Teaching needs of persons dealing with stroke as perceived by allied health professionals

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Teaching Needs of Persons Dealing with Stroke as Perceived by Allied Health Professionals

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DEDICATION

I wish to dedicate this research study to my supportive husband, Greg, and our three children, Greg, Laurel, and Aubrey. Their love, support, and patience have helped to motivate me throughout this journey. I also would like to dedicate this research study to my sister, Tana Myers. Thank you for being there on my special day.
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CHAPTER 1
Introduction

According to the National Stroke Association (2003a), stroke is a type of cardiovascular disease that affects the arteries leading to and within the brain. Strokes are very serious health risks that impact the lives of many people in the United States each year, with approximately 700,000 people experiencing a new or recurrent stroke. Currently, stroke is the number three killer in America and one of the major causes of severe, long-term disability for individuals (National Stroke Association, 2003b). While the care needs of survivors of stroke are often complicated, the estimated number of noninstitutionalized people with stroke steadily increased between the 1970s to early 1990s (National Stroke Association, 2003a). This steady increase in the number of noninstitutionalized survivors of stroke has greatly impacted the caregivers of persons with stroke and their role in the day to day care of these individuals.

Due to shortened hospital and rehabilitation lengths of stay, health care providers must become adept at assessing caregiver’s information needs and making caregiver education a priority to prevent complications and hospital readmissions. While caring for a loved one who has suffered a stroke can be a satisfying experience, it can also be strenuous and emotionally draining. Exall and Johnston (1999) reported that spouses of people with stroke believe that they could have been told more and given more support during both hospitalization and rehabilitation periods. When hospital support ended, caregivers were often overcome with feelings of isolation and abandonment.
(Exall & Johnson). By identifying caregivers’ teaching needs and providing accurate, easily accessible methods to meet them, health care professionals can better prepare these individuals to cope with the home care needs of the person with stroke and also their own feelings of isolation. One effective method of providing information to caregivers of persons with stroke is through the use of an Internet based support site where a variety of information can be obtained.

The definition of stroke, as identified by the National Stroke Association (2003a), and its prevalence in the United States is presented in this chapter. Also, the teaching needs of caregivers of persons with stroke are discussed, as well as potential homecare problems that they may face upon the care recipients’ discharge from hospitalized treatment. The conceptual framework that guides the project is introduced. The main purposes of this study are stated, as well as the research questions that are investigated. The conceptual and operational definitions of all of the variables are identified and a brief review of the conceptual framework is discussed. The significance of this study to the health provider and the caregiver is reviewed along with various assumptions and potential limitations.

Statement of Problem

According to Banford et al. (2001), the education needs of caregivers of persons with stroke are the greatest during the inpatient phase of rehabilitation treatment. However, caregivers have frequently reported a lack of, or dissatisfaction with, the information provided, stating that it was not pertinent to their information needs. This real or perceived lack of information prior to patient discharge to home settings...
has been found to negatively impact the functional status of the caregiver of the
person with stroke post discharge (Banford et al.). This lack of information could
result in a variety of health care complications for the person with stroke leading to
hospital readmission and feelings of loneliness and inadequacy for the caregiver.
Various methods of providing this needed information must be addressed to meet a
variety of learning needs or styles. Possible methods of providing this information
include videotapes, demonstration or observation by a therapist, verbal instructions,
handouts, and training in the home environment (Banford et al., 2001). Every month,
approximately 1 million adults in the United States look for health information on the
World Wide Web (Nua Publish, 2001). As more and more people are becoming
familiar with the World Wide Web, health care professionals must look at this form
of communication as a viable resource. By identifying the most frequent teaching
needs of caregivers of persons with stroke and providing individualized information
that is specific to their needs, health care professionals can better prepare persons
with stroke and their caregivers for the discharge process and provide support and
encouragement in the post discharge phase of treatment.

Statement of Purpose

The purpose of this study was to identify the most frequent teaching needs for
persons with stroke and their caregivers as perceived by allied health professionals
(i.e., physical and occupational therapists). Data previously obtained in other
research studies that focused on registered nurses and families’ perceived teaching
needs for persons dealing with stroke (Pierce, Finn, & Steiner, 2004; Pierce, Rupp,
Hicks, & Steiner, 2003) were compared to the data collected from these allied health professionals. The top 12 teaching needs identified by physical and occupational therapists from this current study provide data for interdisciplinary health care teams to use in educating the caregiver for the home care experience.

Conceptual Framework

Orem’s (2001) self-care deficit nursing theory was used to guide this study. Orem’s self-care deficit nursing theory consists of three individual theories, including the theory of self-care/dependent-care, the theory of self-care deficit, and the theory of nursing system, as explained below. The theory of nursing systems was utilized primarily in this study since the focus of the study is allied health professionals.

Orem’s self-care deficit nursing theory (2001) was chosen for this study to be consistent with other studies performed on assessing the information needs of people dealing with stroke (Pierce et al., 2004, 2003). By consistently using Orem’s theory, this facilitated the comparison of the data obtained in the current study with previous studies. Also, due to the physiologic processes related to stroke, people with stroke are temporarily or permanently unable to engage in activities of self management. These survivors of stroke experience self-care deficits in which their self-care demands, or actions needed to achieve self-care, exceed their self care agency, or ability to carry out actions needed for self-care. This ultimately leads to persons with stroke need for nursing care or dependent care from their loved one or family member. The nursing system which is most appropriate for situations where people are able to perform necessary measures for therapeutic self-care, but are in need of
assistance, is the supportive-educative system. In this nursing system, the person’s requirements for help are limited to decision making, behavior control, and acquiring knowledge and skills. Caregivers or dependent care agents also assist the survivor of stroke in performing tasks necessary to meet their self-care requisites (Orem). Therefore, Orem’s concepts of self-care deficit and independent/dependent care, along with the supportive-educative system are appropriate for use with the survivor of stroke and his or her caregiver.

Research Questions

The research questions were: 1) What are the top 12 teaching needs for persons with stroke and their caregivers as identified by allied health professionals? 2) Are there differences between teaching needs of persons dealing with stroke as identified by registered nurses, family caregivers, and allied health professionals?

Definition of Terms

Information Needs

*Conceptual definition.* Knowledge needed by the caregiver of the person with stroke to meet the self-care requisites of this person (Orem, 2001).

*Operational definition.* The top 12 teaching needs chosen by allied health professionals, out of 49 topics listed on the survey.

Caregivers

*Conceptual definition.* Individuals who provide direct care to another when self-care demands exceed self-care agency that are necessary to meet self-care deficits (Orem, 2001).
Operational definition. Individuals or family members responsible for coordinating and providing care to persons with stroke in their home environment. Family members may be blood relatives, friends, or neighbors.

Stroke

Conceptual definition. Self-care deficit characterized by occlusion of a cerebral blood vessel by an embolus or cerebral hemorrhage causing ischemia of the brain tissue resulting in the individual’s inability to perform self-care tasks (Orem, 2001).

Operational definition. A physical condition of the brain due to hemorrhage or occlusion causing varying degrees of sensorimotor deficits (National Stroke Association, 2003a) for which caregivers must provide care.

Allied Health Professional

Conceptual definition. Professional physical or occupational therapists currently working in post stroke treatment services, caring for individuals with a self-care deficit resulting from a stroke and their families, assisting them in regaining their highest level of self-care agency (Orem, 2001).

Operational definition. Individuals practicing in the health care field from an accredited institution with a Certificate, Associate, Bachelor, Master or Doctoral degree in physical or occupational therapy and licensed in their state of practice (Clark, Corcoran & Gitlin, 1994).

Significance

Wolfe (2000) stated that there are 4.5 million deaths a year from stroke in the world and over 9 million survivors of stroke. In the United States, after inpatient
rehabilitation services, many of these survivors of stroke will be discharged to the home environment and need care from a family member. Caregivers frequently mention that agencies fail to provide them with necessary information and advice on home care and have considered the assistance they got prior to discharge irrelevant help (Wolfe). As stated by Easton, Zemen and Kwiatkowski (1994) the purpose of rehabilitation is to discharge the person into the community prepared for activities of daily living and able to take care of his or her health care needs. Therefore, a primary goal of health care professionals should be to educate persons with disabilities and their caregivers regarding primary information needs so that they can function to the best of their abilities.

The significance of this study to the medical profession is to identify the top 12 teaching needs of persons dealing with stroke. Knowing these teaching needs will better prepare the caregiver and survivor of stroke for the transition from inpatient rehabilitation treatment to living in the home environment. Using this information to develop teaching materials will help allay the caregivers’ feelings of frustration and anxiety while providing care to the person with stroke in the home. This study is unique because of its focus on the importance of interdisciplinary health care teams in the formulation of teaching programs.

Assumptions

The following assumptions were made about this study: 1) caregivers require information in caring for the person with stroke in home settings to maintain their caregiver roles, 2) teaching needs will vary with each caregiver, and 3) caregivers of
persons with stroke desire to have the capabilities of maintaining their own life, health, and well-being according to Orem’s (2001) self-care deficit nursing theory. The caregiver of a person with stroke desires to engage in activities which maintain their life, health, and well-being, thus information related to caring for self and the person with stroke is needed. Health care professionals can identify the caregiver who is unable to engage in these activities, and can therefore, implement a supportive-educative nursing system. The goal of the supportive-educative nursing system is for caregivers to accomplish their own self-care and the development of their self-care agency (Orem).

Limitations

Limitations of this study included Orem’s (2001) basic conditioning factors such as age, health status, education level, environment, and resources of the caregivers. Age and health status affected the learned behaviors of the caregivers to maintain their own life, health and well-being required for the theory of self-care. Decreased awareness and knowledge related to stroke processes that impact self-care limit the benefits of the theory of self-care deficit and the theory of nursing system for the caregivers of persons with stroke.

Summary

With the growing number of persons with stroke receiving post stroke treatment care and living at home with caregivers, the health care professional must be committed to assessing the teaching needs of caregivers and persons with stroke. This information is important to developing educational materials in preparation for
discharge and in the post discharge setting for persons with stroke and their caregivers.
CHAPTER II

Review of Literature

In this chapter, Orem’s (2001) theoretical framework, the self-care deficit nursing theory is discussed in-depth, as well as why this framework is appropriate for this study. A schematic drawing is included to connect this study with Orem’s theoretical concepts, as well as to demonstrate how this framework was used to guide this study. Multiple research studies were used to provide an in-depth literature review discussing the information needs of caregivers of survivors of stroke, as identified by physical and occupational therapists, and to understand the various situations these caregivers face in the home care setting. Also, physical and occupational therapists’ views on the stroke rehabilitation process and their satisfactions and dissatisfactions are discussed along with their ability to predict the discharge status of the survivor of stroke. Lastly, various methods of educating caregivers and persons with stroke are discussed such as the use of demonstration, pamphlets, and Web-based Internet sites. A brief summary of the information presented concludes this chapter.

Theoretical Framework

According to Nieswiadomy (1998) a theory is a set of related statements that describes or explains phenomena is a systematic way. Orem’s (2001) self-care deficit nursing theory provided a framework that was used to guide this study on the teaching needs of caregivers of persons with stroke as identified by allied health professionals. Orem’s theory was chosen because of its emphasis on promoting and reinforcing the attainment of optimal health, or health care information increasing
one’s ability to perform self-care and lessen the need for dependent care by the
caregiver. By providing caregivers of persons with stroke with adequate amounts of
information specific to their needs, the health care team can empower them to
increase their self-care agency and help them to provide care to their loved one in a
confident and informed manner. Meeting caregivers’ teaching needs may prevent
them from being dependent on health care professionals in the post discharge period
and empower them in their caregiver role.

Orem’s (2001) self-care deficit nursing theory is made up of three sub-theories
which include: (1) the theory of self-care/dependent-care, (2) the theory of self-care
deficit, and (3) the theory of nursing system. All three main concepts of Orem’s self-
care deficit nursing theory were used in this study.

The theory of self-care/dependent-care (Orem, 2001) is at the core of this
framework and provides explanations about how and why people care for themselves
or are dependent upon others for their care. Generally, healthy individuals are in a
state of self-care and are able to meet their own self-care requisites or needs (Orem).
Persons with stroke are often in a state of compromised health and unable to perform
even the simplest everyday tasks. This places the person with stroke in a state of
needing dependent-care and in need of a competent, well informed caregiver to assist
them in meeting their self-care needs. This dependent care can be temporary or
permanent depending on the person’s ability to reestablish self-care. For this study,
the dependent-care agent is the caregiver who is often relied upon in the discharge
phase to provide most, if not all, of the direct care for the person with stroke. Orem
defined the dependent-care agent as the person who is performing actions of dependent care continuously and over time to meet the self-care requisites of another.

Self-care deficit theory provides explanations regarding why persons are in need of nursing care (Orem, 2001). Orem defined self-care agency as the practice of activities that individuals initiate and perform on their own to maintain life, health, and well-being. Basic conditioning factors are characteristics or attributes which actively influence an individual’s need for self-care or dependent-care as well as the person’s ability to take an active role in their care. Basic conditioning factors influence the individual’s self-care agency, therapeutic self-care demand, and their need for nursing agency (Orem). The 10 basic conditioning factor described by Orem include: 1) age, 2) gender, 3) developmental state, 4) health state, 5) health care system, 6) sociocultural-spiritual orientation, 7) family system, 8) patterns of living, 9) environment, and 10) available resources. These basic conditioning factors also affect an individual’s ability to meet their self-care requisites (Orem). Orem’s theory contains eight universal self-care requisites (USCR) that individuals must meet by themselves, or with the help of others, to meet their self-care needs. As defined by Orem, self-care requisites are the purposes or goals of self-care or dependent-care. If individuals are unable to meet these needs, they develop a self-care deficit. These eight USCR include the: 1) maintenance of air, 2) maintenance of water, 3) maintenance of food, 4) provision of care related to elimination and excrements, 5) maintenance of balance between activity and rest, 6) maintenance of balance between
solitude and social interaction, 7) prevention of hazards to life, functioning and well being, and 8) promotion of normalcy (Orem).

Nursing systems theory seeks to define what nursing care is and establishes the nature of the helping service provided by nurses. Nursing system is an action system created and performed by nurses that is directed toward health related self-care deficits of those persons engaged in self-care or dependent-care (Orem). The supportive-educative nursing system provides support, guidance, appropriate teaching methods and learning environments necessary for persons with stroke and their family caregivers to manage and function in their altered states. The end goals of the actions produced by the nursing system protect and develop the survivor of stroke’s existing self-care/dependent-care agency and assists individuals in achieving therapeutic self-care (Orem). The physical and occupational therapists’ care, as well as the registered nurses’ care, and input on the teaching needs of caregivers of survivors of stroke, represent the nursing agency in this study, since all health care team members impact the self-care of others. A conceptual map of the concepts as they pertain to this study is included in Figure 1.

Literature Review

When an individual faces a health crisis, often it is a family member who must provide direct care and comfort to him or her after discharge from the hospital or rehabilitation setting. This can be a very scary time if the family caregiver has no formal medical training. Information, given at the right time and in the right amount,
Figure 1: Conceptual Map: Study Concepts Related to Orem’s (2001) Self Care Deficit Nursing Theory

Decreased:
Risk of complications to persons with stroke and Hospital readmissions

Increased:
Ability of caregiver to provide informed care to person with stroke

PT/OT Agency:
Allied health professionals survey results Re: Teaching Needs about Self-Care of Caregivers and Persons with Stroke

Supportive-Educative System:
Provide education information for use in home environment by caregiver of survivor of stroke.

Increased:
Caregiver’s Dependent Care Agency
Self Care Agency
can be the key to unlock a wealth of knowledge that can be empowering to the
caregiver and the person in need of help.

As part of the health care team, physical and occupational therapists are very
involved in the care and treatment plan of persons with stroke. After the initial post-
stroke period, these therapists work closely with people with stroke to help them
achieve their highest functioning level. As each individual is different and unique, so
are their resultant health care needs. As part of the team, physical and occupational
therapists must be able to identify these special needs, determine an effective plan of
treatment, provide appropriate information to the person with disabilities and their
family members, and prepare them for living in home settings.

The purpose of this literature review was to better understand the teaching needs
of caregivers of persons with stroke, understand the various situations the caregivers
face in the home environment, and determine how these teaching needs are perceived
by physical and occupational therapists. This literature review also was focused on
various research articles exploring the physical and occupational therapists’ views on
the stroke rehabilitation process and their satisfactions and dissatisfactions in this
helping process. In addition, the physical and occupational therapists ability to
predict the discharge status of stroke patients is also discussed, as well as addressing
teaching needs of clients and their caregivers. A brief summary will follow that
provides an overall synthesis of the knowledge known regarding post discharge
teaching needs of caregivers of persons with stroke and the therapists role in helping
to provide this information.
Information/Teaching Needs Identified by Caregivers

To properly care for their loved ones after discharge, caregivers must be provided with the appropriate information to feel confident in their home care tasks. Questions arise as to what types of information should be taught, when it should be taught and what are the best teaching methods to provide this information.

In their qualitative study, Wiles, Pain, Buckland and McLellan (1998) found that people with stroke and their caregivers had a desire for information in three main areas. These areas were (1) clinical information, or dealing with recovery and prognosis, (2) practical information, or coping with day to day care, and (3) information on continuing care and resources in the community. Twenty one interviews were carried out with persons post stroke and their caregivers. The sample was evenly distributed with 11 males and 10 females, however, all interviewees were Caucasian and from the upper to middle socioeconomic class. Wiles et al. reported that patients and their caregivers had a desire for more individualized information that was relevant to them and their recovery. Therapists felt this was problematic because of the unpredictable nature of recovery and their fear of criticism by patients. These authors suggested use of a database, containing a wide variety of information regarding stroke to provide individualized information packages to patients and their caregivers for more individualized teaching.

In a qualitative study by Grant (1996), survivors of stroke and their caregivers identified four main problems after hospital discharge. These results were obtained by interviewing 10 survivors of stroke/caregiver couples. The sample was recruited
from the hospital setting immediately after discharge, from a rehabilitation setting, and from an outpatient clinic. Face to face interviews at their initial follow-up visit were performed with the couples and ranged from 1-2 hours. One week after the initial interview, the caregivers were telephoned to discuss the home care problems they faced in the initial post discharge period (Grant). These problems included loss of identity of the survivor of the stroke and feelings of discouragement and depression after discharge. Grant also discussed the negative effect plateau periods can have on the emotional status of the survivor of the stroke. This was similar to the findings discussed by Chang and Hasselkus (1998) in the following section.

Survivors of stroke expressed frustration in management of their activities of daily living (ADLs). These ADLs included bathing, dressing, transferring, walking and feeding. Caregivers also expressed difficulties finding assistive services in helping people with stroke with their ADLs. Lastly, survivors of stroke and their caregivers cited loneliness and a need for emotional and social support as a problem area (Grant).

In their descriptive study involving families and caregivers of survivors of stroke, Pierce et al. (2004) determined that families felt the need for more information regarding preventing falls, maintaining adequate nutrition, maintaining a healthy, active lifestyle, and dealing with emotional and mood changes. Similarly, other studies reported results that indicated patients and their caregivers were not receiving adequate information regarding stroke symptoms, medical terminology, and information regarding treatments and drugs (Driscoll, 2000; McLennan, Anderson &
Pain, 1996; O’ Mahony, Rodgers, Thomson, Dobson & James, 1997). While the findings by McLennan et al. were significant and the sample was representative of the general adult population at the hospital, the results should be interpreted with caution because the validity and reliability of their self administered questionnaire were not determined. This is in contrast to the article by Driscoll which employed both qualitative and quantitative methods of data collection. Questionnaire validity was achieved by review from six experts in the field and a pilot test of the questionnaire. However, no mention was made of the number of interviewers or if they received any special training. These methodology flaws could have influenced the way participants responded to the interviewers’ questions resulting in inaccurate data collection (Driscoll). This is in contrast to the study by O’Mahony et al., where one interviewer carried out all of the interviews. This helped maintain consistency and decreased the potential for inaccurate results related to different interviewing techniques.

Information/Teaching Needs Identified by Health Care Professionals

In their study assessing stroke survivors’ long-term learning needs, Johnson, Pearson, and McDivitt (1997) determined that professionals in rehabilitation, survivors of stroke and caregivers believe it is essential to investigate survivors of stroke and caregivers’ learning needs to better understand the concerns and challenges they face upon return to the community. Johnson and associates noted that a common error made by health care educators is to assume that they know their clients learning needs. While survivors of stroke and their caregivers have a large
knowledge deficit early in the recovery period, these authors reported that survivors of stroke have changing educational needs related to rehabilitation care as far as two years post stroke. Similarly Hanger, Walker, Paterson, McBride, and Sainsbury (1998) also reported that while the nature of the questions may change, patients with stroke continue to seek answers to relatively simple questions regarding their illness even 2 years post stroke.

Pierce, et al. (2003) surveyed rehabilitation and home care registered nurses in their quantitative study and determined that overall registered nurses felt that priority should be given to educating the caregiver and survivor of stroke on the stroke disease process, preventing pressure ulcers, performing safe transfer techniques, and coping with impairments in communication. These teaching needs fall under Orem’s (2001) universal self-care deficit of normalcy and prevention of hazards (Pierce et al.).

These studies provide insight on various information or teaching needs that may prevent caregivers of survivors of stroke to successfully care for their loved ones in the home. Being informed and prepared may help allay feelings of nervousness and frustration in the home setting leading to a more confident, competent caregiver. Health care professionals play a key role in providing this information.

Therapists Satisfactions and Dissatisfactions

The relationship that is formed between the therapist and the client and family member is a key factor in the potential success of the rehabilitation process. The inability to make this connection may result in a breakdown in helping processes and
failure of the person, client or caregiver, to reach his or her optimal functioning status post stroke. By developing and maintaining an optimal therapeutic relationship with the survivor of stroke and their family caregiver, the physical and occupational therapist will better understand their educational needs in preparation for discharge. This better understanding will allow the physical and occupational therapist to focus on information needs that are specific to the survivor of stroke and their caregiver. Rosa and Hasselkus (1996) identified the concept of “connecting with patients” as the very essence of the helping relationship for the therapists surveyed (p. 249). Success at achieving connectivity with patients, as well as the patient’s willingness to participate in rehabilitation, helped to determined whether or not therapists were satisfied or dissatisfied with the helping relationship (Rosa & Hasselkus). Chang and Hasselkus (1998) reported that occupational therapists were driven by expectations in their work with persons with stroke. The therapist’s satisfaction or dissatisfaction with the helping relationship was greatly influenced by the degree to which the therapist and patient shared the same expected outcomes of therapy (Chang & Hasselkus). Similarly to Rosa and Hasselkus (1996) and Chang and Hasselkus (1998), Lewinter and Mikkelsen (1995) found other factors influencing satisfaction with rehabilitation relationships including negotiation between the patient and the therapist, as well as the importance of patients being involved in goal setting.

Chang and Hasselkus (1998) were the only investigators to identify plateau periods as a great source of frustration for the person with stroke and a strong symbol of failure for the therapist. Despite plateau periods being a universal stage in stroke
recovery, Chang and Hasselkus stated that it is poorly discussed between therapists, therefore it contributes to the survivor’s of stroke difficulty dealing with this phenomenon when it happens.

Valuable information was obtained that is useful in the clinical setting from these studies (Rosa & Hasselkus, 1996; Chang & Hasselkus, 1998; Lewinter & Mikkelsen, 1995). Therapists should be encouraged to explore their satisfactions and dissatisfactions in the clinical setting with survivors of stroke. Methods to promote connectedness with their patients should be explored to promote a productive, positive working relationship in which both the therapist and the patient report satisfaction with the therapy process. Potential areas for further research include identifying the effects plateau periods have on survivors of stroke, and exploring how persons’ with stroke satisfactions and dissatisfactions with the helping relationship influence their commitment and progress toward achieving the optimal functional status for all involved.

Synthesis

The data obtained from this literature provide valuable information for the physical and occupational therapist, and all health care professionals, in the clinical and rehabilitation setting. The importance of being connected with clients and their caregivers can increase the therapists’ and survivors’ of stroke satisfaction in the rehabilitation process. It is important that these therapists develop and maintain excellent assessment skills, provide information, and revise the goals of therapy as needed with the involvement of the survivor of stroke and their caregiver.
Therapists must be sensitive to the teaching needs of survivors of stroke and their caregivers and make attempts to individualize teaching information that is specific to their needs. By providing client specific information, the survivor of stroke and their caregiver will be better prepared for the discharge process and hospital readmission rates will be greatly reduced. Finally, the therapist must be aware of plateau periods in the rehabilitation process and educate the survivor of stroke and caregiver on the potential emotional effects this period will have upon them.

Summary

In this chapter, Orem’s (2001) self-care deficit nursing theory was discussed along with how this theory provides the framework for this study. The basic concepts of Orem’s self-care deficit nursing theory were defined, as well as how these concepts were integrated in this study. A conceptual map of this study was included as a visual aid.

A literature review was performed and various themes were identified in the helping relationship between allied health professionals and caregivers of survivors of stroke. There is a need for education to be available and accessible to the caregiver of survivors of stroke to better prepare them for the discharge experience and to feel less anxious and isolated while providing care in the home setting. This will ultimately lead to better health outcomes for the person with stroke and caregiver and, in general, less stress on the health care system.
CHAPTER III

Method

The purpose of this study was to identify the most frequent teaching needs for persons with stroke and their caregivers as perceived by allied health professionals (i.e., physical and occupational therapists). The research design, a description of the sample, and the inclusion and exclusion criteria used for the study are described in this chapter. Methods used for data collection, controls to assure internal and external validity, and ethical considerations to protect the rights of the subjects are also discussed. The assumptions and limitations of the study are clarified. Lastly, the methods chosen and rationale for statistical analysis of the data are discussed.

Design

A descriptive research design was used to describe the teaching needs of caregivers and people with stroke as identified by allied health professionals.

Data Collection

Data collection was in September 2003. This time period was chosen to achieve the maximum response rate from participants since summer vacations are usually completed. A survey was mailed to prospective participants and they were given 2 weeks to respond. After this time period, another complete set of surveys was sent out to all participants, as there was less than a 50% return rate. A complete mailing needed to be done since, for anonymity reasons, it was not known which participants returned the survey.
Sample and Setting

The sample surveyed was allied health professionals, physical and occupational therapists, in the United States. The subjects were chosen using convenience sampling methods from a list of physical and occupational therapists obtained from the Internet. Occupational therapy subjects were obtained from the American Occupational Therapy Association (AOTA) website; http://www.aota.org/featured/area6/links/FindAnOT2.asc. Physical therapy subjects were obtained from the American Physical Therapy Association (APTA) website; http://www.apta.org/speccertdirectory/selectCCSForm.cfm. Surveys were sent to 98 physical therapists and to 100 occupational therapists. These allied health professionals are practicing physical and occupational therapists located at various in-patient and out-patient facilities throughout the United States. By using a diverse sample of therapists throughout the United States, the sample is thought to be more representative of physical and occupational therapists in general. This strengthened the accuracy and generalizability of the data obtained.

Inclusion criteria for this study were being listed on the above websites and holding a valid license or certificate to practice physical or occupational therapy. Since membership to the AOTA and APTA require all physical and occupational therapists hold valid licenses or certificates to practice in their state, this inclusion criteria was met for all participants.

Exclusion criteria for this study were participants indicating they had less than 1 year experience working with persons with stroke in an in-patient or out-patient
setting, and no demographic data on the survey. After the surveys were collected and the demographic data were analyzed, no participants were excluded from this study for inadequate clinical experience with persons with stroke. One survey was excluded for failure to complete the demographic data section of the survey.

Materials

Each potential participant was mailed a cover letter specifically stating the purpose of the research study (Appendix A). Along with the cover letter, a sheet was enclosed for standard demographic data collection (e.g., age, gender, and ethnicity). In addition to the standard demographic data, other demographic questions were asked such as how long they had practiced physical or occupational therapy, whether they were currently working with persons with stroke, and if so, what percentage of their practice was involved with the care of persons with stroke (Appendix B). These were forced choice questions. A survey was chosen to maintain a consistent data collection method for identifying teaching needs (Appendix C). By utilizing a consistent data collection method, the researcher was able to compare the results obtained from this study with the results previously obtained from studies involving registered nurses and caregivers of persons with stroke (Pierce et al., 2003, 2004).

Each participant was asked to choose 12 items from a list of 49, which they felt represented the most frequent teaching needs for persons with stroke and their caregivers. The topics on the survey were based on Orem’s (2001) eight universal self-care requisites (USCRs). This survey was adapted from an original survey that was reviewed by an expert nurse with a doctorate degree in the field of biostatistics.
Revisions were made to the original survey to increase the likelihood of obtaining reliable results (Rupp, 2002). The reliability of a survey tool is done to insure the consistency of the results obtained (Burns & Grove, 2001). Such revisions included removing the USCR categories from the survey and reducing the survey down to one page to decrease the tendency of the participant choosing responses from the first page only (Rupp). Prior to administering the original survey tool, it was evaluated for content validity by three advanced practice nurses with master’s degrees. These nurses had extensive experience working with older adults and were experts in the field of rehabilitative nursing (Rupp). Content validity of an instrument concerns its ability to gather the data that it is intended to gather (Burns & Grove, 2001). Additional space was available on the survey for other topics participants felt were a priority which were not included on the survey.

Protection of Human Rights

Prior to data collection, Institutional Review Board approval was obtained (Appendix D). Participants were assured of their anonymity in the cover letter and asked not to place their name anywhere on the survey materials (Appendix A). The return of the completed survey represented the participants’ consent for the study. To insure the protection of the participants’ human rights, the cover letter informed them that their participation in the study was strictly voluntary and there are no personal or professional consequences to them or their place of work if they choose not to participate.
Procedure

All surveys were mailed to the potential participants using the United States Postal Service. A self-addressed stamped envelope was included with each survey packet to encourage an adequate return rate.

*Controls for Threats to Internal and External Validity*

According to Burns & Grove (2001), internal consistency is the extent to which the effects detected in a study are an accurate reflection of reality and not extraneous variables. The data collection phase of this study was completed over a 5 week period. This short period of time prevented the influencing effects of history, maturation, and mortality on the results of the study. Since the first survey yielded a return rate that was less than 50%, the researcher mailed out another survey to all potential participants, as stated in the cover letter. This repeat mailing resulted in a potential for the same person to complete the survey twice and report different priority teaching topics. This was a potential threat to internal validity that the researcher was unable to control, due to the anonymity of the participants in the study. The survey was self-administered, had written instructions on the top of each page and included the researcher’s home phone number if the participants had questions. The researcher did not personally administer the survey, but did talk anonymously with 1 participant on the phone. These actions helped control for the effects of instrumentation on the data collection process.

According to Burns and Grove (2001), external validity is the extent to which the study findings can be generalized beyond the sample used in the study. To avoid
potential threats to external validity, the researcher reported in Chapter IV the number of surveys sent out with both mailings and the total number of surveys received. Also, any surveys that were not used due to incomplete or inaccurate documentation were reported. The researcher was unable to control for the interaction of the setting and treatment due to the data collection method, a mailed survey. The researcher had no way of knowing the participants’ views related to participating in research studies.

Assumptions

The assumptions that underlie this study include allied health professionals responding to the survey will answer the stroke information survey honestly and accurately. It was assumed that the participants completed the surveys in the allotted time frame with honesty and to the best of their abilities choosing only 12 topics and answering all of the demographic data.

Limitations

Limitations for this study include: 1) incomplete data on the surveys, and 2) participants may have filled out the survey again after the second mailing since this was not addressed in the cover letter.

Data Analysis

The survey was designed so that it could be scanned electronically. After the surveys were scanned, data analysis included nonparametric statistics which allowed data to be organized in a manner that provides meaning and insight. Nonparametric statistics are most frequently used to analyze nominal data (Burns & Grove, 2001).
Research Question #1: What are the top 12 teaching needs for persons with stroke and their caregivers as identified by allied health professionals (i.e., physical and occupational therapists)? This research question involved descriptive statistics, which included frequency distributions and percentages. Frequency distributions can be displayed as tables, diagrams, or graphs which provide a visual presentation of numbers that may provide insight into the data (Burns & Grove, 2001). These frequency distributions identified how often each teaching need was chosen by the participants, as well as the top 12 teaching needs chosen by all of the participants combined.

Research Question #2: Are there differences between identified teaching needs of caregivers of persons with stroke as identified by registered nurses, allied health professionals, and family caregivers? This research question involved comparing the data obtained from this study with physical and occupational therapists and the data obtained from registered nurses and family caregivers from previous work (Pierce et al., 2003, 2004). Similarities and differences between the three groups were identified using descriptive statistics such as frequency distributions and percentages.

Summary

In this chapter, the method and design chosen for this study were discussed as well as the sample. Methods used to obtain the sample were identified. Inclusion and exclusion criteria for the sample were reviewed. The participant survey tool was discussed, as well as methods used by the researcher to ensure the content validity and reliability of the survey tool. Data collection methods were described and
methods to protect the participants’ human rights were listed. Various assumptions and limitations to the data collection process were reviewed along with various controls to maintain internal and external validity. Lastly, methods for data collection were reviewed, as well as the rationale for choosing statistical analysis procedures.
CHAPTER IV

Results

The sample participating in this survey is described in this chapter. The degree of representativeness of the data obtained in this survey to the target population is discussed. All pertinent survey findings are identified and the top 12 teaching needs of caregivers and survivors of stroke, as identified by physical and occupational therapists, are listed. Other information topics identified by physical and occupational therapists as pertinent for the caregiver to know are also listed. The top teaching needs from this study are compared to registered nurses and caregivers from other studies (Pierce et al., 2003, 2004).

Sample

The response from the initial survey mailing yielded 82 surveys (41%), 46 from physical therapists and 36 from occupational therapists. Since this response rate was less than 50%, a repeat survey was mailed to all potential participants 2 weeks later. The second mailing yielded 33 more surveys for a total of 115 surveys, 48 from physical therapists, 65 from occupational therapists, 1 from a speech pathologist, and 1 containing no demographic data. These last two surveys were not used. The final response rate was 57%. Twenty-five surveys were returned unopened from the postal service. After the surveys were collected and reviewed, the appropriate statistical analyses were performed.

The sample size used for this study was 113. Descriptive statistics, such as percentages and frequencies, were used to analyze the data collected. In Table 1, the
Table 1 Demographic Profile (n=113).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percent</th>
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</thead>
<tbody>
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<td><strong>Type of Therapist:</strong></td>
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<tr>
<td>Physical Therapist</td>
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<td>mid-western United States</td>
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<td>1</td>
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</tr>
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<td>Black or African American</td>
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<td>2</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
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<td>1</td>
</tr>
<tr>
<td>White</td>
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<td>96</td>
</tr>
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<td><strong>Total</strong></td>
<td><strong>113</strong></td>
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*(table continues)*
Table Continued

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<tr>
<th>Characteristics</th>
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<td>Ph.D.</td>
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<td><strong>Total</strong></td>
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<td><strong>100</strong></td>
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<tr>
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<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
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<td>2</td>
</tr>
<tr>
<td>1-5 years</td>
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<td>7</td>
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<tr>
<td>5-10 years</td>
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</tr>
<tr>
<td>&gt; 10 years</td>
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<tr>
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<tr>
<td><strong>Total</strong></td>
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<td><strong>100</strong></td>
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<tr>
<td><strong>Currently Work with People with Stroke:</strong></td>
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</tr>
<tr>
<td>Yes</td>
<td>82</td>
<td>73</td>
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<tr>
<td>No</td>
<td>31</td>
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<tr>
<td><strong>Total</strong></td>
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<td><strong>100</strong></td>
</tr>
<tr>
<td><strong>Time Spent Currently Working with Survivors of Stroke:</strong></td>
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</tr>
<tr>
<td>&lt; 25%</td>
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<td>59</td>
</tr>
<tr>
<td>&lt; 50%</td>
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<td>29</td>
</tr>
<tr>
<td>&gt; 50%</td>
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<td>7</td>
</tr>
<tr>
<td>&gt; 75%</td>
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<td><strong>Total</strong></td>
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<td><strong>Have Cared or Currently Caring for Loved One with Stroke:</strong></td>
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<td>31</td>
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<tr>
<td>No</td>
<td>76</td>
<td>67</td>
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<tr>
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<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>113</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

respondents were occupational therapists and 42% were physical therapists. The study sample was identified as primarily white females living in the northern, eastern, or mid-western United States. Over half of the respondents held a master degree and slightly more than one fourth held a bachelor degree in either physical or
occupational therapy. All 113 respondents had experience working with people with stroke. There was fairly equal representation of both physical and occupational therapists in the survey with three quarters having practiced therapy for more than 10 years.

Findings

Research Question 1: What are the top 12 teaching needs of caregivers and persons with stroke as identified by allied health professionals? The top 12 teaching needs are listed in Table 2. Ninety-three of the 113 respondents (82%) identified demonstrating safe transfer techniques as the most frequent teaching need of caregivers and persons with stroke. This falls under the USCR of hazards according to Orem (2001).

An area was available on the survey for respondents to write in other types of information caregivers of survivors of stroke needed. Forty-five respondents (40%) commented on additional teaching needs. These included: 1) managing range of motion in the affected limbs/normalcy, 2) dealing with issues related to driving for the survivor of stroke/normalcy, 3) splinting and orthotics/normalcy, 4) managing tone/normalcy, 5) retraining handwriting skills/normalcy, 6) managing wheelchairs and propulsion/hazards, 7) understanding insurance utilization/normalcy, 8) providing education to decrease the likelihood of a repeat stroke/normalcy, 9) using community resources for equipment banks/normalcy, and 10) understanding the importance of a long-term exercise program/normalcy.
Table 2

*Top 12 Teaching Needs Chosen by Physical and Occupational Therapists.*

<table>
<thead>
<tr>
<th>Teaching Need/Universal Self-Care Requisite</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and Occupational Therapists (n=113)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstrating Safe Transfer Techniques/Hazards</td>
<td>93</td>
<td>82</td>
</tr>
<tr>
<td>Comprehending Availability and Use of Assistive and Adaptive Devices/Normalcy</td>
<td>88</td>
<td>78</td>
</tr>
<tr>
<td>Understanding Prevention of Falls/Hazards</td>
<td>80</td>
<td>71</td>
</tr>
<tr>
<td>Developing Household Safety Strategies/Hazards</td>
<td>80</td>
<td>71</td>
</tr>
<tr>
<td>Dealing with Problems in Communication/Solitude and Social Interaction</td>
<td>74</td>
<td>65</td>
</tr>
<tr>
<td>Managing Visual Field Losses/Hazards</td>
<td>64</td>
<td>57</td>
</tr>
<tr>
<td>Dealing with Emotional Changes/Normalcy and Solitude and Social Interaction</td>
<td>62</td>
<td>55</td>
</tr>
<tr>
<td>Managing Changes in Roles and Relationships/Solitude and Social Interaction</td>
<td>58</td>
<td>51</td>
</tr>
<tr>
<td>Understanding Stroke Disease Process/Normalcy</td>
<td>57</td>
<td>50</td>
</tr>
<tr>
<td>Learning about Exercise/Normalcy</td>
<td>54</td>
<td>48</td>
</tr>
<tr>
<td>Managing Memory Loss/Normalcy &amp; Solitude and Social Interaction</td>
<td>50</td>
<td>44</td>
</tr>
<tr>
<td>Staying Active/Normalcy</td>
<td>47</td>
<td>42</td>
</tr>
</tbody>
</table>
Research Question 2: Are there differences between teaching needs of persons with stroke and their caregivers as identified by registered nurses, family caregivers, and allied health professionals? In Table 3, the top three teaching needs of caregivers of persons with stroke as identified by registered nurses include: 1) understanding stroke disease process/normality (82%), 2) preventing pressure ulcers/hazards (61%), and 3) demonstrating safe transfer techniques/hazards (57%) (Pierce et al., 2003). In Table 3, the top three self care needs of caregivers of persons with stroke as identified by family caregivers include: 1) preventing falls/hazards (71%), 2) maintaining adequate nutrition/food (63%), and 3) staying active/normality (63%) (Pierce, et al., 2004). Caregivers and physical and occupational therapists both identified safety issues and fall prevention as their number one teaching need. Nurses identified education and understanding the stroke disease process as the priority teaching need. These findings will be discussed further in Chapter V.

Summary

Of the 115 surveys returned, 113 were deemed usable for this study for a 57% return rate. The results of the survey were discussed along with the top 12 teaching needs of caregivers and survivors of stroke as identified by physical and occupational therapists. Additional caregiver teaching needs, identified by individual physical and occupational therapists, were discussed.
Table 3

Top 12 Teaching Needs Chosen by Families and Registered Nurses

<table>
<thead>
<tr>
<th>Self Care Need/Universal Self-Care Requisite (Pierce, Finn, &amp; Steiner, 2004)</th>
<th>Families (n=24)</th>
<th></th>
<th>Percent</th>
<th>Registered Nurses (n=28)</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preventing Falls/Hazards</td>
<td>17</td>
<td>71</td>
<td></td>
<td>Understanding Stroke Disease Process/Normalcy</td>
<td>23</td>
<td>82</td>
</tr>
<tr>
<td>Maintaining Adequate Nutrition/Food</td>
<td>15</td>
<td>63</td>
<td></td>
<td>Preventing Pressure Ulcers/Hazards</td>
<td>17</td>
<td>61</td>
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<tr>
<td>Staying Active/Normalcy</td>
<td>15</td>
<td>63</td>
<td></td>
<td>Demonstrating Safe Transfer Techniques/Hazards</td>
<td>16</td>
<td>57</td>
</tr>
<tr>
<td>Managing Stress/Normalcy and Solitude and Social Interaction</td>
<td>14</td>
<td>58</td>
<td></td>
<td>Preventing Aspiration/Air</td>
<td>15</td>
<td>54</td>
</tr>
<tr>
<td>Dealing with Emotional and Mood Changes/Normalcy and Solitude and Social Interaction</td>
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<td>50</td>
<td></td>
<td>Dealing with Problems in Communication/Solitude and Social Interaction</td>
<td>15</td>
<td>54</td>
</tr>
<tr>
<td>Managing Roles and Relationships/Solitude and Social Interaction</td>
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<td>46</td>
<td></td>
<td>Understanding the Prevention of Falls/Hazards</td>
<td>15</td>
<td>54</td>
</tr>
<tr>
<td>Learning Activities to Increase Dexterity, Memory, and Function/Normalcy</td>
<td>11</td>
<td>46</td>
<td></td>
<td>Managing Anticoagulation Therapy/Hazards</td>
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<td>50</td>
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<tr>
<td>Preventing Constipation/Elimination</td>
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<td>42</td>
<td></td>
<td>Comprehending Availability and Use of Assistive or Adaptive Devices/Normalcy</td>
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(table continues)
Table Continued

<table>
<thead>
<tr>
<th>Self Care Need / Universal Self-Care Requisite</th>
<th>Frequency</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Families (n=24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding the Stroke Disease Process/Normalcy</td>
<td>10</td>
<td>42</td>
</tr>
<tr>
<td>Dealing with Communication Problems/ Solitude and Social Interaction</td>
<td>09</td>
<td>38</td>
</tr>
<tr>
<td>Dealing with Behavior and Personality Changes/Normalcy</td>
<td>09</td>
<td>38</td>
</tr>
<tr>
<td>Learning about Exercise/Activity and Rest and Normalcy</td>
<td>07</td>
<td>29</td>
</tr>
<tr>
<td>Registered Nurses (n=28)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developing Household Safety Strategies/ Hazards</td>
<td>12</td>
<td>43</td>
</tr>
<tr>
<td>Preventing Constipation/Elimination</td>
<td>11</td>
<td>39</td>
</tr>
<tr>
<td>Managing Changes in Roles and Relationships/ Solitude and Social Interaction</td>
<td>10</td>
<td>36</td>
</tr>
<tr>
<td>Dealing with Emotional Changes/ Normalcy and Solitude and Social Interaction</td>
<td>10</td>
<td>36</td>
</tr>
</tbody>
</table>
CHAPTER V

Discussion

In this chapter, the study findings presented in Chapter IV are discussed in relation to the literature previously cited as well as the theoretical framework for this study. The conclusions of this study are discussed as well as potential limitations. Implications for nursing practice and further research recommendations are reviewed, as well as how this study impacts the health care field.

Findings

Three of the top five teaching needs of caregivers and survivors of stroke, identified by physical and occupational therapists, were classified under Orem’s (2001) prevention of hazards universal self-care requisite (USCR). Demonstrating safe transfer techniques was the most frequently chosen teaching need (82%). According to Orem, the maintenance of human integrity and functioning is accomplished through the prevention of hazards to life. Prevention of hazards is linked to all of the other USCR and focuses on the control the person has over both their internal and external environments (Orem). Since survivors of stroke are in need of some form of dependent care due to physical limitations, the caregiver must take actions to identify, remove or protect the survivor of stroke from actual or potential hazards that may affect their functional well being.

Safety and the prevention of hazards is a priority not only for the person with stroke, but for the caregiver as well. Safe transfer techniques are critical to both individuals in the homecare setting to prevent injuries and to maintain functional
integrity. This is consistent with the findings by Pierce and associates (2004). They determined family caregivers of survivors of stroke were most concerned with gathering information regarding safety measures and the prevention of falls (71%). This need is also supported by Grant (1996) in her qualitative study which found the most frequent problem caregivers and survivors of stroke faced in the home environment regarding activities of daily living involved deficits in mobility and the desire to have assistance with patient transfers. Similarly, Wiles et al. (1998) determined that people with stroke and their caregivers desired information in three general areas. One of these areas includes coping with day to day care such as transfer techniques. Pierce et al. (2003) found that the registered nurses as a whole ranked demonstrating safe transfer techniques as the third most frequently requested information need for caregivers (57%). The nurses surveyed were more concerned with providing the survivors of stroke and their caregivers with information regarding understanding the stroke disease process (82%). This may be due to the registered nurses emphasis on health promotion and disease prevention instead of long-term home care or emotional issues.

The second most frequent teaching need identified by physical and occupational therapists involved comprehending the availability and use of assistive and adaptive devices (78%). This teaching need is identified by Orem (2001) as the promotion of normalcy. According to Orem, the promotion of normalcy prevents the development of conditions that lead to internal hazards to human life. Therefore, the promotion of normalcy and prevention of hazards are closely related. Also, by assisting the
caregiver and survivor of stroke with the proper use of assistive devices, the survivor is encouraged to become more independent, as they strive to reach their maximum functioning capacity post-stroke (Orem). This also impacts the functioning of the caregiver, emotionally and physically. This finding is also supported by Wiles et al. (1998) and O’Mahony et al. (1997) in their studies suggesting that people with stroke and their caregivers desire more information on continuing care and available services and resources in the community, such as the attainment of assistive devices.

Other teaching needs identified by more than half of the physical and occupational therapists surveyed included: 1) understanding prevention of falls/hazards; 2) developing household safety strategies/hazards; 3) dealing with problems in communication/solitude and social interaction; 4) managing visual field losses/normalcy; 5) dealing with emotional changes/solitude and social interaction; 6) managing changes in roles and relationships/solitude and social interaction; and 7) understanding stroke disease process/normalcy (Table 3). According to Orem (2001), other USCRs that these priority teaching needs fall into include solitude and social interaction and normalcy. Orem believed that there should be a balance between solitude and social interaction. This balance helps individuals acquire knowledge, form values and expectations and is essential for developmental growth (Orem). Solitude provides individuals with quiet, reflective time while social interaction provides a sense of belonging and is an essential part of the educational process for caregivers and survivors of stroke.
The promotion of normalcy focuses on human functioning and development within social groups and the individuals desire to be normal and adapt to their changing life circumstances (Orem, 2001). This USCR fosters all aspects of human development and helps the individual with stroke strive to develop and maintain a positive self-concept and body image (Orem). Learning to adapt to changes in lifestyle can be challenging for the survivor of stroke and his/her caregiver. As the survivor and his/her caretaker become more adjusted to their environment and changing life circumstances, they will gain a greater sense of self and wholeness. This in turn will decrease the survivor’s need for dependent care and promote a positive sense of self for both the person with stroke and the caretaker.

Other frequently mentioned teaching needs written in on the survey by the respondents include: 1) managing range of motion in affected limbs; 2) splinting the affected limb and orthotics; 3) managing tone; 4) managing a wheelchair and propulsion; and 5) understanding the importance of long-term exercise programs. These are supported by the findings of Hanger et al. (1998) which found that, despite changes in the nature of the questions, a percentage of persons with stroke and their caregivers continued to have questions regarding rehabilitation and the importance of exercise 6 months to 2 years post stroke.

The physical and occupational therapists surveyed did not choose the USCR of air, water, food or elimination in the top 12 teaching needs. Orem (2001) defined the USCR of air, water and food as focusing on the necessary materials and resources that are essential to the individual to sustain life and bodily processes. Elimination
focuses on the need for self care or dependent care actions necessary for managing the excretion of bodily wastes (Orem). These USCR may not have been a priority for physical and occupational therapists due to their primary focus on motor functioning and adaptation to the environment. This is in contrast to the studies by Pierce et al. (2003, 2004) in which rehabilitation registered nurses ranked preventing aspiration the number one need for caregivers of survivors of stroke (77%) and families of people with stroke ranked maintaining adequate nutrition number two (63%). These differences may be due to the registered nurses’ primary focus on maintaining an open airway, adequate oxygenation and basic human needs of individuals such as bowel and bladder elimination, as well as the family’s desire to assist their loved ones in regaining strength and maximum functioning through adequate nutrition.

Conclusions

This descriptive study suggests that physical and occupational therapists perceive safety issues as the primary teaching need for caregivers and survivors of stroke while caring for their loved ones in the home environment. While safety issues accounted for three of the top five teaching needs identified by physical and occupational therapists, they also identified the importance of caregiver’s understanding the use of and ways to obtain assistive and adaptive devices in the community. Dealing with problems in communication also were identified as an area that needed to be addressed with caregivers, as they prepare to care for their loved ones in the home environment. By addressing the identified teaching needs of physical and occupational therapists, along with those of registered nurses and caregivers
themselves, health care team members can provide a more comprehensive discharge teaching program which better prepares caregivers for managing the care of their loved ones in the home environment. This may lead to a reduction in the number of post discharge complications and hospital readmissions for the person with stroke. In addition, the caregivers may experience more positive feelings of self.

Limitations

Identified limitations of this study which may influence the ability to generalize these results include that the respondents were predominately white females. Therefore, this homogeneous sample was poorly representative of different ethnic/cultural backgrounds, which may have altered the results of this survey. Also, respondents between the ages of 20 – 29 and 55 – 65 years of age were poorly represented in the survey. This may have influenced the results since individuals with varied years of experience working with survivors of stroke and their caregivers may offer valuable opinions and experiences as they care for these individuals. Another potential limitation of this study involves the recruitment strategy used to obtain participants for the survey. The sample was obtained on the Internet and was limited to those choosing to belong to the APTA and the AOTA. This may have prevented the attainment of a more culturally and racially diverse sample. Another limitation to this study was that respondents were asked to identify the top 12 teaching needs of caregivers and survivors of stroke on the survey. This may have been confusing to the respondent since the caregiver and survivor of stroke may have different needs. Since persons dealing with stroke may have different time frames for teaching needs,
it may have been beneficial to ask physical and occupational therapists to break down the teaching needs into categories such as, early recovery, middle recovery, and late recovery. Lastly, the southern and western United States were poorly represented in this study. This may have impacted the results due to differing values and priorities of care in these regions.

Implications

Implications for Health Care Professionals

This study clearly demonstrates the teaching needs of caregivers and survivors of stroke prior to discharge and also in the post discharge phase when caring in home settings. The caregivers need for basic information related to the stroke itself, as well as information related to the actual care of the survivor as long as 2 years post stroke, was clearly identified in the study by Hanger et al. (1998). While physical and occupational therapists views on the priority of teaching needs of caregivers of persons with stroke may differ from those of family caregivers themselves and registered nurses, each health care team member offers valid input on priority teaching needs that can and should be addressed. Encouraging input from various health care disciplines as well as caregivers themselves will strengthen the development of a comprehensive teaching program for survivors and their caregivers. An interdisciplinary approach to survivor and caregiver education will promote a team atmosphere that will allow each member of the health care team to be heard, educate each other, and contribute key teaching information that they feel will better prepare these individuals for discharge. If all involved health care team members feel
they have had input into the program, they will be more likely to utilize it. The advanced practice nurse can utilize his/her leadership skills by coordinating this team approach to survivor and caregiver education. By initiating referrals and following up with survivors and their caregivers in the post discharge setting, the advanced practice nurse can assure a smooth transition and offer assistance where needed. The advanced practice nurse can also serve to evaluate the effectiveness of the interdisciplinary teaching program and make revisions where needed to better assist the survivor and their caregiver. There are various methods of teaching that can be utilized at differing phases in the care process that can be employed both in the acute, pre-discharge phase as well as the post discharge phase in the home environment. Pamphlets and caregiver demonstrations can be a successful method to provide information to caregivers in the hospital and rehabilitation setting, while the benefits of Internet learning also need to be explored and available to caregivers in the home setting as other information needs arise. This pertinent information may help to improve the functional status of the caregiver of the person with stroke post discharge (Banford et al.). It is important to understand that caregivers and survivors of stroke will have different time tables regarding their readiness for various information topics. To better assist caregivers with their adjustment to the home setting and in allaying their feelings of helplessness, this information must be available for them as these needs arise.
Implications for Administrators

Administrators in the health care setting must be sensitive to the importance of meeting the educational needs of survivors of stroke and their family caregivers as they are prepared for discharge to home. By providing needed information and support, persons with stroke and their caregivers will feel more empowered in the home setting. Better patient education programs may require hiring more highly trained nursing professionals such as advanced practice nurses. This may result in more money being paid up front in payroll expenses, however, in the long-term could contribute to fewer hospital readmissions.

Implications for Educators

Another important implication from the results of this study include the opportunity for collaboration between physical and occupational therapists, caregivers, registered nurses, and other members of the health care team. Successful collaboration by all health care team members will provide a more comprehensive teaching program which better prepares persons with stroke and their family caregivers for the discharge process. With their focus on health promotion and disease prevention, advanced practice nurses can take a leading role in preparing teaching plans for survivors of stroke and their caregivers that are specific to individual needs. By utilizing Orem’s (2001) supportive-educative nursing system, advanced practice nurses are able to help persons with stroke and their caregivers acquire the knowledge and skills they need for successful home care. By communicating this information with each other, all members of the health care team,
in collaboration with the caregiver and person with stroke, can be united as they work together for optimal outcomes.

Recommendations for Further Research

Areas for further research include exploring at what stage in the rehabilitation process survivors of stroke and their caregivers feel most ready and accepting of information regarding the stroke disease process and information regarding the care of persons with stroke. The various settings and methods caregivers and persons with stroke feel most comfortable obtaining their information need to be explored, as well as factors underlying effective communication patterns between the caregiver and health care professional. Also, the willingness of the interdisciplinary health care team to coordinate the care and education of persons with stroke and their caregivers to provide a comprehensive teaching program in the inpatient and outpatient environment should be explored. Attention should be paid to obtaining a more diverse sample representing a wider range of ethnic backgrounds that is not gender biased. This will allow the study results to be more applicable to the general population.

Summary

The results of the physical and occupational therapists surveyed in this study were discussed, as well as how the top teaching needs identified differ among groups of caregivers of persons with stroke, registered nurses, and allied health professionals. Conclusions based on the data obtained in this study were made and various limitations to this study were identified. Implications for the care of persons with
stroke were discussed, as well as the roles physical and occupational therapists and registered nurses can play in the delivery of these important information needs. Areas for further research were identified that would serve to strengthen these findings.
REFERENCES


Hello, my name is Amanda Cook and I am a registered nurse in the graduate program at the Medical College of Ohio School of Nursing. Dr. Linda L. Pierce, PhD, RN is my faculty advisor. For my Master of Science in Nursing degree, I am currently working on my thesis which involves discovering the most frequent teaching needs that you, as an allied health professional, provide to persons dealing with stroke. I received contact information for you from the Internet.

On the next page there is a list of information topics that may be helpful. Also, to get a clearer picture of you, the respondent, please fill in the demographic data on the opposite side of the survey. To assure anonymity, please do not put your name anywhere on the survey materials.

The results of this survey may be shared with a professional journal and its readers; however, all respondents will remain anonymous. Any other information obtained in connection with this study will also remain confidential and be used solely for the purpose of this study.

Your participation in this study is strictly voluntary; however, it is greatly appreciated. If you decide not to participate in the survey process, your decision will not affect current or future relations with your agency or the Medical College of Ohio. If you decide to participate, I ask that you complete and return the enclosed survey within the next week in the self-addressed stamped envelope. Your consent to participate in this study is implied with the return of the completed survey. All persons will receive a second mailing notice to return their survey, if the majority of surveys are not returned within two weeks of mailing this letter. Since I do not know the names of persons who did/did not return the survey, all persons getting the first mailing will receive the second mailing as well.

If you have questions or concerns, Amanda can be contacted at 419.624.1919. Please do not leave a voice mail message that identifies you, if you do not want your name and number known. Thank you in advance for assisting me with this study.

Amanda M. Cook, BSN, RN, Graduate Student

Linda L. Pierce, PhD, RN, Professor

APPROVED BY MCQ IRI
**DEMOGRAPHIC DATA:** Please complete all of the following questions, so that specific characteristics of the participants completing the survey will be identified. Use pen or pencil and completely fill in the square; DO NOT USE X's or Vs.

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) My age is:</td>
<td>□ 20-24, □ 25-29, □ 30-34, □ 35-39, □ 40-44, □ 45-49, □ 50-54, □ 55-59, □ 60-65</td>
</tr>
<tr>
<td>2) I am:</td>
<td>□ Male, □ Female</td>
</tr>
<tr>
<td>3) My ethnicity is:</td>
<td>□ Hispanic or Latino, □ Not Hispanic or Latino</td>
</tr>
<tr>
<td>4) I am:</td>
<td>□ American Indian or Alaska Native, □ Asian, □ Black or African American, □ Native Hawaiian or Pacific Islander, □ White</td>
</tr>
<tr>
<td>5) My highest degree of education is:</td>
<td>□ Certificate, □ Associate's Degree, □ Bachelor's Degree, □ Master's Degree, □ Ph.D.</td>
</tr>
<tr>
<td>6) I am a:</td>
<td>□ Occupational Therapist, □ Physical Therapist</td>
</tr>
<tr>
<td>7) My practice is located in:</td>
<td>□ northern United States, □ southern United States, □ eastern United States, □ western United States, □ mid-western United States</td>
</tr>
<tr>
<td>8) I have practiced therapy for:</td>
<td>□ less than 1 year, □ 1-5 years, □ 5-10 years, □ more than 10 years</td>
</tr>
<tr>
<td>9) I have worked with people with stroke:</td>
<td>□ Yes, □ No</td>
</tr>
<tr>
<td>10) I now work with people with stroke:</td>
<td>□ Yes, □ No</td>
</tr>
<tr>
<td>11) If yes to #10, my time working with people with stroke is:</td>
<td>□ Less than 25%, □ Less than 50%, □ More than 50%, □ More than 75%</td>
</tr>
<tr>
<td>12) I care or cared for a family member/friend with stroke:</td>
<td>□ Yes, □ No</td>
</tr>
</tbody>
</table>
APPENDIX C
Top Information Needs Survey

DIRECTIONS: Please fill in the circle next to the TWELVE items (AND ONLY 12) that, in your opinion, represent the MOST FREQUENT teaching and/or needs for persons with stroke and their caregivers. Please use pen or pencil and completely fill in the circle; DO NOT USE X. Use the back of the survey to write any other MOST FREQUENT topic not included on the list. Also, please fill out the DEMOGRAPHIC DATA on the BACK of this survey. Thank you.

- Preventing Aspiration
- Managing Oxygen Therapy
- Learning Smoking Cessation Techniques
- Understanding Low Fat Diet
- Understanding Low Sodium Diet
- Understanding Low Cholesterol Diet
- Understanding Mechanical Soft Diet
- Managing Care of Feeding Tube
- Limiting Alcohol Intake
- Maintaining an Adequate Caloric Intake
- Developing Weight Reduction Program
- Preventing Constipation
- Managing Bowel Incontinence
- Managing Urinary Incontinence
- Demonstrating Catheter Care
- Dealing with Problems in Communication
- Managing Changes in Roles and Relationships
- Dealing with Emotional Changes
- Dealing with Behavioral Changes
- Learning about Exercise
- Staying Active
- Managing Sleep Disturbances
- Learning Diversional or Recreational Activities
- Understanding Energy Conservation
- Demonstrating Safe Transfer Techniques
- Understanding Prevention of Falls
- Developing Household Safety Strategies
- Managing Pain / Providing Comfort
- Managing Anticoagulation Therapy
- Managing Blood Pressure Medications
- Managing Diuretic Medications
- Managing Seizures
- Preventing Pressure Ulcers
- Managing Edema
- Monitoring Blood Pressure
- Managing Stress
- Coping with Life
- Learning Foot Care
- Managing Dry Skin
- Comprehending Availability and Use of Assistive or Adaptive Devices
- Understanding Stroke Disease Process
- Dealing with Changes in Body Image
- Identifying Relaxation Techniques
- Identifying Caregiver Support Groups
- Managing Visual Field Losses
- Managing Memory Loss
- Managing and Dealing with Changes in Sexuality
- Managing Adequate Fluid Intake
- Finding Respite Care

APPROVED BY MCO IRB

IRB# 103261
APPENDIX D
Institutional Review Board Approval

Medical College of Ohio
INSTITUTIONAL REVIEW BOARD

MEMORANDUM

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

FROM: Eric A. Schaub, M.D.
Chair, Institutional Review Board
Research and Grants Administration

DATE: July 29, 2003

SUBJECT: IRB #103261 - The Caring-Web: Web-based Support for Stroke Caregivers

Your amendment (addition of Amanda Cook as study personnel, addition of new demographic and mail surveys, and a cover letter to potential participants) to the above protocol were reviewed and approved by the Chairman of the Institutional Review Board. The requirement to obtain a signed Consent/Authorization for Use and Disclosure of Protected Health Information Form has been waived as this amendment is determined to be minimal risk and a signed Consent/Authorization Document would be the only record linking the subject to the data for this particular portion of this research. It was determined that this waiver for signed Consent/Authorization for Use and Disclosure of Protected Health Information form will not adversely affect the rights and welfare of the participants. The Principal Investigator must provide a copy of the cover letter to all participants prior to participation. This action will be reported to the committee at its meeting on 08/21/2003. Thank you for your notification.

PROTOCOL EXPIRATION DATE: 04/13/2004

NOTE: THE ATTACHED COVER LETTER WITH THE IRB APPROVAL STAMP IS THE ONLY VALID VERSION FOR THIS PORTION OF THIS RESEARCH. THIS FORM MUST BE COPIED AND USED FOR ALL STUDY PARTICIPANTS BEING RECRUITED FOR THIS PORTION OF THIS RESEARCH. STUDY PARTICIPANTS MUST BE GIVEN A COPY OF THIS FORM PRIOR TO CHOOSING TO PARTICIPATE IN THIS PORTION OF THIS RESEARCH.

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

1. Abide by all federal, state, and local laws and regulations; the MCO federal assurance and institutional policies for human subject research and protection of individually identifiable health information and be sure that all members of your research team have completed the required education in these areas.

2. Ensure that all subjects, or their legally authorized representatives, are provided a copy of the Cover Letter prior to choosing to participate in this research.

3. Comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule Privacy Rule (45 CFR 164) and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information.

4. Promptly notify the IRB at (419) 383-4251 of any untoward incidents or unanticipated adverse reactions that develop in the course of your research on human subjects. Please complete and submit RGA Form 317 for ALL SUCH REPORTS for this protocol. The Principal Investigator is also responsible for submitting to the MCO 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 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).
5. Report promptly to the MCO IRB any deviations, violations, participant non-compliance from the 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 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.

6. Obtain prior IRB review and approval for changes in procedures, inclusion/exclusion criteria, study personnel, source of participants, new or additional advertising materials, modifications to subject payments, and for any and all changes to the cover letter and survey tool.

7. Report promptly new information affecting the risk/benefit ratio and obtain prior IRB approval for any changes in the study documents that may be required by the new information.

8. Obtain prior 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.

9. Approval by the MCO Institutional Review Board does not take the place of any other approval required by the Medical College of Ohio, non-MCO performance sites, the government and/or the study sponsor.

To request review and approval for changes to IRB approved research, please complete and submit RGA Form 314 (http://www.mco.edu/Research/rga_frmz/rga314.doc) with a copy of all materials relevant to the requested change (including the cover letter and survey tool if applicable) with the changes underlined. If you are requesting review and approval of a cover letter or survey tool, please attach a clean copy of the revised forms for the IRB to stamp.

IRB protocols must be reviewed and reapproved not less than once per year. Research and Grants Administration will try to remind you when reapproval is due. However, your office should have a reminder system in place to initiate the reapproval process at least a month prior to the expiration date shown above. When you decide to stop this research, you must complete and submit a final report (RGA Form 320) to the IRB for review.

Enclosures: Stamped Cover Letter and Survey Tool

EAS/fw

DHHS MPA # M-135
ABSTRACT

Educational planning is essential for successful transitions from hospital to home for persons with stroke and their caregivers. Guided by Orem’s self-care deficit nursing theory, the aims of this study were: 1) identification of the most frequent teaching needs for persons with stroke and their caregivers as perceived by physical and occupational therapists and 2) comparison of these identified needs with those of registered nurses and family caregivers. The subjects (n=113) were mostly white women prepared at the occupational therapy graduate educational level in the eastern United States. Descriptive statistics revealed demonstrating safe transfer techniques (82%) [hazards in Orem’s terms] was the top teaching need identified by physical and occupational therapists. Caregivers were concerned with preventing falls (71%) [hazards], and nurses’ focused on understanding the disease process (82%) [normalcy]. Educational interventions designed by healthcare teams and focused on optimal self-care outcomes promote well-being for caregivers and their care recipients.