The Effects of Emotional Support and Physical Help on the Health of Caregivers of Persons with Stroke

Submitted by

Erin J. Nofziger

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Major Advisor
Linda Pierce, Ph.D., R.N.

Academic Advisory Committee
Victoria Steiner, Ph.D.
Tracy Szirony, Ph.D., R.N.C.

Dean, College of Nursing
Jeri A. Milstead, Ph.D., R.N., FAAN

Dean, College of Graduate Studies
Keith K. Schlender, Ph.D.
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Erin J. Nofziger

Medical University of Ohio

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DEDICATION

This paper is dedicated to my husband, Glenn, for his belief in me, and his faithful love and support.
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CHAPTER I

Introduction

About 4.8 million stroke survivors are alive today (American Stroke Association, 2006). Due to early discharge from acute care and rehabilitation settings, many of these persons spend a significant portion of their recovery in the home (Moore, Maiocco, Schmidt, Guo, & Estes, 2002). Continued care in this setting is often provided by informal caregivers, most of whom are family members (Dennis, O’Rourke, Lewis, Sharpe, & Warlow, 1998; Dorsey & Vaca, 1998; Moore, et al.).

Providing care for persons who have survived a stroke can be burdensome and stressful, and can contribute to the development of physical health problems in caregivers (Beach, Schulz, Yee, & Jackson, 2000; Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Schulz & Beach, 1999). These problems may be influenced by variables both internal and external to the caregiver, including age and gender of the caregiver, length of time in the caregiving role, functional and cognitive impairments of the person with stroke, and available forms of emotional and physical support (Beach, et al.; Burton, et al.; Sit, Wong, Clinton, Li, & Fong, 2004; White, Mayo, Hanley, & Wood-Dauphinee, 2003). All of these variables are subject to change over time. An understanding of the relationships among these variables will enable nurses and other health care providers to better meet the needs of this population of caregivers.

Of particular interest to this study is the relationship between caregivers’ physical health and the receipt of two important resources – emotional support and physical help.
Background information related to the study population and variables, evidence of the need for the current study and its significance to nursing, a description of the theoretical framework chosen to guide the study, research questions and definitions of the study variables, and assumptions and limitations of the theoretical framework are presented in this chapter.

Statement of Problem

Caring for a person with stroke is not an easy task. At least 50% of persons with stroke have some degree of functional or cognitive disability (White, et al., 2003). Depending on the type and degree of impairment, caregiving duties may range from companionship to complete assistance with activities of daily living such as bathing, dressing, and feeding. Caregivers often experience emotional distress as they make lifestyle adjustments and grieve losses of ability in their loved ones (Kerr & Smith, 2001). When the situation of providing care interferes with the caregivers’ ability to meet their own self-care needs, their physical health may be compromised (Beach, et al., 2000; Burton, et al., 2003; National Alliance for Caregiving and American Association of Retired Persons, 2004; Schulz & Beach, 1999).

A variety of community services exist to help meet the physical and emotional needs of both caregivers and care recipients. These include (but are not limited to) adult day care and respite programs, home health care, Meals on Wheels, and counseling and support groups. Caregivers who employ community services benefit from personal renewal, a sense of community, and acquisition of knowledge to improve their care
(Winslow, 2003). Unfortunately, many caregivers are unable or choose not to use formal services for reasons related to cost/insurance, lack of knowledge about the services, or worry about the quality of care provided (Moore, et al., 2002; Winslow). The majority of caregivers of persons with stroke look first to family and friends for emotional support and assistance with the physical duties of caring (Winslow).

Informal networks of support, both inside and outside the home, are a vital component of most caring relationships (McGarry & Arthur, 2001). While the specific composition of these networks varies between cases, spouses, adult children, and/or close relatives often provide the main means of help and support (Choi & Wodarski, 1996; McGarry & Arthur; Schulz & Beach, 1999). The type of support provided also varies between cases and includes assistance with housework, help with the physical aspects of caring, emotional support, and financial assistance (O’Connell & Baker, 2004). Caregivers view this support from family and friends as essential to coping with the challenges of caring for a person with stroke (O’Connell & Baker).

While the positive effects of general social support on psychological well-being have been well-documented in the literature (George, 1996), the relationship between social support and physical health remains ambiguous (Choi & Wodarski, 1996). The assumption behind a possible relationship is based on the buffering effects of social support. In the case of caregivers of persons with stroke, this implies that emotional support and physical help provided by family members and friends may serve as a buffer
against the negative health effects of caring (Choi & Wodarski). In other words, the informal care network protects against poor health outcomes in the caregivers.

The relationship between informal support and physical health has received some attention in the caregiver literature. One study in particular suggested that social support, measured by the size of the support network and the type and adequacy of support received, has a positive impact on the general health of caregivers of persons with stroke (Sit, et al., 2004). This study provides valuable information about the relationship between these variables, but does not account for the dynamic nature of caring, as it only describes one point in time.

The experience of caring for someone with stroke is expected to change over time as the survivor makes functional gains and/or the caregiver adjusts to the caring role (White, et al., 2003). The amount of emotional support and physical help received by the caregiver is also likely to change with time based on these factors. Time, therefore, is an important variable to consider in the interpretation of the effects of caregiving (White, et al.).

Several qualitative studies have revealed that caregivers of persons with stroke feel inadequately prepared to take on the physical and emotional aspects of caring (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Kerr & Smith, 2001), suggesting that the early weeks and months after discharge are an uncertain and vulnerable time for caregivers. Few studies have explored the experiences of first-time caregivers of persons with stroke during this acute phase of caring (Dewey, et al., 2002; Pierce, et al., 2004).
Statement of Purpose

The purpose of this study is to examine the effects, in the first 6 months of caring, of emotional support and physical help on the health of caregivers of persons with a new diagnosis of stroke.

Theoretical Framework

The theory that was used to conceptualize this study is Orem’s (2001) self-care deficit nursing theory. Orem specifically addresses the role of the caregiver with her concept of dependent-care agency, which is defined as “the developed and developing capabilities of persons to know and meet the therapeutic self-care demands of persons socially dependent on them or to regulate the development or exercise of these persons’ self-care agency” (p. 515). The person who provides this kind of care to another is called a dependent-care agent (Orem), such as caregivers of persons with stroke.

Within Orem’s (2001) theory, a caregiver would also be defined as a self-care agent. Self-care refers to the activities an individual performs on his/her own behalf to maintain life, health, and well-being. Self-care agency is a person’s potential or ability to engage in self-care activities. It is influenced and shaped by basic conditioning factors, such as age, gender, developmental state, health state, family system factors, environmental factors, and resource availability. A self-care deficit occurs when the person is no longer able, for whatever reason, to meet his/her self-care demands (Orem).
Research Questions

The research questions are:

1. Does the health of the caregivers of persons with stroke change in the first 6 months of caring?
2. Does the emotional support that the caregivers receive change in the first 6 months of caring?
3. Does the physical help that the caregivers receive change in the first 6 months of caring?
4. Is there a relationship among the health of the caregivers of persons with stroke and the emotional support and physical help they receive, and is this relationship different at three periods in time?

Definition of Terms

Caregivers’ Health

*Conceptual definition.* A “state characterized by soundness or wholeness of developed human structures and of bodily and mental functioning” (Orem, 2001, p. 186).

*Operational definition.* This study will focus on the bodily, or physical, aspect of health. An assessment of the physical condition of the caregivers based on general ratings of health at three different time periods in the course of the study: baseline, 3 months, and 6 months.
Caregiver

*Conceptual definition.* A person who assumes the responsibility to take care of another person with a diagnosis of stroke (Orem, 2001).

*Operational definition.* The primary person responsible for the care of a relative or loved one who has survived a stroke and who was a participant for 6 months in the study.

Emotional Support

*Conceptual definition.* A dimension of social relationships which includes “reassurance, sharing emotional burdens through sympathy or empathy, providing encouragement and expressing concern” (Sit, et al., 2004, p. 818).

*Operational definition.* An assessment of the assistance the caregivers receive to deal with the feelings and emotions of caregiving based on answers to interview questions about support received from family members or friends.

Physical Help

*Conceptual definition.* Tangible or instrumental support which includes “taking over duties or doing a chore for needy persons” (Sit, et al., 2004, p. 818).

*Operational definition.* An assessment of the informal assistance the caregivers receive to meet the needs of their loved ones based on answers to interview questions about help received from family members or friends.
Significance

Stroke is the third leading cause of death and a leading cause of long-term disability in the United States (American Stroke Association, 2006). About 4.8 million people with stroke are alive today, and are cared for by an estimated 5% of the informal caregiver population (American Stroke Association; National Alliance for Caregiving and American Association of Retired Persons, 2004). Research has found that the stress and burden of caring for persons with a disability contributes to psychiatric morbidity and increases the risk for physical health problems leading to increased mortality (Schulz & Beach, 1999). The economic cost of caregiving is also great. The estimated value of the family caregivers’ services is $257 billion annually (National Family Caregivers Association, 2002). Despite the rapid adjustment caregivers of persons with stroke must make to their caring role, little research with this group has focused specifically on the experiences of new caregivers in the initial weeks and months of caring. The current study provides valuable information about this growing segment of the caregiving population.

Nurses can play an important role in promoting and maintaining the self-care and dependent-care agency of caregivers (Orem, 2001). Successful nursing care depends on complete and accurate assessment of the therapeutic self-care demands of caregivers and the development of appropriate nursing systems to encourage self-care. An understanding of the relationship (or lack thereof) among the physical health of caregivers of persons with stroke and the emotional support and physical help they
receive from family members and friends will only serve to increase nursing agency in this regard (Orem).

Assumptions

One major assumption being made in this study is that health is a priority for the caregivers, and that they want to continue exercising and developing their own self-care capabilities in addition to meeting the self-care demands of their loved ones (Orem, 2001). It is also assumed that caregiver health will in some way be affected by the presence or absence of emotional support and/or physical help in their caregiving duties (Choi & Wodarski, 1996).

Limitations

One limitation of this study is the absence of clear definitions for the variables of emotional support and physical assistance in Orem’s (2001) theory. These variables are not described specifically in the theory, but they can be linked to several different concepts defined by Orem. For example, emotional support and physical help could both be considered either a family system factor (one of the basic conditioning factors) or a self-care requisite (solitude/social interaction). Also, Orem’s definition of health is not limited to one aspect of human existence, as it is by the purpose of this study.

Summary

Many people with stroke today receive informal care in their homes by family members and friends. Unfortunately, the emotional and physical toll of providing care to these persons can be great, and can contribute to the development of physical health
problems in the caregivers (or dependent-care agents). The receipt of emotional support and physical assistance from family members and friends may help relieve some of the stress and burden of caring, thereby increasing both the self- and dependent-care agency of the caregivers. Orem’s (2001) self-care deficit nursing theory is an appropriate framework for this study because it addresses the unique role of caregivers as both self-care and dependent-care agents. This study explores the effects, in the first 6 months of caring, of emotional support and physical help on the health of first-time caregivers of persons with stroke. An understanding of the relationship among these variables can increase nursing care agency, as it relates to this specific population of caregivers.
CHAPTER II

Literature

This chapter contains two main sections: (1) an expanded discussion of Orem’s (2001) self-care deficit nursing theory, and (2) a review of literature. The discussion of Orem’s theory is focused specifically on how it was used to conceptualize and guide this study. The literature review evaluates the contributions of previous research to the present understanding of the relationships between the study population and variables – caregivers of persons with stroke, their health, and the emotional support and physical help they receive from family members and friends to perform their role.

Theoretical Framework

The theory chosen to conceptualize and guide this study is Orem’s (2001) self-care deficit nursing theory. The following discussion elucidates the relationships among the four main concepts or variables of the study: caregivers, physical health, emotional support, and physical help.

Central to Orem’s (2001) theory is the concept of self-care, which is defined as “the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being” (p. 45). Normally, mature adults engage in self-care voluntarily. The sum of actions these persons must perform at any given time to meet their basic needs, or self-care requisites, is referred to as their therapeutic self-care demand (TSCD). When the individuals’ capabilities for meeting their TSCD become
inadequate, a self-care deficit occurs and assistance is required to maintain healthful functioning.

Orem’s (2001) theory lends itself well to the study in regard to caregivers because of its inclusion of the concept dependent-care agency (DCA). Dependent-care agency is defined as “the developed and developing capabilities of persons to know and meet the therapeutic self-care demands of persons socially dependent on them or to regulate the development or exercise of these persons’ self-care agency” (p. 515). An example of a person who may require dependent-care is someone who has cognitive and physical disabilities as the result of a stroke. The persons who provide dependent care are called dependent-care agents. The caregivers of persons with stroke examined in this study are conceptualized as dependent-care agents. From this point on the terms caregiver and dependent-care agent are used interchangeably.

Caregivers in general are unique in that they play dual roles (Orem, 2001). They are both dependent-care agents and self-care agents. This means that they are responsible to know and meet their own and the dependent person’s self-care demands simultaneously. Sometimes, the demands of caring are so great that the caregivers neglect or lose the ability to meet their own TSCD, and a self-care deficit occurs.

The self-care deficits of caregivers of persons with stroke may manifest as a decline in personal health. Orem (2001) defined health as “a state of a person that is characterized as soundness or wholeness of developed human structures and of bodily and mental functioning” (p. 186). It should be noted that Orem believes a complete
picture of health includes four aspects of human existence: physical, psychological, interpersonal, and social. For the purpose of this study, health was limited to the bodily or physical aspect, not rejecting the fact that all four aspects are interrelated and have important conditioning effects on each other.

There are many variables internal and external to any caregiving situation that have the potential to influence caregiver health outcomes. Emotional support and physical help from family members and friends are two such variables examined in this study. Specific definitions for these variables do not exist in Orem’s (2001) theory, but they can be linked to several different concepts inherent to its structure. Basic conditioning factors are those things such as age, gender, sociocultural orientation, family system, developmental state, health state, environment, and resources that influence people’s ability to meet their own self-care demands (self-care agency) or provide care to a dependent (dependent-care agency). The composite of these factors constitutes the condition from which caregivers respond to their situation (Orem). Emotional support and physical help may be perceived as family system factors or resources that are available or unavailable to caregivers based on their unique situation.

Emotional support and physical help may also fall within Orem’s (2001) definition of universal self-care requisites. These are activities that are necessary to meet the basic needs of daily living, such as the maintenance of a balance between activity and rest and the need for solitude and social interaction. The condition of the universal requisites at any given point in time helps determine TSCD and guide self-care (Orem).
Emotional support and physical help may be perceived as components of the social interaction requisite. For the purpose of this study, these two variables are conceptualized as both basic conditioning factors and universal self-care requisites.

How all of these concepts interact to affect the health of caregivers is displayed in Figure 1. Basic conditioning factors (Orem, 2001), including the presence of emotional support and physical help in family systems and resource pools, influence the universal self-care requisites of caregivers, which also include the need for social interaction with others. The condition of these requisites at any given time determines caregivers’ TSCD. TSCD, in turn, affects the ability of caregivers to meet both their own needs (self-care agency) and the needs of the person with stroke (dependent-care agency). The actual self-care and dependent-care actions that caregivers perform are influenced both by their situational abilities (agency) and by their own and the stroke survivor’s TSCD.

As depicted in Figure 1, the dual roles that caregivers play can condition each other at different levels of the model. Depending on the caregiving situation and the type and character of interactions that take place, caregiver health may ultimately be affected in one of three ways: positively, negatively, or not at all. For example, a negative outcome (or self-care deficit) may result when the demands of caring for the person with stroke outweigh the caregivers’ ability to meet their own self-care needs, or when no or little support is received from family members and friends. A positive outcome may result when caregivers receive sufficient help and support from family and friends. No change in health also is possible as a result of the interactions among these variables.
Figure 1. Conceptual map of Orem’s (2001) concepts and study variables.

Basic Conditioning Factors
Emotional Support & Physical Help

Universal Self-Care Requisites
Emotional Support & Physical Help

Role 1 Self-Care Agent

Role 2 Dependent-Care Agent

TSCD

Self-Care Agency

Dependent-Care Agency

Self-Care

Dependent-Care

TSCD

Caregiver Health

Positive Health Outcome

No Change in Health

Negative Health Outcome (Self-care Deficit)

Note: TSCD = Therapeutic Self-Care Demand
In summary, Orem’s (2001) self-care deficit nursing theory was used to conceptualize this study as relationships among the caregivers’ health and the receipt of emotional support and physical help from family members and friends. Caregivers play dual roles; they are both dependent-care agents and self-care agents. Sometimes the stress and burden of providing dependent-care causes caregivers to neglect their own TSCD, and a self-care deficit occurs. This deficit can be manifested as a decline in physical health. Emotional support and physical help from family members and friends may influence the caregiving situation at several different levels to help buffer the negative effects of caring.

Literature Review

The following review of literature examines what is currently known about caregivers of persons with stroke, their health, and their receipt of emotional support and physical help from family members and friends. The three study variables will be discussed independently first, followed by a review of several studies that examined the relationship between caregiver health and various forms of support.

*Caregivers of Persons with Stroke*

The incidence of chronic illness, the aging population, and the growing need for long-term care highlight the increasing need for dependent-care and its importance (Orem, 2001). Many informal caregivers unselfishly donate large amounts of time and energy to their families and to society each year (Vitaliano, 1997). Unfortunately, this commitment to care often poses a significant risk to the caregivers’ own health and well-
being (Schulz, Mittelmark, Burton, Hirsch, & Jackson, 1997). Understanding the effects of caring on health and how caregivers cope with the demands and stresses of their role enables nurses and other health care providers to better meet the needs of this important and growing population. This study focused on a subset of the caregiving population, those caring for persons with stroke, and the impact of informal emotional support and physical help on their health.

The experiences of caregivers have received considerable attention over the last 2 decades. Han and Haley (1999) noted that the main focus of this attention has been on Alzheimer’s dementia (AD) caregiving. Less research has been conducted on the experiences of caregivers of persons with stroke, despite the high prevalence of stroke and the potentially high burden associated with caring for those it affects (Han & Haley). Since the nature of onset and trajectories of AD and stroke are different, the caregiving responsibilities associated with these diseases also are expected to be divergent (Wright, Hickey, Buckwalter, Hendrix, & Kelechi, 1999). Clearly there is a need to increase our knowledge about the unique experiences of caregivers of persons with stroke.

Due to the nature of the disease, many caregivers of stroke survivors enter the caring role abruptly, with little time to adapt to their new circumstances (Kerr & Smith, 2001; Low, Payne, & Roderick, 1999). Many caregivers feel inadequately prepared to face the emotional and physical challenges of caring for someone with a disability (Bakas, et al., 2002; Kerr & Smith, 2001), suggesting that the early weeks and months after discharge are an uncertain and vulnerable time for caregivers. Despite these
findings, few studies have specifically addressed the needs and experiences of first-time caregivers of persons with stroke during the acute phase of caring (Dewey, et al., 2002; Pierce, et al., 2004).

**Caregivers’ Health**

Many studies that have used caregivers of persons with stroke as their sample population have focused mainly on the psychological impact of caring (Han & Haley, 1999; Low, et al., 1999). Comparatively few studies have explored the effects of caring on the physical health of these caregivers (Han & Haley; Low, et al.). Four stroke-specific studies are reviewed here in detail, but because research on health in this population is limited, several other relevant studies using populations other than stroke caregivers also are reviewed to provide a more complete picture of what is known about the caregiving experience as it relates to the purpose of this study.

White et al. (2003) conducted a study with 97 stroke caregivers to examine their health-related quality of life (HRQL) and overall quality of life (QoL) in the initial 2 years following stroke. They assessed physical health using a 24-item symptoms checklist and the physical component summary (PCS) scale of the Medical Outcome Study 36-Item Short Form Health Survey (SF-36), which measures perceived health status. They found that the caregivers reported a modest number (4-5) of physical symptoms in both the first and second years of caregiving. The most frequently reported symptoms were “feeling tired, headaches, stiff joints, and trouble falling asleep” (p. 182). The caregivers also scored slightly higher on the physical subscale of the SF-36 than age-
and sex-matched population norms, indicating they perceived better HRQL related to their physical functioning and health. Over time the caregivers reported very little change in their physical health (White, et al.).

Another longitudinal study employing the SF-36 assessment tool found the health of caregivers of persons with stroke to be relatively poor compared to the general population, although the differences were not enough to be statistically significant (Bugge, Alexander, & Hagen, 1999). Caregiver health was assessed at three different times – 1 month, 3 months, and 6 months post-stroke. At all three time points, at least 23% of the 110 caregivers reported that their health was worse than 1 year earlier. However, their perceived health did not change substantially over the 6 months of the study. These researchers found that those caregivers in poorer health also experienced greater strain (Bugge, et al.).

Teel, Duncan, and Lai (2001) also assessed the health of stroke caregivers \( (n = 83) \) during the first 6 months of caring. They used the health subscale of the Caregiver Reaction Assessment (CRA), and found that the caregivers reported consistent perceptions of their health over time. Despite this stability, “more fatigue, recurrent sorrow, perceived stress, depressive symptomatology, problems with scheduling and finances, and difficulties with family support” correlated with more physical health problems after 3 and 6 months of caring (Teel, et al., p. 57).

The findings of Wright et al. (1999) are similar to those of the first study (White, et al., 2003). These researchers explored the course of AD \( (n = 14) \) and stroke
caregivers’ \( n = 14 \) emotional and physical health over a 1-year period. They measured physical health using the short form of the Multilevel Assessment Inventory, and found that the scores for both groups remained stable over time. This finding was consistent with their original hypothesis. They did not expect to observe negative physical health consequences at such an early stage in the caregivers’ career (Wright, et al.).

These four studies (Bugge, et al., 1999; Teel, et al., 2001; White, et al., 2003; Wright, et al., 1999), focusing specifically on stroke caregivers, yielded conflicting results. The researchers suggested that the experience of caring may have negative (Bugge, et al.; Teel, et al.), positive (White, et al.), or no effects on caregivers’ physical health (Wright, et al.). One consistent finding, however, was that perceived health did not change significantly over time. This variable has been studied more extensively in other populations of caregivers. An examination of some of these studies may provide a more comprehensive view of the factors affecting physical health.

A number of quantitative studies have explored the health effects of caregiving in the same large sample of elderly spousal caregivers. Schulz et al. (1997) used a variety of objective and subjective physical health outcome measures to assess the effects of caring in a sample of 395 caregivers of disabled spouses. They found that the most significant negative health effects were observed among caregivers who characterized themselves as being strained. These caregivers were more likely to report lower levels of perceived health and insufficient time for self-care activities (Schulz, et al.). Using the data collected in this previous study, Schulz and Beach (1999) did a 4-year follow-up on
the same group of caregivers to assess the relationship between caregiving demands and all-cause mortality. They concluded that the caregivers who reported strain were 65% more likely to die within 4 years than non-caregivers (Schulz & Beach). Two more studies with this group of caregivers focused on the effects of changes in caregiving involvement over time (Beach, et al., 2000; Burton, et al., 2003). These researchers found that increases in caregiver involvement and strain, as well as increases in disability levels of the dependent spouses, consistently predicted poor physical and mental health outcomes (Beach, et al.; Burton, et al.). When caregivers did not perceive strain associated with their role, they reported better mental health (Beach, et al.). This series of four studies yielded consistent results in the same large sample of spousal caregivers over an extended period of time. The common factor for determining physical health decline among these caregivers was the strain associated with providing care. Those experiencing greater strain had poorer health outcomes. This finding also was noted in one of the stroke caregiver studies (Bugge, et al., 1999).

One study with AD caregivers employed a unique design to measure changes in physical health (Shaw, et al., 1997). These researchers followed a group of 150 caregivers for up to 6 years, measuring the time lapse before one of three major health events occurred: (1) onset of an extended illness or disability lasting more than 1 month, (2) an unhealthy medical rating from a nurse interview, or (3) hospitalization. Though the results revealed no significant difference between the caregivers and the control group, there was a trend for the caregivers to have a greater risk for serious illness. This
risk was greater among caregivers who provided more assistance in activities of daily living (ADL). The caregivers who encountered more problem behaviors in their spouses were less likely to be hospitalized. The researchers suggested that these may be cases where the demands of caring overrode the caregivers’ attention to their own physical needs (Shaw, et al.).

The study by Shaw et al. (1997) suggested that caregivers may sometimes neglect their own self-care when the demands of caregiving are great. Preventive health behaviors were the focus of a study by Burton and associates (1997) with a sample of spousal caregivers, using the same sample as in the studies by Beach et al. (2000), Burton et al. (2003), Schulz et al. (1997), and Schulz and Beach (1999). High-level caregiving, defined as providing care to a spouse with at least one ADL impairment, was associated with “not getting enough rest, not having enough time to exercise, not having time to rest to recuperate from illness, forgetting to take prescription medications,” and not finding time for doctor appointments (Burton, et al., p. 162).

Gräsel (2002) compared a group of active AD caregivers ($n = 427$) with a group of former caregivers ($n = 121$) to examine changes in their physical health and use of medical services. He discovered that the occurrence of physical symptoms decreased significantly from baseline to 1 year in the group of former caregivers, while in the active group it remained stable at a relatively high level. Also, the former caregivers made twice as many visits to their physicians compared to the active caregivers. Gräsel
interpreted this as an indication that the former caregivers had more time once caregiving ceased to attend to their own health needs.

In contrast to the majority of studies reviewed thus far, a study by Taylor, Ford, and Dunbar (1995) found no evidence of the negative effects of caring on health. These researchers analyzed data from a previous study, which had measured the physical health of caregivers \( n = 267 \) using a symptoms scale and self-reports of chronic illness. Instead of the expected decline in health, the results indicated a trend in the opposite direction. Caregivers actually reported better health than the non-caregivers (Taylor, et al.). It should be noted that the age of the participants in this study (55 years) was quite a bit lower than that of participants in many of the other studies mentioned up until this point.

The health of caregivers has been examined extensively in the literature, though not in the specific population of caregivers of persons with stroke. The majority of studies reviewed here indicated a decline in physical health and preventive health behaviors associated with the demands of the caregiving role (Bugge, et al., 1999; Beach, et al., 2000; Burton, et al., 1997, 2003; Gräsel, 2002; Schulz, et al., 1997; Schulz & Beach, 1999; Shaw, et al., 1997). A few studies, however, suggested that caring may have no meaningful effect on the physical health of caregivers (Wright, et al., 1999) or may even influence this outcome in a positive direction (Taylor, et al., 1995; White, et al., 2003). More research is needed to examine the variables present in caregiving
situations that influence and help determine health outcomes among caregivers of persons with stroke.

Many different factors are expected to affect the health of caregivers and consequently their ability to provide care. One common indicator of poor physical health among caregivers in the studies mentioned above was a high level of caregiving, defined as assistance with one or more ADLs, and perceived strain associated with the caring role (Bugge, et al., 1999; Beach, et al., 2000; Burton, et al., 1997, 2003; Schulz, et al., 1997; Schulz & Beach, 1999; Shaw, et al., 1997). Two variables that may or may not counter these negative health effects in caregivers of persons with stroke are emotional support and physical help from an informal network of family members and friends (Choi & Wodarski, 1996; Goode, Haley, Roth, & Ford, 1998; Sit, et al., 2004).

*Emotional Support & Physical Help*

Potential sources of emotional strain for caregivers of persons with stroke are many. They include things like competing demands, less opportunity for recreational activities, social and emotional isolation, anxiety about the care they are providing, financial concerns, changes in their relationship with the stroke survivor, and uncertainties about the future (Fultmer & Raudonis, 2000). Several studies have linked poor emotional outcomes in caregivers to a high degree of functional impairment and emotional distress in the persons with stroke (Bakas, et al., 2002; Dennis, et al., 1998). The combination and influence of these factors is expected to vary with individual caregivers and the unique dynamics of their caring situation.
The need for emotional support is unquestioned in the literature. Dorsey and Vaca (1998) stated, “Caregivers, no matter what personality, need support and respite from care to be successful in their efforts” (p. 64). This need was directly voiced by caregivers of persons with stroke in a qualitative study by Kerr and Smith (2001). These researchers interviewed 22 informal caregivers at 1 year post-stroke to identify their perceived needs at different times during the 1-year period. The caregivers commented that adjusting to changes in their own and the care recipients’ lifestyle was emotionally draining in the early weeks and months at home. Emotional support also was mentioned as a significant need after 1 year of caring (Kerr & Smith). A similar study by McLean, Roper-Hall, Mayer, and Main (1991) identified “emotionalism” as an affective need of caregivers ($n = 20$) of persons with stroke.

Caring for a person with significant cognitive and functional impairments also can be physically stressful (Fultner & Raudonis, 2000). Strain caused by the frequent bending, lifting, and moving required at high levels of care can be especially difficult for older caregivers (Fultner & Raudonis; McGarry & Arthur, 2001). The detrimental effects of caring on the physical health of caregivers were discussed at length earlier in this chapter.

A major concern for many caregivers both before and after the person with stroke leaves the hospital is how they will manage the physical aspects of care, e.g., enhancing mobility, preventing falls, ensuring a proper diet, and assisting with bathing and toileting (Bakas, et al., 2002; Kerr & Smith, 2001). As mentioned earlier, these caregivers often
enter their new role rather suddenly due to the nature of stroke, and do not have a gentle period of adjustment during which to prepare for the changes and learn necessary skills. The need for physical help from others often results from their “inability to provide adequately for the stroke survivor’s basic care” (McLean, et al., 1991, p. 562).

Sometimes all caregivers may need is information about what to expect, or training in the skills required to perform certain tasks (McLean, et al.). In other cases, they may need someone else to either assist them with care or provide it for them. One study found that 75% of the stroke caregivers interviewed needed assistance with some form of physical care (McLean, et al.).

*Informal support.* A common theme in the caregiving literature is that caregivers rely on family and friends for help and support to a much greater extent than formal services (Moore, et al., 2002; National Alliance for Caregiving and American Association of Retired Persons, 2004; Zarit, Gaugler, & Jarrott, 1999). Studies have reported that 58%-66% of primary caregivers of persons with stroke receive some form of help from relatives and friends (Anderson, Linto, & Stewart-Wynne, 1995; Dewey, et al., 2002). In the study by Dewey et al., the secondary caregivers (n = 146) contributed an average of 5 hours of care per week in the first 6 months after stroke (Dewey, et al.).

In their study of the experiences of older caregivers, McGarry and Arthur (2001) concluded that informal networks of support, both inside and outside of the home, were a vital component of most caring relationships. While the specific composition of these networks varies between cases, spouses, adult children, and/or close relatives often
provide the main means of help and support (Choi & Wodarski, 1996; McGarry & Arthur; Schulz & Beach, 1999; Sit, et al., 2004). The type of support provided also varies between cases and includes assistance with housework, help with the physical aspects of caring, emotional support, and financial assistance (O’Connell & Baker, 2004). Caregivers view this support from family and friends as essential to coping with the challenges of caring for a person with stroke (O’Connell & Baker).

While the literature attests to the importance of informal support for caregivers of persons with stroke, only a few studies have explored how receipt of this support changes over time. Dorsey and Vaca (1998) noted that as time passes, social activities and contacts begin to disappear. Caregivers in one study reported noticing a decrease after 3 months in the support offered by health care providers (Moore, et al., 2002). The majority of these caregivers mentioned how they also relied on physical help from family and friends to provide care, but the extent and duration of this help was not indicated (Moore, et al.). Since formal services are employed far less frequently than unpaid help from family and friends, it is imperative that more attention be paid to the informal support network for caregivers and its impact at different stages of the caring process.

*Relationships Among Health, Emotional Support, and Physical Help*

While the positive effects of general social support on psychological well-being have been well-documented in the literature (George, 1996; Sit, et al., 2004), the relationship between social support and physical health remains ambiguous (Choi & Wodarski, 1996). The assumption behind a possible relationship is based on the
buffering effects of social support. In the case of caregivers of persons with stroke, this implies that emotional support and physical help provided by family members and friends may serve as a buffer against the negative health effects of caring (Choi & Wodarski). In other words, the informal care network protects against poor health outcomes in the caregivers.

The relationship between informal support and physical health has received recent attention in the caregiver literature. One study examined the impact of social support on the general health of 102 caregivers of persons with stroke during the first 12 weeks following hospital discharge (Sit, et al., 2004). These researchers found that the caregivers with better tangible supports and social companionship reported better psychosocial health (Sit, et al.). Physical health status was measured by the presence or absence of physical symptoms and the need for medical consultation. After 12 weeks, about 40% of the caregivers reported having physical symptoms to the extent that they needed to see a doctor (Sit, et al.). Based on this finding, the researchers concluded that without assistance or support, these caregivers were likely to become the “second patient in the family” (Sit, et al., p. 822). The validity of this assumption is uncertain given that the relationship between social support and physical health was not statistically analyzed in the study. Grant, Elliott, Giger, and Bartolucci (2001) found no correlation between social support and general health in their assessment of 40 caregivers of persons with stroke, although social support was found to be the best predictor of life satisfaction.
Two studies investigating the relationship between informal support and health among AD caregivers yielded differing results. The first study employed a stress process model to examine the indirect effect of informal support on the relationship between care recipient disability and caregiver well-being in a large sample of caregivers ($n = 327$) (Raina, et al., 2004). The researchers found that poor physical health associated with an increase in care recipient disability was not significantly modified by the use of informal support (Raina, et al.). In contrast, another study with AD caregivers ($n = 121$) found that social support provided a protective effect on physical health changes over time (Goode, et al., 1998). Those caregivers who reported higher levels of social support (i.e., more people in their informal support network) at baseline showed improved health 1 year later (Goode, et al.). This finding supports the assumption by Choi and Wodarski (1996) that social support may actually buffer the negative effects of caring.

While all four of these studies contribute to a better understanding of the relationship between caregiver health and informal support from family and friends, several limitations highlight the need for more research. Only one of the studies employed a longitudinal design to examine the effects of support over time (Goode, et al., 1998). This study was conducted with AD caregivers whose caring situation is noted to be quite different from that of stroke caregivers (Low, et al., 1999; Wright, et al., 1999). Because the transition to caring for a person with stroke often happens suddenly, a logical time period for analysis among this population of caregivers is the initial weeks and months following discharge. The study by Sit et al. (2004) focused on this transitional
period, but the researchers only collected data at one point in time (12 weeks post-discharge). Clearly, there is a need for more research to examine the longitudinal effects of informal support on the health outcomes of caregivers of persons with stroke in the early months of caring.

Summary

Orem’s (2001) self-care deficit nursing theory was used to conceptualize this study as relationships among the caregivers’ health and the receipt of emotional support and physical help from family members and friends. Her theory lends itself well to the study in regard to caregivers because of its inclusion of the concept dependent-care agency. Caregivers of persons with stroke are both dependent-care agents and self-care agents. Emotional support and physical help from family and friends are conceptualized as both basic conditioning factors and universal requisites that affect the caregivers’ ability to meet their self-care needs, and consequently their health.

Much research has been conducted to explore the effects of caring on the physical health of caregivers. A common finding in many studies is that poor health is associated with a high level of caregiving and perceived strain associated with the caring role (Bugge, et al., 1999; Beach, et al., 2000; Burton, et al., 1997, 2003; Schulz, et al., 1997; Schulz & Beach, 1999; Shaw, et al., 1997). Only a few studies have examined this relationship in samples of caregivers of persons with stroke (Bugge, et al., 1999; Teel, et al., 2001; White, et al., 2003; Wright, et al., 1999), and these have yielded conflicting results. Two variables that may or may not counter the negative effects of caring on
health are emotional support and physical help received from family and friends. It is assumed that when caregivers receive help in their caregiving role, they are less likely to neglect their own self-care needs (Choi & Wodarski, 1996). This is expected to reflect positively on their physical health. Longitudinal studies examining the effects of emotional support and physical help on the health of stroke caregivers in the early months of caring are lacking (Bugge, et al., 1999; Grant, et al., 2001). The current study sought to fill this knowledge gap in the caregiving literature.
CHAPTER III

Method

The purpose of this study was to examine the effects, in the first 6 months of caring, of emotional support and physical help on the health of caregivers of persons with a new diagnosis of stroke. The design of the study, sample selection, sample size, and inclusion criteria are described in this chapter. Materials for the study, data collection procedures, assumptions, limitations, and data analyses also are discussed. The chapter concludes with a summary of the contents.

Design

This research study used a descriptive-correlational design. This particular design is used to examine relationships that exist in a situation without controlling or manipulating the situation (Burns & Grove, 2005). In this study, a secondary analysis of data collected for a larger National Institutes of Health (NIH) study was used to examine the effects of emotional support and physical help (provided informally by family members and friends) on the physical health of caregivers of persons with stroke in the first 6 months of caring. The original NIH study examined a Web-based intervention of education and support for caregivers of persons with stroke. All subjects were followed for 1 year and asked to complete a telephone interview every 2 weeks.
Subjects

Setting

The caregiver subjects for the original NIH study were recruited from rehabilitation facilities in northwestern Ohio and southeastern Michigan where their care recipients were receiving treatment for stroke. The caregivers were enrolled in the study when the persons with stroke were discharged home.

Sample

The sample for this study \((n = 40)\) included all members of the control group (non-Web users) who completed 6 months of the NIH study. It was concluded that examination of the effects of informal support (emotional and physical) on the physical health of caregivers would be less confounded by a sample that did not have access to an organized and intentional form of support (i.e., the Web-based intervention). In this case, the control group would be more representative of the general population of caregivers of persons with stroke.

Inclusion Criteria. The participants in this study were: adults \((\geq 21\) years); caregivers of a person with a new diagnosis of stroke; caregivers of a care recipient who completed an in-patient rehabilitation program and was discharged home; residents in an urban setting; able to read, write, and understand English; and able to access a telephone.

Materials

The NIH study employed telephone interviews every 2 weeks to collect information about the caregivers’ experience of caring. Several other interview questions
were asked every 3 months related to caregiver well-being as well as factors that might affect the ability of the caregivers to provide care for the person with stroke. Three variables were used for this study: (a) caregiver health, (b) emotional support, and (c) physical help from family members and friends.

Two interview questions addressed the support received informally from family members and friends. Specifically, caregivers were asked, “Are you receiving emotional support from family members or friends in caring for your relative?” and “Are you receiving physical help from family members or friends in caring for your relative?” Responses were measured with on a 3-point Likert scale: Not at all (1), Somewhat (2), or A lot (3).

Health was the other key variable in this study. Caregivers were asked to rate their health on a 5-point Likert scale: Poor (1), Fair (2), Good (3), Very good (4), or Excellent (5). This item was obtained from the Multidimensional Functional Assessment of Older Adults (Fillenbaum, 1988). Previous research has documented that self-rated health correlates strongly with objective measures of health (LaRue, Bank, Jarvik, & Hetland, 1979; Mossey & Shapiro, 1982).

Data Collection

As mentioned previously, data for the original study were collected via telephone interviews. Interviewing by telephone is becoming more common in nursing research (Burnard, 1994). A study by Korner-Bitensky, Wood-Dauphinee, Siemiatycki, Shapiro,
and Becker (1994) found that telephone interviews provided information comparable to that received from face-to-face interviews.

The data of interest to this study were collected at baseline, 3 months, and 6 months in three separate interviews. Each caregiver in the control group was interviewed by the same trained research assistant for all three interviews. The calls were made using a cellular phone and answers to the questions were entered directly into an online database. The interviews lasted approximately 20 minutes. Answers to the questions described earlier about health, emotional support, and physical help were extracted from the online database for analysis in the current study.

Protection of Human Rights

Participation in the NIH study was voluntary and subjects who met the inclusion criteria were asked to sign a consent form. They were assured that any information provided by them during the interviews would be held confidential and used only for the research purposes. All subjects participated under the agreement that they could choose to drop out for whatever reason at any time during the course of the NIH study.

The current study was approved by the University Institutional Review Board for the protection of human subjects (see Appendix). Confidentiality was maintained by ensuring that data pulled from the online database contained no subject identifiers (i.e., names or telephone numbers) aside from identification numbers assigned during the NIH study.
Control for Threats to Internal Validity

One major threat to the internal validity of the NIH study was the possibility that subjects in the control group would start to use the Internet, and therefore have access to educational and support content similar to that provided by the Web-based intervention being examined in the study. This threat was controlled in two ways. First, the subjects in the control group were requested not to purchase WebTV™ or Internet access at the beginning of the study. Second, they were asked at four different times during the course of the study if they had purchased these services. If their answer was yes, they were unable to continue in the study.

For this study, the possibility of extraneous variables affecting the caregivers’ responses to interview questions could not be ruled out. One example of a factor that may have influenced responses to the questions about health was the occurrence of a significant life event (such as a birth or death in the family, a new job, or retirement). Since the environment of the study was unique to each subject (his or her home), it was impossible to identify and control for all of the extraneous variables that could affect the study results.

Control for Threats to External Validity

Threats to the external validity of the NIH study were minimized by the recruitment of women and minorities (African and Hispanic Americans) from the rehabilitation centers. This recruitment strategy helped generate a more representative
As mentioned previously, a threat to the external validity of this study was controlled by choosing to analyze only data collected from the non-Web users in the original study. It was concluded that the results of a study examining the effects of informal support (emotional and physical) on the health of caregivers would be more valid from a sample that did not have access to an organized and intentional form of support (i.e., the Web-based intervention). In this case, the control group would be more representative of the general population of caregivers of persons with stroke.

Assumptions

In this study, it was assumed that the caregivers had provided accurate and honest responses to the interview questions. It was assumed that caregiver health would in some way be affected by the receipt of emotional support and/or physical help from family members and friends. It also was assumed that these variables would change over the course of the caregiving experience. One final assumption is that each of the control subjects remained the primary person providing daily care to a person with stroke throughout course of study.

Limitations

One limitation of this study related to the setting from which the subjects were recruited. All subjects were recruited from urban rehabilitation centers, therefore limiting the generalizability of the study findings to those caregivers whose relatives with stroke
have access to this type of facility. Also, the ordinal level of measurement of the data for this study limited the number of statistical analyses that can be conducted to detect significant differences between the variables. Generally, nonparametric techniques are not considered to be as powerful as their parametric counterparts (Burns & Grove, 2005).

Data Analysis

To answer the research questions for this study, the variables were analyzed using descriptive and correlational statistics. Data were imported into the computer program SPSS 13.0 for Windows, Student Version (SPSS Inc., 2005). Because of the exploratory nature of the study, a two-tailed significance was used with alpha set at 0.05. The appropriate statistical analyses were chosen for the research questions as described below:

1. Does the health of the caregivers of persons with stroke change in the first 6 months of caring? The interview questions about health yielded ordinal-level data from the same subjects at three different periods in time. Frequency statistics and the non-parametric Friedman Two-Way Analysis of Variance by Ranks test were used to answer this research question. Kendall’s coefficient of concordance (Kendall’s $W$) was computed as a strength-of-relationship index for the Friedman test.

2. Does the emotional support that the caregivers receive change in the first 6 months of caring? The interview question dealing with this variable also yielded ordinal-level data from the same subjects. Frequency statistics and
the Friedman test were used to answer this research question. Kendall’s $W$ was computed as a strength-of-relationship index for the Friedman test.

3. Does the physical help that the caregivers receive change in the first 6 months of caring? Frequency statistics and the Friedman test with Kendall’s $W$ were used to answer this question as well, for the same reasons stated above.

4. Is there a relationship among the health of the caregivers of persons with stroke and the emotional support and physical help that they receive, and is this relationship different at three periods in time? Again, the ordinal level of measurement of the data required that a non-parametric test be used for analysis. The Spearman Rank-Order Correlation Coefficient was used to answer this question. A Bonferroni adjustment was made to control for Type I error across the correlations.

Summary

This chapter reported how a descriptive-correlational study design was used to examine the effects of emotional support and physical help on the health of caregivers of persons with stroke. The study was a secondary analysis of data collected for a larger NIH study. The sample included caregivers of persons with stroke who were assigned to the control group in the NIH study (those who did not have access to a Web-based intervention of education and support). Responses to questions pertaining to the physical health of the caregivers and the receipt of emotional support and physical help from family members and friends were obtained via telephone interviews conducted at three
different times during the NIH study (baseline, 3 months, and 6 months). The ordinal data produced by these questions were analyzed using non-parametric statistical tests, specifically the Friedman Two-Way Analysis of Variance by Ranks and the Spearman Rank-Order Correlation Coefficient.
CHAPTER IV

Results

The main purpose of this study was to examine the effects of emotional support and physical help on the health of caregivers of persons with a new diagnosis of stroke during the first 6 months of caring. Demographic characteristics of caregivers in the sample were analyzed using descriptive statistics. Data obtained from the caregivers about their perceived health and their receipt of emotional support and physical help from family members and friends were analyzed using non-parametric, descriptive and correlational statistics. The results of these statistical analyses are reported in this chapter.

Sample

Caregiver and care recipient characteristics for the sample (n = 40) are displayed in Table 1. On average, the caregivers were younger than the persons with stroke (\(M = 54.7\) years and \(M = 63.7\) years, respectively). Thirty-three women (83.5%) and seven men (17.5%) comprised the sample of caregivers. Twenty-three men constituted the majority of the care recipients (57.5%). Most of the caregivers were wives (50.0%), were white (85.0%), and worked at least part time (52.5%) in addition to providing care for the person with stroke (see Table 1). The caregivers had completed an average of 13 years of school (the equivalent of a high school education).
Table 1.

*Characteristics of caregivers (n = 40) and care recipients (n = 40).*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Caregivers Frequency (Percent)</th>
<th>Care Recipients Frequency (Percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship to care recipient:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>20 (50.0)</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Husband</td>
<td>7 (17.5)</td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>9 (22.5)</td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>Friend</td>
<td>1 (2.5)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3 (7.5)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnic background:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>1 (2.5)</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Black, not of Hispanic origin</td>
<td>5 (12.5)</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>Hispanic origin</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>White, not of Hispanic origin</td>
<td>34 (85.0)</td>
<td>34 (85.0)</td>
</tr>
<tr>
<td>Other or unknown</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td><strong>Caregiver employment:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>17 (42.5)</td>
<td></td>
</tr>
<tr>
<td>Part time</td>
<td>4 (10.0)</td>
<td></td>
</tr>
<tr>
<td>Unemployed or retired</td>
<td>19 (47.5)</td>
<td></td>
</tr>
</tbody>
</table>

Findings

*Question One*

Descriptive statistics revealed that the most frequent rating for health at all three time periods was *Good* (3). At least 42.5% of the caregivers selected this rating at
baseline and after 3 and 6 months of caring (see Table 2). The second most frequent rating was *Very good* (4). At all three time periods, 20% or less of the sample rated their health as *Poor* (1) or *Fair* (2). A Friedman test was conducted to evaluate differences among the caregivers’ median ratings of health over time. The results were not significant, $\chi^2 (4, n = 40) = 1.957, p = 0.376$, and the Kendall coefficient of concordance was correspondingly low (0.024), indicating weak differences among the ratings. In other words, the caregivers’ ratings of their health did not change significantly from baseline to 6 months of caring.

Table 2.

*Frequency of health ratings by caregivers (n = 40) at three periods in time.*

<table>
<thead>
<tr>
<th>Health ratings</th>
<th>Baseline Frequency (Percent)</th>
<th>Time 3 Months Frequency (Percent)</th>
<th>6 Months Frequency (Percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor</td>
<td>1 (2.5)</td>
<td>2 (5.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Fair</td>
<td>3 (7.5)</td>
<td>6 (15.0)</td>
<td>6 (15.0)</td>
</tr>
<tr>
<td>Good</td>
<td>21 (52.5)</td>
<td>17 (42.5)</td>
<td>17 (42.5)</td>
</tr>
<tr>
<td>Very good</td>
<td>10 (25.0)</td>
<td>14 (35.0)</td>
<td>14 (35.0)</td>
</tr>
<tr>
<td>Excellent</td>
<td>5 (12.5)</td>
<td>1 (2.5)</td>
<td>3 (7.5)</td>
</tr>
</tbody>
</table>

*Question Two*

According to the frequency statistics, caregivers’ ratings for emotional support showed a small amount of variability over time (see Table 3). At baseline, 22 (55.0%) of
the caregivers selected the highest rating for emotional support (*A lot*). At 3 and 6 months of caring, the majority of the sample (60.0% and 50.0%, respectively) selected the *Somewhat* (2) rating. Very few caregivers reported receiving no emotional support at all three time periods (see Table 3). The Friedman test revealed that the observed differences among the ratings were not enough to be statistically significant, $\chi^2 (2, n = 40) = 1.680, p = 0.432$ (Kendall’s $W = 0.021$). The caregivers’ ratings of emotional support did not vary appreciably from baseline to 6 months of caring.

Table 3.

*Frequency of emotional support ratings by caregivers (n = 40) at three periods in time.*

<table>
<thead>
<tr>
<th>Emotional support ratings</th>
<th>Baseline</th>
<th>3 Months</th>
<th>6 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (Percent)</td>
<td>Frequency (Percent)</td>
<td>Frequency (Percent)</td>
</tr>
<tr>
<td>Not at all</td>
<td>3 (7.5)</td>
<td>1 (2.5)</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>Somewhat</td>
<td>15 (37.5)</td>
<td>24 (60.0)</td>
<td>20 (50.0)</td>
</tr>
<tr>
<td>A lot</td>
<td>22 (55.0)</td>
<td>15 (37.5)</td>
<td>17 (42.5)</td>
</tr>
</tbody>
</table>

*Question Three*

Frequency statistics for the physical help variable revealed only small changes in the caregivers’ ratings over time (see Table 4). The ratings were also more evenly distributed within each time period. At least 25% of the sample reported receiving no physical help at all three time periods. At baseline, the most frequently selected rating was *A lot* (3). At 3 and 6 months, the most frequent rating was *Somewhat* (2). These
findings are similar to those described for emotional support. Again, the Friedman test revealed no significant differences among the caregivers’ ratings over time, $\chi^2 (2, n = 40) = 1.973, p = 0.373$ (Kendall’s $W = 0.025$). The caregivers’ ratings of physical help did not change significantly from baseline to 6 months of caring.

Table 4.

*Frequency of physical help ratings by caregivers (n = 40) at three periods in time.*

<table>
<thead>
<tr>
<th>Physical help ratings</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
</tr>
<tr>
<td></td>
<td>Frequency (Percent)</td>
</tr>
<tr>
<td>Not at all</td>
<td>11 (27.5)</td>
</tr>
<tr>
<td>Somewhat</td>
<td>12 (30.0)</td>
</tr>
<tr>
<td>A lot</td>
<td>17 (42.5)</td>
</tr>
</tbody>
</table>

**Question Four**

A 9 x 9 correlation matrix was generated to examine the relationships among the health, emotional support, and physical help ratings at the three different times of measurement (baseline, 3 months, and 6 months). Spearman correlation coefficients were computed for each of the 36 relationships represented in the matrix. Using the Bonferroni approach to control for Type I error across the 36 correlations, a $p$ value of less than or equal to 0.001 ($0.05 / 36 = 0.001$) was required for significance. The results of the correlational analyses presented in Table 5 show that only three correlations were statistically significant at the 0.001 level and had coefficients greater than or equal to
0.511. Two of these represented relationships between the same variables at different points in time. For example, a positive, strong relationship was found to exist between ratings of physical help at 3 months and ratings of physical help at 6 months, \( r_s = 0.747, p = 0.000 \). In other words, those caregivers who rated their receipt of physical help high or low at 3 months also rated their receipt of physical help high or low at 6 months. A similar positive relationship existed between the caregivers’ ratings of their health at 3 months and 6 months, though the correlation was of moderate strength in this instance \( (r_s = 0.539, p = 0.000) \).

Table 5.

*Correlations among caregiver-rated health, emotional support, and physical help at three periods in time (n = 40).*

<table>
<thead>
<tr>
<th></th>
<th>Health baseline</th>
<th>Health 3 month</th>
<th>Health 6 month</th>
<th>ES baseline</th>
<th>ES 3 month</th>
<th>ES 6 month</th>
<th>PH baseline</th>
<th>PH 3 month</th>
<th>PH 6 month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health baseline</td>
<td>0.226</td>
<td>0.423</td>
<td>0.113</td>
<td>0.244</td>
<td>0.069</td>
<td>0.086</td>
<td>-0.030</td>
<td>-0.099</td>
<td></td>
</tr>
<tr>
<td>Health 3 month</td>
<td></td>
<td></td>
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<td>0.296</td>
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<td>0.511*</td>
<td>0.054</td>
<td>0.084</td>
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*Note. ES = Emotional Support; PH = Physical Help*

*p ≤ 0.001.
The other correlation that was significant at the 0.001 level represented a relationship between two different variables. A positive, moderately strong relationship existed between emotional support at 6 months and caregiver health at 6 months, \( r_s = 0.511, p = 0.001 \) (see Table 5). This indicates that those caregivers who rated their receipt of emotional support high or low at 6 months also rated their health high or low at this time.

Summary

The caregivers in this sample were younger, on average, than the persons receiving care. The majority of the caregivers were female and the wife or daughter of the person with stroke. They were a relatively well-educated group, with an average of 13 years of school completed (the equivalent of a high school education). Nearly half of the caregivers were working full-time jobs in addition to providing care to the person with stroke.

Statistical analyses revealed no significant differences in caregiver health over time. The same was true for receipt of emotional support and physical help, although descriptive statistics indicated trends of lower ratings for these variables after 3 and 6 months of caring. A significant correlation was found to exist between caregiver health and emotional support at 6 months, suggesting a relationship between these variables.
CHAPTER V

Discussion

This study focused on the experiences of first-time caregivers of persons with stroke during the first 6 months of caring. Of primary interest to the study was the relationship between the caregivers’ health and their receipt of emotional support and physical help from family members and friends. A secondary aim was to examine how these three variables, and any relationships among them, changed over time. While analysis of the data did not reveal any significant longitudinal changes in the caregivers’ perceived health or their receipt of emotional support and physical help, several correlations between the variables were significant. A discussion of these findings, subsequent conclusions, limitations of the study, implications for nursing practice, and recommendations for further research are presented in this chapter.

Findings

Discussion of the Results and the Literature

The most frequent rating for health at all three times of measurement (baseline, 3 months, and 6 months) was Good (3), indicating that the majority of caregivers in this study perceived their health to be average. The reason why an average rating was selected at the initiation of the caring role is uncertain. The health status of the caregivers prior to entering the study (i.e., before the incidence of stroke in the care recipient) was not examined. It is possible that preexisting illnesses may have influenced the caregivers’ baseline perceptions of their health (Schulz & Beach, 1999). At the same
time, a rating of *Good* (3) need not be considered an indication of poor health. The findings suggest that the average caregiver in this study actually perceived his or her health to be somewhere between *Good* (3) and *Very good* (4).

While the most frequent rating at all three time periods was *Good* (3), the second most frequent rating was *Very good* (4) (see Table 2). These findings support those of another study that used the same rating scale to evaluate health in a large sample of caregivers ($n = 680$) (Beach, et al., 2000). The researchers reported that the average caregiver in their study perceived his or her health to be between *Good* (3) and *Very good* (4) at the time of the first interview. In a second interview 1 year later, the majority of the sample (61%) gave the same response to the question about perceived health, indicating stability of the caregivers’ health over time (Beach, et al.).

Stable health also was a notable finding of this study. The caregivers’ ratings of their health did not change significantly during the first six months of caring, a time period that is often associated with increased stress for stroke caregivers (Bakas, et al., 2002; Kerr & Smith, 2001). This finding supports those of two other studies that measured perceptions of physical health in the same population of caregivers during the 6-month transitional period after stroke (Bugge, et al., 1999; Teel, Duncan, & Lai, 2001). The study by Bugge et al. found this to be true despite the fact that the proportion of caregivers under considerable strain increased from 1-6 months.

There are several possible explanations for the stability of health among the caregivers in this study. First, the 6-month time period considered in the study may not
have been long enough to observe the impact of caring on health (Bugge, et al., 1999). Wright et al. (1999) correctly hypothesized that 1 year would be inadequate to detect physical health consequences in stroke and AD caregivers. White et al. (2003) reported very little change in caregivers’ perceived health even after 2 years of caring. Second, it is assumed that caregivers’ perceptions of their health are influenced by a variety of life factors, such as age, health state, family system, or environment, which interact with each other and are subject to change over time (Bugge, et al., 1999; Orem, 2001). Stability may be expected in cases where these variables either remain constant or balance each other in response to changes. In this study, a stable perception of health may have resulted from the complex interactions among these factors over time (Bugge, et al.)

This study examined the effects of two specific variables, emotional support and physical help from family members and friends, on the health of caregivers of persons with stroke. The results indicate that the majority of the caregivers were receiving at least some emotional support and physical help at all three time periods (see Table 3 and Table 4). The most support and help from family members and/or friends was received at baseline. Caregivers’ ratings were slightly lower after 3 and 6 months of caring, but overall changes were not statistically significant. Again, 6 months may have been too early to observe appreciable differences in caregiver support. A decrease in social support has been documented in caregiver studies that examined this variable over the course of 1 year (Anderson, et al., 1995; Goode, et al., 1998).
In terms of relationships among caregiver health, emotional support, and physical help, several findings are noteworthy. Two significant correlations were found to exist between the same variables (health and physical help) at different points in time. These relationships are not surprising based on the stability of the caregivers’ ratings of their health and receipt of support over time. Perhaps the most important finding was that of a moderately strong, positive relationship between caregiver health and emotional support at 6 months. This indicates that those caregivers who rated their emotional support high or low at 6 months also rated their health high or low at this time. However, it cannot be said that emotional support predicted better or poorer caregiver health due to the nature of the statistical analysis.

This finding suggests that the relationship between emotional support and health may be important for caregivers of persons with stroke. The need for emotional support to cope with the challenges of caring has been well-documented in the literature (Dorsey & Vaca, 1998; Kerr & Smith, 2001; McLean, et al., 1991). It is assumed that support from an informal network may protect against poor health outcomes in caregivers (Choi & Wodarski, 1996). However, testing of this assumption has yet to yield conclusive results (Goode, et al., 1998; Grant, et al., 2001; Raina, et al., 2004; Sit, et al., 2004).

The reason why physical help did not correlate with caregiver health at any time period is uncertain. In general, the caregivers rated physical help lower than emotional support at all three time periods. More caregivers received physical help at baseline than they did at after 3 and 6 months of caring. It is possible that less help was needed as time
progressed because of improvement in the stroke survivors’ symptoms and/or the positive adjustment of the caregivers to their role (White, et al., 2003; Wright, et al., 1999). In a similar way, physical help from family members and friends may not have been needed or received if the caregivers were already receiving help from formal services. Several studies suggest that when formal services, such as in-home respite, are employed by the primary caregiver, other family members withdraw their support (Lyons, Zarit, & Townsend, 2000; Zarit, et al., 1999).

Discussion of the Results and the Theoretical Framework

The results of this study are consistent with Orem’s (2001) self-care deficit nursing theory. The caregivers of persons with stroke were conceptualized as both self- and dependent-care agents (Orem). Emotional support and physical help were conceptualized as both basic conditioning factors and universal self-care requisites. Through their influence on TSCD and self- and dependent-care agency, these variables were seen as being capable of affecting caregiver health in one of three ways: positively, negatively, or not at all. Orem’s theory allows for the possibility of any one of these health outcomes as a result of the complex interactions among the component variables.

The caregivers’ perceived health did not change significantly from baseline to 6 months. Their receipt of emotional support and physical health also did not change significantly during this time. Orem’s (2001) theory accounts for the possibility that stable emotional support and physical help from family and friends influenced the stability in perceived health.
Conclusions

Based on the findings of this study, several conclusions can be made about the experiences of first-time caregivers of persons with stroke. First, the way these caregivers perceive their health does not change significantly during the first 6 months of providing care. The fact that their health does not appear to worsen during this time is encouraging. On the other hand, stability which begins at an average level of health may not be ideal for these caregivers considering the potential stresses of their role (Schulz & Beach, 1999).

Second, emotional support from family members and friends is present at least Somewhat for caregivers of persons with stroke and remains stable during the first 6 months at home. This support is slightly higher at baseline than at 3 and 6 months. At least some physical help from family and friends also is present for the majority of stroke caregivers, although this form of assistance is not received as often as emotional support. Physical help may not be needed by caregivers who have learned to perform their role independently or whose care recipients have made functional gains.

Third, there is a positive relationship between the receipt of emotional support and caregiver health after 6 months of caring. The nature of this relationship is uncertain and warrants further research because of its potential to benefit the experience of caregivers.
Limitations

Several limitations of this study must be acknowledged. First, the sample size was relatively small ($n = 40$). Generally, at least 50 participants are recommended for studies examining relationships between variables (VanVoorhis & Morgan, 2001). Second, the sample consisted of mostly white women living in Ohio and Michigan. Thus, the findings may not be representative of the entire population of first-time caregivers, especially those belonging to racial and ethnic minorities and those living outside of the midwestern U.S. Third, this study is limited by the fact that the data are based entirely on caregiver reports which may be biased. The subjective nature of the data also limited the number of statistical analyses that could be conducted to detect significant differences among the variables. Generally, nonparametric techniques are not considered to be as powerful as their parametric counterparts (Burns & Grove, 2005).

Implications

Nurses, which Orem (2001) refers to as nurse agents, can be an invaluable source of support and education for first-time caregivers of persons with stroke. To ensure a smooth transition from hospital to home for both the caregiver and the stroke survivor, much of this support and education should be offered prior to discharge. Research has shown that many caregivers feel unprepared to meet the challenges of providing care in the home setting, especially when residual deficits in the persons with stroke are severe (Bakas, et al., 2002; Kerr & Smith, 2001). Nurses are in an ideal position to address the needs and concerns of caregivers because of their close contact with clients and their
families. They are often the first health care professionals to initiate discussion of outcomes and rehabilitation with the families of persons with stroke (Dorsey & Vaca, 1998).

The findings of this study suggest that nurses must assess the health of persons preparing to enter the caregiving role. Caregiver health did not change significantly during the first 6 months of caring, but this stability was based on a rating of Good (3), which indicates an average perception of health. This is a concern because the health of caregivers is not likely to improve as a result of providing care. Caregivers may be at risk for health decline due to a variety of factors which may not be apparent to them in the early stages of caring. It is important for nurses to assess the health condition of caregivers prior to discharge to ensure that the challenges of caring will not cause them to become the “second patient in the family” (Sit, et al., 2004, p. 187).

The existence of a significant relationship between emotional support and caregiver health at 6 months suggests that this form of support from family members and friends may have a positive effect on the way caregivers of persons with stroke perceive their health. Nursing services, such as case management and/or discharge planning, must assist caregivers to establish and maintain an accessible network of emotional support (Sit, et al., 2004). Caregivers should be encouraged to seek out and accept support from family members and friends. The composition and availability of this informal network should be assessed by nurses prior to discharge. If informal supports are lacking, caregivers should be encouraged to avail themselves of appropriate community services,
such as support groups or in-home respite. Case management nurses can arrange these services and provide direct support and continued assessment of caregiver needs through regular follow-up visits.

The findings related to physical help also have implications for nursing. In general, the caregivers did not receive as much physical help from family members and friends, as they did emotional support. Adequacy of the help received was not addressed in this study. As discussed previously, the caregivers may not have required as much assistance with care. However, it is also possible that help was needed, but lacking. In either case, it is important for nurses to assess the needs of caregivers related to the physical aspects of caring because of the direct strain these activities can impose on the body (Fultner & Raudonis, 2000; McGarry & Arthur, 2001). Assessment in this area must take into account the functional deficits of the person with stroke and the home environment where care will take place. Again, if physical help is needed and cannot be provided by family members or friends, caregivers should be linked with formal services, such as adult day care or home health care. Ongoing assessment will ensure that the needs of caregivers and care recipients are being met as they make adjustments to a new way of life.

Recommendations for Further Research

This study was a secondary analysis of data collected for a larger NIH study. Although data for the larger study were collected over the course of 1 full year, the current study focused on a small portion of data from the first 6 months of interviews. A
repeat of the current study focusing on months 6-12 of caring would further increase the understanding of the longitudinal effects of informal support on caregiver health. Reproduction of the study in a larger, more diverse sample would enhance the generalizability of the results to the population of stroke caregivers. Also, the current study identified a positive relationship between emotional support and physical health among caregivers of persons with stroke. However, the simplicity of the study design and the nature of the data and statistical analyses did not allow for causal inferences to be made. Various factors both internal and external to the caregiving situation are expected to impact the relationship between caregivers’ perceived health and the receipt of emotional support and physical help from family and friends. Further analysis of the interactions among these variables may eventually allow for the prediction of caregivers at risk for ill health.

Summary

The purpose of this study was to examine the effects, during the first 6 months of caring, of emotional support and physical help from family members and friends on the health of first-time caregivers of persons with stroke. Based on the results, it can be concluded that the way these caregivers perceive their health does not change significantly during the acute phase of caring. The caregivers’ health remains stable at an average level, a finding that is consistent with the literature. Six months may not be sufficient to observe the impact of caring on health. At least some emotional support from family members and friends is present for most caregivers during the first 6 months.
at home. Physical help also remains stable over time, although this form of assistance is not received as often as emotional support. Evidence of a positive relationship between emotional support and caregiver health after 6 months of caring was the most significant finding of this study. The nature of this relationship warrants further research because of its potential to benefit the experience of stroke caregivers. Nurses can help preserve the stability of caregivers’ health during the initial 6 months of caring and beyond by assisting them to establish and maintain an accessible network of emotional and physical support from family, friends, and formal services.
REFERENCES


APPENDIX: Institutional Review Board Approval

TO: Linda Pierce, Ph.D., R.N.
    MUOT Department of School of Nursing

FROM: Connie Roth-Sautter, Ph.D., R.N., Vice Chair
    MUOT Institutional Review Board

DATE: June 30, 2005


Your amendment (Add Erin Noetziger B.S., Rosalyn Pawlak B.S., R.N., Heidi Havens B.S., R.N., Heidi Pitzen-Oswald B.S., and Kevin Weber and delete Kimberly Drummond and Judy Dawson-Weiss as study personnel; add secondary data analyses to be done by Noetziger, Pawlak, Havens, and Weber; and add an additional phone interview (data collection tool for phone survey included) and analysis of de-identified information from the interview by Pitzen-Oswald) to the above protocol was reviewed and approved by the Vice Chair of the Institutional Review Board. This does not change the previous determination that this research meets the criteria for Consent/Authorization for Use and Disclosure of Protected Health Information to be waived. It was determined that this waiver will not adversely affect the rights or welfare of the participants. This action will be reported to the committee at its meeting on 08/18/2005. Thank you for your notification.


It is the Principal Investigator's (P.I.'s) responsibility to:

1. Abide by all federal, state, and local laws and regulations; the MUOT federal assurance and institutional policies for human subject research and protection of individually identifiable health information including those related to record keeping and be sure that all members of your research team have completed the required education in these areas.
2. Comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information and security of protected health information.
3. Promptly notify the MUOT IRB at (419) 383-6796 of any untoward incidents or unanticipated adverse events that develop in the course of your research. Please complete and submit RGA Form 317 for ALL SUCH REPORTS for this protocol. The Principal Investigator is also responsible for submitting to the MUOT IRB reports of adverse events that occur at other sites conducting this study and for maintaining an up-to-date cumulative table of adverse events (RGA Form 316) and submitting it to the MUOT IRB for each research project. The Principal Investigator is responsible for reporting adverse events to the appropriate federal agencies and the sponsor (when one exists).
4. Report promptly to the MUOT IRB any deviations or violations from the MUOT IRB approved protocol in accordance with the procedures outlined in RGA Form 309. In your report include the protocol number and title, the subject's initials/specimen identifier (as appropriate) and study I.D. number, date of the event, a brief description of the occurrence and a description of any corrective actions taken. The Principal Investigator is responsible for reporting deviations, violations and participant non-compliance to the appropriate federal agencies and the sponsor (when one exists) in accordance with federal regulations, institutional policy and any other legal agreements with these organizations.
5. Obtain prior MUOT IRB review and approval for changes in study personnel and for any and all changes/new information that may require additional information be provided to participants.
6. Report promptly to the MUOT IRB, sponsor (if this research is sponsored) and all other required federal and state agencies all new information affecting the risk/benefit ratio and obtain prior MUOT IRB approval for any changes in the study documents that may be required by the new information.
7. Obtain prior MUOT IRB review and approval for all modified and/or added incentives going to the P.I., study coordinator, other study personnel, and/or the institution. These incentives may be in the form of money or other...
items of value, including, but not limited to, equipment, such as computers, and intangibles, such as frequent flyer miles.

8. **Promptly** notify the MUOT IRB; other required MUOT committees, departments or individuals; the sponsor (if this research is sponsored); and all other required federal and state agencies of all potential conflicts of interest before beginning this research and, during the course of this research report to these committees, individuals and agencies any changes that may affect conflict of interest for any of the study personnel. **Prior MUOT IRB approval** must be obtained for any changes in the study documents that may be required by information related to conflict of interest or any changes in this information during the course of the research.

9. **Promptly** notify the MUOT IRB of any changes in contracts, budgets, grants or other agreements with sponsors, agencies or individuals regarding the conduct of this research **before** initiating these changes. The IRB reserves the right to review these study related documents and changes to them to verify accuracy and consistency with regard to the research protocol in order to protect the rights and welfare of the study subjects. Changes in these documents that have the potential to affect the rights, welfare or willingness of the study subjects to participate in or continue to participate in this research and changes in subject documents (such as informed consent, assent or authorization for use and disclosure of protected health information forms, etc.) that are a result of these changes **must** be reviewed and approved by the MUOT IRB **prior** to being instituted.

**Additional Information:**

- **Other Required Review(s) or Approval(s)**
  Review or approval by the MUOT Institutional Review Board does **not** take the place of any other review or approval required by the Medical University of Ohio at Toledo, non-MUOT performance sites, the government and/or the study sponsor.

- **Required Procedure to Request Review and Approval for Changes/Updates to MUOT IRB Approved Research:**
  Please complete and submit the [Request for Amendment/Changes/Updates (RGA Form 314)](http://www.meduohio.edu/research/rga_firms/rga314.doc) with a copy of all materials relevant to the requested change (including consent/assent/authorization for use and disclosure of protected health information forms if applicable) with the changes underlined. If you are requesting review and approval of consent/assent/authorization for use and disclosure of protected health information forms, please attach a clean copy of the revised forms for the MUOT IRB to stamp. Please remember that all changes and correspondence submitted to the MUOT IRB (regardless if they are generated by a sponsor, the P.I. or requested by the MUOT IRB) must be **in writing, signed and dated by the Principal Investigator**.

- **Federally Mandated Continuing Review:**
  MUOT IRB protocols must be reviewed and reapproved **not less than once per year**. The Institutional Review Board will try to remind you when reapproval is due. **However, it is the responsibility of the Principal Investigator to have his/her own reminder system in place to initiate the re-approval process at least a month prior to the expiration date shown above. Please note that Federal Regulations prohibit the extension of this expiration date. Please see the Application for Continuing Review (RGA Form 319) found at [http://www.meduohio.edu/research/rga_firms/rga319.doc](http://www.meduohio.edu/research/rga_firms/rga319.doc) for items required for continuing review.**

- **Required Final Report Upon Termination of Research:**
  When you decide to stop this research, you are responsible for completing and submitting a **Final Report (RGA Form 320)** to the MUOT IRB for review.

MCO Amendment #4016
ABSTRACT

The purpose of this study was to examine the effects, in the first 6 months of caring, of emotional support and physical help on the health of first-time caregivers of persons with stroke. This study was a secondary analysis of data collected during baseline, 3-month, and 6-month telephone interviews for a large NIH study. Only the control group for the NIH study was used \((n = 40)\) and a descriptive-correlational design was employed. The data were analyzed using non-parametric statistics. Caregivers’ perceived health and their receipt of emotional support and physical help did not change significantly over time. A significant, positive relationship was found to exist between emotional support and caregiver health at 6 months. Nurses can help preserve the stability of caregivers’ health during the initial 6 months of caring and beyond by assisting them to establish and maintain an accessible network of emotional and physical support from family, friends, and formal services.