making wheelchair transfers as independent as possible for the care receiver could help decrease the caregiver's frustrations of managing the wheelchair. Getting involved in legislation regarding wheelchair accessibility is another avenue occupational therapists can take to increase the accessibility for wheelchairs in the community.

The caregivers identified some ways occupational therapists can improve their interactions with both the caregiver and care receiver. They suggested that occupational therapists treat the "whole person" and demonstrate good communication skills. The caregivers in this study valued being listened to and cared about more than anything else. Also, being offered realistic suggestions versus unrealistic recommendations was appreciated by the caregivers.

Occupational therapists can assist the caregivers by acknowledging that there are stages that they will go through as caregivers. In this study, participants commented that they were frustrated when they were not informed about the status of their loved ones or of what outcomes to expect. Occupational therapists should not assume that someone else has already given caregiver information regarding strokes and resources. Evans and associates (1991) found that families that had optimal post-stroke home care had more knowledge about the stroke by the time the patient was discharged from the hospital than those in less optimal situations. As caregivers in this study discussed the importance of education, McLean and colleagues (1991) also identified education as one of the six perceived needs of family caregivers of stroke survivors.

Health care professionals should understand that readiness to receive information depends upon the stage the caregiver and care receiver are in the rehabilitative process. The literature warns health care professionals to be cautious about the burden they add to already difficult family situations by involving families in therapy, especially for less functional families (Evans et al., 1992). Evans and colleagues (1992) stated that expecting compliance with treatment instructions when families are coping poorly can be useless. Also, according to a study by Evans and colleagues (1992), supportive counseling is more effective than education in reducing family dysfunction. Humphry and colleagues (1993) report that lack of effective interaction with families can create a negative attitude and thus may not develop the necessary skills or experience for successful family-therapist involvement (Humphry et al., 1993). Therefore, occupational therapists need to assess their own strengths and weaknesses in family interactions to work towards more effective encounters.

In addition, therapists can help caregivers by instructing them in stress management techniques. Teaching caregivers what to do in medical emergencies, such as seizures, can help relieve stress, as well. Occupational therapists can further help reduce stress by teaching caregivers how to prevent health hazards by conducting home safety evaluations.

As indicated in the literature review, there have been few studies done in occupational therapy that have explored the needs of family caregivers of those who have experienced a CVA. Further research would be helpful in more completely determining caregiver needs and the role of occupational therapists. Replication of this study as well as longitudinal and comparative studies would be appropriate for comparison and expanding the existing data. Studying caregiver activities for coping and efficacy of current caregiver and occupational therapy intervention would also be beneficial. For example, a comparison study of persons who have received occupational therapy services to those who have not could be conducted.

Socioeconomic, cultural, and gender differences could be explored as well as comparing needs among caregivers at different stages in their experience. For example, studies could explore in more depth the needs of new caregivers (less than 1 year post-stroke), since that is when most rehabilitative services are given.

Other research topics include caregiver training in self-care and functional transfers, knowledge of the physiological effects of the stroke, awareness and use of adaptive equipment and awareness of community resources. As researchers learn more about the needs of caregivers, occupational therapists can learn to better meet their needs as caregivers and help them more effectively accomplish their tasks.

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APPENDIX A

LETTER TO FACILITY DIRECTORS

Letter to Facility Directors

Date

Dear :

We are occupational therapy graduate students at San Jose State University who are currently working in the field and are doing this research for our thesis. The purpose of our study is to explore the needs of family caregivers of older people who have previously had a cerebral vascular accident (stroke). It is our hope that occupational therapists can better understand how to assist family caregivers through this research.

For this research we are planning to conduct in-depth interviews of family caregivers. We are asking for your help in locating any potential interview subjects. The criteria for subject selection are as follows:

1) A subject is a relative whether of blood relation or legal formality (marriage, adoption, etc.) to the care receiver.

2) The person being cared for has as his/her primary diagnosis a cerebral vascular accident (stroke) and is 60 years or older.

3) The caregiver has been caregiving for the person who has had the stroke for at least 2 months and lives with them.

4) The subject lives in the San Francisco Bay Area of California.

5) The older person requires daily care from the family caregiver.

6) The caregiver is 21 years of age or older.

We hope that the interviews can take place in subjects' homes. The interviews will take a total of two to four hours which will be divided into approximately two to four different sessions--whatever is convenient for the caregiver. The interviews will be audiotaped for later transcription. Of course, the subjects' involvement will be completely voluntary and any information obtained will be kept in the strictest of confidence.

We would greatly appreciate it if you would read the enclosed short text to any potential subject and send it back to us in the enclosed form in the self-addressed-stamped-envelope. Your assistance with this research would be most helpful and is greatly appreciated.

Please feel free to call us if you have any questions regarding our research.

Sincerely,

Sonja Johnson-Egertson, OTR
(415) 967-4181

Jean S. Koketsu, OTR
(408) 267-5058

APPENDIX B

TEXT TO BE READ BY POTENTIAL SUBJECTS

Text to be read by potential subjects

You are invited to participate in a research project that will be conducted by two occupational therapists who are graduate students from San Jose State University. The purpose of the study is to explore the needs of family members caring for older people who have had a stroke. It is hoped that the research can help occupational therapists to understand how to better assist family caregivers such as yourself.

The study will be conducted using an interview format. If you choose to be a part of this study, one researcher will interview you in your home for approximately two to four hours. The interviews will be tape recorded and can be spread out over several sessions, depending upon your schedule.

Your participation in the study is completely voluntary and any information obtained from you will be kept in the strictest of confidence. Whether or not you choose to be involved in the study, your decision will have no bearing on your relationship with your therapist. If you agree to participate in the study, please fill in the bottom of this form and the occupational therapist (or other health care professional) will give your name and phone number to the two researchers. One of the researchers will then contact you by phone to set up an appointment. Thank you for your consideration in being part of this research. Please feel free to call either researcher if you have any questions regarding the study.

Sonja Johnson-Egertson	Jean Koketsu
(415)967-4181	(408)267-5058

Potential Subject:________________________

Phone Number:____________________________

APPENDIX C

CONSENT FORM

Consent Form
Agreement to Participate in Research
San Jose State University

Responsible Investigators: Sonja Johnson-Egertson & Jean Koketsu
Title of Protocol: An Exploration of the Needs of Family Caregiver of Older Persons After a Cerebral Vascular Accident

I have been asked to participate in a research study that is investigating the experiences and needs of family caregivers of older persons who have experienced a stroke.

I understand that
1.) I will be asked to be interviewed and audiotaped for two to four hours in my home about my experiences as a caregiver.

2.) the possible risks of this study are that I might be asked to reveal personal information about my caregiving experiences.

3.) the possible benefits of this study to me are that I can share my experiences as a caregiver to someone who will listen and be non-judgmental.

4.) alternative procedures may include being interviewed for short periods of time on several occasions or being interviewed for longer periods of time on fewer occasions.

5.) the results from this study may be published, but any information from this study that can be identified with me will remain confidential and will be disclosed only with my permission.

6.) any questions about my participation in this study will be answered by Sonja Johnson-Egertson (415) 967-4181 and Jean Koketsu (408) 267-5058. Complaints about the procedures may be presented to Kathleen Barker Schwartz, Ed.D at (408) 924-3073. For questions or complaints about research subject's 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.

7.) my consent is given voluntarily without being coerced. I may refuse to participate in this study or in any part of this study, and I may withdraw at any time, without prejudice to my relations with San Jose State University.

8.) I have received a copy of this consent form for my file.

I HAVE MADE A DECISION WHETHER OR NOT TO PARTICIPATE. MY SIGNATURE INDICATES THAT I HAVE READ THE INFORMATION PROVIDED ABOVE AND THAT I HAVE DECIDED TO PARTICIPATE.

Date:________________
Subjects Signature____________________________
Investigators' Signatures________________________

APPENDIX D

DEMOGRAPHIC INFORMATION/QUESTIONNAIRE

Demographic Information/Questionnaire

1. Initials of Caregiver/ID #:______________________________

2. Age of caregiver:_____________

3. Sex of caregiver: M F

4. Marital status of caregiver: Married Single Divorced Separated Widowed

5. Ethnicity of caregiver:____________________________

6. Primary language spoken:__________________________

7. If not American culture, what culture do you identify with?_______________________

8. How many people live in your household?__________

9. Do you have any children (under age 18) living at home? If yes, how many and what are their ages?____

10. Age of care receiver:______________

11. Sex of care receiver: M F

12. Marital status of care receiver: Married Single Divorced Separated Widowed

13. Ethnicity of care receiver:___________________________

14. Primary language spoken:_________________________

15. If not American culture what culture does the care receiver identify with more?____

16. Relationship of caregiver to receiver (example: wife, son, daughter-in-law, etc):

____

17. When did the stroke occur?_________________________________

18. Has the care receiver ever had a stroke before?______ **If yes, when and how many?**____

19. Do you live with the care receiver? Yes No

20. How long have you been caring for the care receiver?_____________________

21. What other health conditions does the care receiver have?

22. How is your general health and well-being? Poor Fair Good Excellent
Please explain:

APPENDIX E

INTERVIEW GUIDELINE

Interview Guideline

Interview Introduction:

My research partner and I would like to thank you for your participation in our study. There are a few things I would like to go over with you before we start the interview. The purpose of our study is to explore the needs of family caregivers of people 60 years and above who have had a stroke. Our hope is that through this study we can learn how to better meet your needs. We want to remind you that any information you share with us is completely confidential and only myself and my research partner will know your identity. If it's okay with you, I would like to tape record our interview to ensure accuracy of the information collected. For the purposes of transcription, I will be introducing a set of questions with a phrase and number. For example, I may say "Section 2, Life Tasks." Please feel free to stop the interview at any time to ask questions and if you don't feel comfortable answering a question, just let me know. Also, let me know if the interview is going too long and if we need to finish it at another time. Before we get started, do you have any questions?

Introduction Questions

1. Tell me about yourself.
2. Tell me about your significant other.
3. Tell me about your family.
4. Tell me about the circumstances around the stroke.
4. Tell me about what you have been told about ________________'s (care receiver) medical condition from healthcare providers.

Life Tasks

ADL

1. Describe a typical, 24 hour day for you.
2. a. Tell me about the things that ________________(care receiver) can do for himself.
   b. Tell me about the things that ________________ can't do for him/herself.
3. What kind of personal care do you assist ________________ (care receiver) with?
4. How much time does it take to provide the personal care for ______________(care receiver)?
5. How do you feel about offering the personal care you give?
6. Do you feel adequately trained to care for ________________ (care receiver)? If not, do you feel you could be trained?
7. Has your personal care of yourself changed since you started caregiving? If so, how?
8. What have you found to be most helpful in your daily management with ______________?

Work

9. Are you currently employed (paid work) or go to school? Do you do volunteer work? How much of your time is spent working, studying (or in classes) or volunteering? Describe what you do.
10. Are you a homemaker, or do you engage in homemaking tasks? Describe what you do.
11. Do you currently engage in parenting tasks? Describe what you do.
12. Has anything related to work/volunteering/studying/homemaking/parenting changed since you started caregiving? What? How?
13. If you're not employed or volunteering, would you like to be? If yes, doing what?
14. What is the significance of paid work/volunteering/homemaking/parenting to you?

Leisure

15. What is your favorite way to spend your leisure time? How often do you engage in such tasks now? Before caregiving?
16. Has your favorite way to spend your leisure time changed since you started caregiving? If so, how?
17. What other ways do you spend your leisure time?
18. How much of you time is spent in leisure? Is that enough for you?

Activities with care receiver
19. What is your favorite activity to engage with ________________ (care receiver)?
20. What activity do you not enjoy doing with ______________ (care receiver)?

Perceptions of self as caregiver
1. Do you feel you do an adequate job as a caregiver? If yes, how? If no, why not?
2. If you don't feel adequate as a caregiver, how have you dealt with those feelings?
3. How do you feel you've succeeded as a caregiver?

Role as caregiver
1. How did it come about that you became the primary caregiver?
2. How do you feel about having the role as primary caregiver?

Perceptions of relationship
1. What are the joys of caregiving?
2. What are the challenges of caregiving?
3. Tell me about your relationship with the care receiver. How has it changed since the stroke?

Needs
1. What do you see that health care professionals could provide for you as a caregiver?
2. What do you see as your greatest need as a caregiver?
3. If you do have needs, how do you feel those needs could be met? By whom?
4. Are your needs as a caregiver ever met? By whom?
5. If your needs aren't being met, what is preventing you from meeting those needs?
6. How have people in the past helped you out to meet any needs that you have? Who provided the help?
7. What advice about care would you give to a family caregiver in a situation similar to yours?

Training
1. Did you receive any caregiving training? By whom? If yes, what in? Was the training adequate?
2. If you could receive any type of training what would it be in?
3. What advice would you give to an occupational or physical therapist regarding training a family caregiver?

Home Health
1. Have you had any home care O.T.? How much? What did they do? Was it helpful? How?
2. Does ________________(care receiver) receive any outpatient rehabilitation? By whom? For how long?

Support Group

1. Are you or the care receiver in any support groups? If yes, which ones? For how long? Are they helpful? How?
2. Are you or the care receiver in any other groups, classes or social groups? Please describe them.