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Questions asked by male and female caregivers of persons with stroke in a Web-based support group

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MEDICAL UNIVERSITY
OF OHIO

COLLEGE OF GRADUATE STUDIES

FINAL APPROVAL OF THESIS
Master of Science in Nursing

Questions Asked by Male and Female Caregivers of Persons with Stroke in a Web-based Support Group

Submitted by

Bridget M. Wicks

In partial fulfillment of the requirements for the degree of
Master of Science in Nursing

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DEDICATION

I wish to dedicate this thesis to my husband, Tobin, and children, Cohen and Emily, for all their support.

ACKNOWLEDGMENTS

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CHAPTER 1

Introduction

Stroke is the leading cause of long-term disability in the United States and the third leading cause of death (American Heart Association [AHA], 2005).

With improved detection and treatment methods, survival has increased (National Stroke Association [NSA], 2005; NSA, 2002), leading to a population of over 4 million survivors of stroke. An estimated 2.4 million of these persons with stroke live within the community (AHA). With a reduction in the average length of stay in the hospital (Mardis & Brownson, 2003; McBride, White, Sourial, & Mayo, 2004), people with skilled care needs are returning home sooner and caregiver demands are escalating (Bakas, Austin, Okonkwo, Lewis, Chadwick, 2002; Lindgren, 1990).

Caregiver roles have been increasingly examined over the past decade. Research has been conducted to examine both the short- and long-term effects of becoming a caregiver. The caregiver role is a dichotomous existence. In it, an individual must maintain care for themselves in order to function in their secondary role of caring for another (Navale-Waliser, et al., 2002). This dual role, often undertaken during a time of emotional duress, has been shown to have a variety of consequences. Much research has been done on the role of caregivers and the burden of care (Bakas, et al., 2002; Blake, Lincoln, & Clarke, 2003; McBride, et al., 2004; Navale-Waliser, et al.), however, gender-based distinctions related to individual needs of these caregivers has received less focus within nursing research (Bhogal, Teasell, Norine, & Speechley, 2003; Coe & Neufeld,

1999; Pierce & Steiner, 2004). Historically, females often assume the role of caregiver (Coe & Neufeld; Gwyther, 1992; Ingersoll-Dayton, Starrels & Dowler, 1996; Songwathana, 2001). Although male caregivers are fewer in numbers, it has been discussed that they are no less committed than their female counterparts, just less thoroughly examined (Harris, 1998; Lauderdale & Gallagher-Thompson, 2002). This has created a body of knowledge specific to female gender needs. Increased research needs to be done to determine if there are differences in the needs of male and female caregivers. In this chapter, the statement of the problem and purpose, nursing conceptual framework, research questions, and significance are discussed.

Statement of Problem

The National Stroke Association cited a general lack of awareness regarding the disease process of stroke (NSA, 2005). Combine this with multiple factors that have been attributed to caregiver burnout and a caregivers' chance of success while caring for a loved one at home seems remote. Connecting with other individuals who also have taken on the challenge of caring for a family member is critical for success in caring. Using Web-based education and support are excellent means of connecting with these caregivers (Govoni, Pierce, Steiner, 2003).

It has been reported that a majority of stroke survivors and their caregivers are elderly (NSA, 2005.) Reaching out to these caregivers through the use of computers and the Internet may seem farfetched, however, it has been documented that older adults can become competent users of a computer and the

Internet when training and education are made available (Alexy, 2000; Pierce, Rupp, Hicks, Steiner, 2003; Steiner, Pierce, Herceg, 2004). Due to the reported increase in isolation after assuming the role of caregiver, finding ways to increase education and provide support to people in their home is vital. Identifying the needs of male versus female caregivers may provide insight into gender specific challenges. Identifying these needs could provide more positive outcomes for caregivers of persons with stroke and the care recipients through development of educational materials and support activities that more closely align with a caregiver's gender-based needs.

Statement of Purpose

The purpose of this study was to explore the differences between the questions asked by male and female caregivers participating in a Web-based support group. Providing caregiver support and education that is gender-based is anticipated to increase the appropriateness of the support to those involved and increase the quality care for the care recipient. The results of this study and the information generated may help in the development of more gender specific support groups and educational materials in order to maintain or promote both the caregiver's and care recipient's emotional and physical health.

Research Questions

The research questions were:

1. What are the questions asked by men in the first year of caring for persons with stroke?

2. What are the questions asked by women in the first year of caring for persons with stroke?
3. Is there a difference in the themes of the questions asked in this first year between men and women?
4. Is there a change in the themes of the questions asked between the first 6 months of caring and the second 6 months of caring?

Conceptual Framework

Information gathered was drawn to Friedemann's (1995, 2005) framework of systematic organization. Friedemann's conceptual approach to families and nursing center around five main concepts: environment, person, health, family, and family health. Within each of these five concepts, the framework contains main themes that define the concepts, as well as the intricate process through which each of these concepts are interrelated. Within the five concepts of Friedemann's framework are four domains that help comprehend the rhythm and patterns of a life process. These domains or process dimensions are: system maintenance, system change, coherence, and individuation. These dimensions are in constant motion as persons seek congruence or balance in their lives (Friedemann). Persons with stroke rely on caregivers for personal and health care related needs. The new role of caregiver or as a care recipient can cause a disruption in their lives, thus leading to a state of personal incongruence. This personal incongruence was explored through analysis of questions asked of male versus female caregivers in this study.

Friedemann's Process Dimension Definitions

In this study, the new role of caregiving was drawn to the four dimensions of Friedemann's (1995, 2005) framework: system maintenance, system change, coherence, and individuation. System maintenance includes overall family organization including: rules, roles, monitoring behavior, planning activities, and screening information. System change encompasses drastic change and the accepting of new knowledge that is required to process an unplanned event. This is the dimension that allows for flexibility within a family. Coherence incorporates emotional bonding, family identity, sharing, and mutual concern and respect. Individuation, the dimension affected when accepting the new role of caregiver includes: self-development, searching for meaning, developing outside relationships and involvement in the community (Friedemann).

Significance

Analysis of the questions asked on a Web-based support group aid in revealing unique needs of both male and female caregivers. The results of the study determined key information to help plan and implement future gender-based caregiver interventions. Several studies have stated that male caregivers typically perform caregiving tasks according to traditional family roles (Coe & Neufeld, 1999; Neal, Ingersoll-Dayton, & Starrels, 1997; Yee & Schultz, 2000). These studies revealed that men were more likely to continue with home maintenance and financial matters, as well as hire housekeeping and/or nursing services. Women, however, tended to adopt the role of the man, thus assuming the new

roles of both breadwinner and caregiver, while maintaining all previous responsibilities of a spouse (Coe & Neufeld; Moch, 1988, Yee & Schultz).

Summary

The frequency and impact of stroke in the United States was described. The role of caregiver and the importance of connecting with individuals who assume this role also was discussed. The problem statement, purpose and nursing conceptual framework were described. Research questions and significance of this study also were reviewed in this chapter.

CHAPTER 2

Literature

The purpose of this study was to identify the differences in questions asked by male and female caregivers of persons with stroke on a Web-based support group. This study examined the narrative content of questions during the first year of caring, as well as at a 6-month and at a 12-month time frame, in order to evaluate the content and expressed themes over time. The theoretical framework, Friedemann's (1995, 2005) framework of systematic organization, is presented in this chapter. Concepts of the four process dimensions are explained. A review of the literature related to the research questions also is presented.

Theoretical Framework

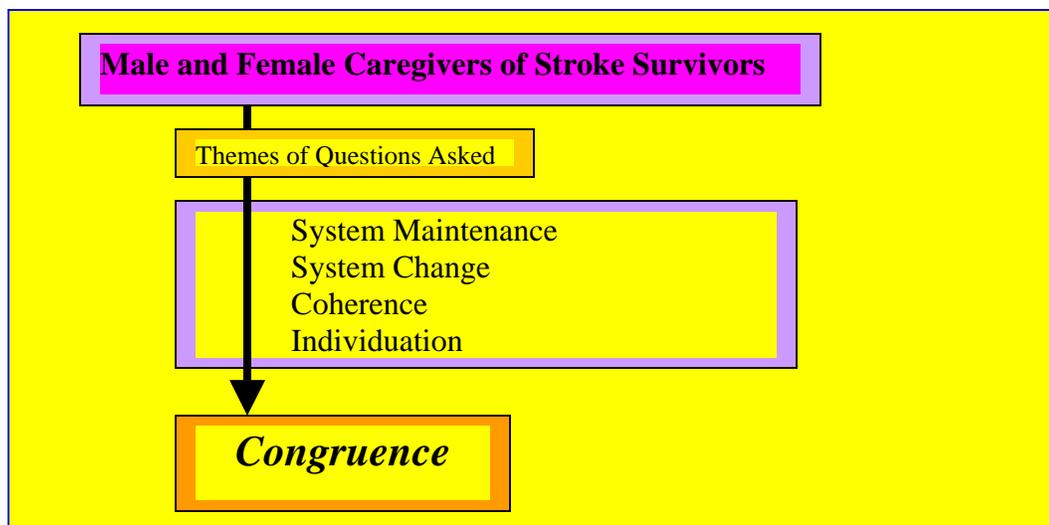
Application of Friedemann's (1995, 2005) framework of systematic organization was utilized to serve as the basis for conceptual definitions in relating the differences between questions asked in a Web-based support group by male and female caregivers of persons with stroke. According to the framework, all matter and energy is organized into systems, which are further described as rhythms and patterns. The theorist contends that each system must attenuate with each other in order for energy to flow freely between units. If there is a disruption of flow, incongruence results. Congruence (or incongruence) is the overall result of conscious or unconscious actions. When individuals are faced with change in their system (blocked energy), internal and external measures will be taken by these persons to once again obtain congruence. If congruence cannot be obtained, anxiety escalates until the flow of energy is restored. This energy flows through

the system network as well as the individual's system. The system network includes process dimensions of system maintenance, system change, coherence and individuation. The individual system includes stability, growth, control, and spirituality. The abrupt onset of becoming a caregiver of a survivor of stroke has the potential to disrupt or block the flow of energy. Using Friedemann's (1995, 2005) framework to guide the analysis, questions can be evaluated for the expression of gender-based themes by new caregivers as they attempt to establish congruence or balance in their lives.

In this study, it was anticipated that questions asked by new caregivers of persons with stroke could be drawn to Friedemann's (1995, 2005) concepts of system maintenance, system change, coherence, and individuation. Questions asked can reflect an individual's (caregiver) attempt to restore both personal and family congruence. By comparing male and female caregivers, themes and patterns of this process can be established (see Figure 1).

Figure 1

Conceptual map of male and female caregivers of persons with stroke drawn to Friedemann's (1995, 2005) framework of systematic organization.



Review of Research Literature

This literature search was done to determine gaps in the nursing research related to acute and chronic care needs of male versus female caregivers of persons with stroke. Relevant research studies were selected and organized into five categories: becoming a caregiver, negative and positive aspects of caring, information needs of caring, identifying gender differences, and using Internet support. A synthesis of the information follows this discussion.

Becoming a Caregiver

Adopting the new role of a caregiver encompasses many dimensions including medical case manager, advocate, and physical-care provider (Navalie-Waliser, et al., 2002). Reorganization of personal, family, and household activities occur, with 65% of caregivers reporting the inability to pursue personal leisure time as they once had (Periard & Ames, 1993). Multiple studies have been done to evaluate the emotional and personal effects the role of caregiver can place on an individual (Lindgren, 1990; Periard & Ames; Wyller et al., 2003). These effects can express themselves as stress, burden, and burnout and have implications for both the caregivers as well as the care recipient (Lindgren; Navale-Waliser et al.; van den Heuvel, deWitte, Schure, Sanderman, Meyboom-de Jong, 2001).

Negative Effects of Caring

Often times, the caregiver is the sole provider of social and emotional support for the care recipient and the demands can be overwhelming (Lindgren, 1990). Miller and Cafasso (1992) studied caregivers and found a positive

correlation between stress and social and emotional isolation. This isolation was found to have an overall negative effect on the health and well being of the caregiver. A decline in the health of the caregiver was demonstrated to have a direct effect on the health of the care recipient (Blake et al., 2003; Lindgren; Navale-Waliser, et al., 2002; van den Heuvel et al., 2001).

In a recent study of caregivers of persons with stroke, it was found that the “perceived burden” of care could cause more stress for the caregiver than did actual hands-on care provided or the level of existing deficits possessed by the patient (Wyller et al., 2003). It was stated, however, that regardless of the actual hours of hands on care delivered, male caregivers more readily hired outside direct and indirect help while also reporting a lower overall burden score (Wyller et al.).

Caregiver burden has been evaluated from many angles attempting to determine the root of the stress. In the 2002 study by Navale-Waliser et al., sociodemographic factors were evaluated. These factors, such as gender, race, and socioeconomic level, are contrasted in other studies on health of the caregiver (van den Heuvel et al., 2001), teaching related to disease process at the time of discharge from the hospital (Bakas, et al., 2002), and the level of dependence/severity of deficits of the person with stroke (Wyller et al., 2003). Gender also played an important role in predicting stress in that females demonstrated increased stress (Neal et al., 1997).

The 1990 study by Lindgren and the 2001 study by van den Heuvel and associates used Lazarus’s model of stress and coping (Lazarus & Folkman, 1984),

to determine the cause of caregiver stress. Two variables included in these particular studies were coping resources and behavioral manifestations of stress as burnout. Lazarus' model states that people under stress have a primary and secondary reaction to an event that then will trigger an active or passive coping strategy. Under this model, resources such as education, self-assertiveness, and social support directly affect a coping strategy and indirectly affect overall well being (van den Heuvel et al.). This current model was contrasted with a historical perspective of caregiver burden. In the retrospective examination of caregiver burden, Hoffman and Mitchell (1998) believed that changes in role performance and increased expectations of children and men as caregivers has led to an increase in caregiver burden.

Positive Effects of Caring

Much research has been done related to the burden of caregiving. However, positive aspects of caring also have been recorded and capitalizing on prominent themes could help to generate teaching methods to increase the satisfaction of caring for persons with stroke. Nolan and Grant (1989) distributed 2050 questionnaires to caregivers of persons with stroke. After receiving 726 responses, 671 were included in the qualitative analysis. Fifty-seven percent of the respondents had statements related to positive aspects of caring with four main themes emerging. These included: giving of small pleasures, personally developing as a caregiver, feeling needed and useful, and being appreciated by a care recipient. Appreciation was demonstrated in a quote from the research participant, "When I put my mum to bed she always smiles and says 'you're so

kind'. After all the strains and stresses this can always bring a tear to my eye" (p. 957).

Mays and Holden (1999) discussed positive aspects of caring as expressed by 9 out of 10 male caregivers of mentally ill relatives. The caregivers stated that they felt less stress as time progressed and experienced increased satisfaction through role affirmation. One of the male caregivers stated, "It is good to know that a man can take care of someone and be proud of it" (p. 25).

Pierce (2001), in a study of African American urban caregivers of persons with stroke, found positive aspects of caring. Pierce stated that love was a motivating force to becoming a caregiver. Caregivers drew upon family relationships for strength, with the motivation of caring providing stability for the family. One participant discussed her grandmother's memory limitations, but she stated that she was able to recall events from the past. The granddaughter stated, "...the most satisfying times we have now are when we talk about the past" (p. 105).

Connectedness in caring also was found to have a positive effect on the caregiving experience (Fang-pei & Greenberg, 2004). This emerged through statements within support group settings and within the family context. The feeling of appreciation and thanks from not only the care recipient, but also from friends and family as well, was used as a motivator to keep going. In a 2004 study of responses made in a Web-based support program, one participant stated, "We were greatly encouraged by all of you...it really meant a lot to all of us...we

looked forward to getting on-line ...to see what was happening” (Pierce, Steiner, Govoni, Hicks, Thompson, et al., p. 37).

Information Needs in Caring

In the qualitative study by Showalter, Burger and Slayer (2000), 5 patients and their spouses were interviewed to discuss the needs for orthopedic patients and families when taking on the responsibility of caring for a post-surgical person at home. Lack of education was one of two main themes expressed in regards to the stages of the recovery process. These researchers stated that lack of information caused increased stress and insecurities related to caring for a spouse. One participant in this study stated that once he and his wife left the hospital, they felt abandoned. The patient stated, “At the hospital, you have the whole floor to help you, at home we have no one. We were not prepared” (Showalter et al., p. 54).

In a second study related to stroke, another patient stated, “When I took my mom home, there was no one to tell me about bowel movements, things like that... when I got her home, she was impacted, she was in pain” (Bakas et al., 2002, p. 244). This finding was again revealed in the 2003 review of literature by Bhogal et al., in that caregivers felt as if they were providing skilled care for which they had received no formal training. It was stated that caregivers felt they had to learn proper care under a system of trial and error (Bhogal et al.). Caregivers of persons with stroke may continue to have needs even after home health services have been discontinued and questions can continue for up to 3 years after assuming this role (Bhogal et al.; Hartke & King, 2003). This

perception of being overwhelmed leading to feelings of stress appears to be a common outcome of assuming a caretaker role (Mays & Holden, 1999).

Identifying Gender Differences of Caregivers

A look at the traditional roles of the men and women as caregivers was examined. The literature revealed a large pool of information on the female caregiver. Information on the male caregiver also was discovered, but literature searches required that “male” be specified in the title in order to find specific information on men. It can be concluded that while there are both male and female caregivers, when the word “caregiver” is expressed, the general populous would conclude that a female was filling this role. This sentiment is reflected in the societal labeling of caregiving as a “female endeavor” (Miller & Cafasso, 1992, p. 498).

In a national study of over 1,200 caregivers in the United States, 61 percent were female, with a “typical” caregiver being a 46 year-old Caucasian woman with some college education (National Alliance of Caregiving, 2005). A larger percentage of females reported stress from caregiving (40% versus 26% male) and stated that they had no choice in becoming a caregiver (42% versus 34% male.). Between males and females, methods of stress reduction also differed. Eighty percent of females versus 61% of males used prayer and 67% percent of females and 51% of males found talking with family and friends useful (National Alliance of Caregiving, 2005). Female caregivers have reported spending more time caregiving, providing more physical help with self-care and

place more emphasis on the quality of the relationship with the care recipient (Coe & Neufeld, 1999; van den Heuvel et al., 2001).

Development of male and female role socialization through the family is vital to the understanding of the differences in the outcome of stress and role change adaptation (Ingersoll-Dayton, & Raschick, 2004; Miller & Cafasso, 1992). Gender distinctions were made concerning the impact of caregiving duties and the effect of these duties on other personal and social roles (Coe & Neufeld, 1999). Females were more likely to report difficulty in balancing work and family and finding time for oneself (National Alliance of Caregiving, 2005). In two literature reviews, it was determined that the role of caregiver affected both males and females, revealing a greater risk for depression and overall decline in health than non-caregivers. Caregiving females who also were employed outside the home were at the greatest risk for depression (Coe & Neufeld; Yee & Schultz, 2000). This effect was termed “psychological morbidity” on the part of the caregiver (Bhagal et al., 2003; Yee & Schultz).

Gender can be a factor when coordinating education and outreach. Bakas, and associates demonstrated this in a 2002 study, deriving that teaching methods must be directed at the appropriate audience. The Bakas et al. study included 14 female subjects and 1 male subject. The male subject was excluded from the findings because his needs and answers were so different from the other research participants. The researchers did not specifically mention the disparity in findings between the 14 females and the 1 male participant, however, it can be deduced

that if the support and educational materials provided to the 14 females were given to the 1 excluded male, his needs would not be met (Bakas, et al.).

In a recent study of male caregivers, Lauderdale & Gallagher-Thompson (2002) explored factors that prohibit males from utilizing external support systems. This study included 7 male caregivers meeting for 10 weeks for 2 hours at a time. Originally, the caregivers were reluctant to attend the meetings, but they later, near the end of the 10th week, asked for the meetings to be continued. This was interpreted as a common occurrence in that men are hesitant to express emotional needs and feelings publicly, but once they become comfortable, they experience increased personal well-being (Lauderdale & Gallagher-Thompson.) Other male-specific factors found in Lauderdale and Gallagher-Thompson's study that could be categorized as barriers to support included a lack of a male caregiver partnership in a female dominated caregiver group and fear of expressing vulnerabilities in a mixed gender group.

Internet Support

With the increased recognition of the impact of caregiver role changes and their effects on dealing with stroke, new measures are being created, tested, and implemented to promote wellness and education as well as provide support for caregivers through innovative sources, such as the Internet. Tools to evaluate caregiver preparedness and understanding of the long-term effects are fundamental to providing the groundwork for educating informal caregivers of persons with stroke (Blake et al., 2003, Navale-Waliser et al., 2002, Pierce et al.,

2003). The proper and wanted information could be disseminated through creative and effective routes.

Support for the caregiver can be provided through family, friends, community, or, more recently, the Internet. Internet support groups have become increasingly popular with 41.5% of all United States households having Internet access (Houston, Cooper, & Ford, 2002). Without having to leave home, individuals are able to communicate with other caregivers and receive support over the Internet (Smith, 1998). With the national trend of early discharge from the hospital it has been stated that there is a need for information systems to supplement discharge services (Brennan, Moore, & Smyth, 1995). Internet support has been used effectively for several years in conjunction with a variety of disease processes and caregiver situations. While there is a vast array of health related sites on the Internet, the quality of the provided information can be questionable. To find health and disease specific related information, individuals can benefit from the guidance of reputable organizations to assist them in their Internet search (Brennan, et al., (2001). The National Multiple Sclerosis Society (National Multiple Sclerosis Society, 2005) provides a support and chat site for individuals living with MS and the Alzheimer's Association (Alzheimer's Association, 2005) provides an on-line support and chat room for caregivers with Alzheimer's disease. HeartCare, an on-line information system for individuals recovering from coronary arterial bypass graft surgery, was tailored to meet individual patient needs in a timely manner and extend nursing care after discharge from the hospital (Brennan et al., 2001). The Internet has been called

an “...increasingly vital channel for health information and communication among patients, families, and health providers” (Nguyen, Carrieri-Kohlman, Rankin, Slaughter, Stulbarg, 2004, p. 200).

The condition specific Web-based support group for caregivers of persons with stroke used in this study was Caring~Web[®]. Caring~Web is an access restricted Web-based intervention designed to allow discussion with other caregivers, ask questions of an on-line nurse specialist, receive customized educational information and provide links to reputable stroke specific Websites (Steiner & Pierce, 2002). This, and other Web-based support groups, has been found to provide access to individuals when they are unwilling or are unable to attend traditional support groups due to distance, time or financial constraints (Houston et al., 2002; Steiner & Pierce).

Synthesis

Becoming a caregiver is a multidimensional role that can disrupt person or family congruence (Gwyther, 1992, Lindgren, 1990; Periard & Ames, 1993; Wyller et al., 2003). Lindgren (1990) and Miller and Cafasso (1992) discussed the stress that can be felt by caregivers of persons with stroke, which could lead to increased isolation and negative ramifications for the care recipient. Nolan and Grant (1989) discussed the positive aspects of caring and Pierce (2001) examined family connectedness expressed in statements by family members of persons of stroke. Internet support and on-line capabilities as means of information gathering, as well as access to proper teaching and correct information at the time of becoming a caregiver, were found to be useful and supportive (Bakas et al.,

2002, Blake et al., 2003, Navale-Waliser, et al., 2002, Pierce et al., 2003; Showalter et al., 2000). Gender is interwoven throughout these three previous themes incorporating such issues as role reversal (Miller & Cafasso) and barriers to external support (Lauderdale & Gallagher-Thompson, 2002). In this current study, it was anticipated that the secondary analysis of data drawn from questions asked by male and female caregivers of person with stroke would identify themes that could be drawn to Friedemann's (1995, 2005) framework of systematic organization. Based upon findings in the literature, it was anticipated that questions would center on issues related to caregiver activities. It was believed that by examining both male and female caregivers of persons with stroke in a Web-based support group, divergent, gender-related care needs could be known.

Summary

Increased research is being conducted to examine both the short- and long-term effects of assuming the role of caregiver. However, most research is focused on the female as caregiver, since they are more likely to assume this role (Coe & Neufeld, 1999). In the research conducted on caregivers, few male versus female outcomes have been determined, as gender specific needs of male caregivers have not been as thoroughly reviewed and analyzed (Harris, 1998; Lauderdale & Gallagher-Thompson, 2002; Mays & Holden, 1999). This reveals a void in the current knowledge base regarding male caregivers of persons with stroke as compared with that of their female counterparts. This chapter contained the theoretical framework used and a literature review related to this study. The review of literature identified themes in caregiving such as negative and positive

effects of caring, information needs of new caregivers of persons with stroke, gender differences in caring, and Internet support.

CHAPTER 3

Method

The need for identifying the questions of male and female caregivers of persons with stroke was presented in Chapter One. The conceptual model and review of the literature were discussed in Chapter Two. The methodology used in this study is described in this chapter, including the design, sample, materials, data collection, and data analysis.

Design

This qualitative descriptive study is part of a larger study looking at the effects of a Web-based education and support intervention for caregivers of persons with stroke. This secondary data analysis consisted of previously collected data from caregiver responses on the Web-based intervention Caring~Web[®] and its components, Caretalk and Ask the Nurse. Email postings were recorded during the first 12 months in the role as a caregiver. Caring~Web[®] is a secure site to which only the research team and subjects have access. There are several links within the Caring~Web[®] site which include: 1) a changing Tip of the Month, which is created from themes that arose from stated needs and concerns of the caregivers, 2) Ask the Nurse, where questions may be asked confidentially of the research team's on-line nurse specialist, 3) Caretalk, a discussion group where subjects may connect with other caregivers and the nurse in an on-line forum, and 4) links to various educational information (Steiner & Pierce, 2002, Pierce et al., 2003, Govoni et al.; 2003).

This secondary analysis was important because it focused on the questions asked of an on-line nurse specialist and determined if themes or needs can be more greatly attributed to either male or female caregivers of persons with stroke, and if these needs and concerns changed over a 6 or 12 month time period. This dimension was not previously examined in the original research project.

Sample

There was a rolling enrollment in Caring~Web[®] from May 2002 to May 2004, with 16 caregivers completing 12 months of Web-based discussion at the time of this study. These caregivers lived with or near the individual with a first time stroke who required care from them. All participants lived in northern Ohio or southeast Michigan and were enrolled from rehabilitation settings following the care recipient's return to the home setting (Pierce et al., 2003). As of May 2004, 6 men and 10 women had completed 12 months of participation in Caring~Web[®]. To make the sub samples equal, 6 of the 10 women were randomly selected. All questions asked on the Caring~Web by the 6 male and 6 randomly selected females were collected and analyzed.

Materials

All participants of the primary study had access to Caring~Web[®]. Participants were required to read, write, and understand English. They also were required to have a computer, or television and phone line to facilitate the use of MSN/TV[™], as a means of accessing the Internet. MSN/TV[™] was provided to participants and is an economical, easy to use system for Internet access. Technical support was provided to the participants, as well as installation, training

and maintenance. The researchers paid for the equipment (\$100 per set-up) and monthly service fee (\$25) so that the participating caregivers did not incur any costs for the MSN/TV™ (Pierce, Steiner, Govoni, Hicks, 2004; Steiner & Pierce, 2002).

Data Collection

All information used in this study was collected from the larger study conducted after receiving Institutional Review Board approval (see Appendix A) and National Institutes of Health funding. The questions evaluated were extracted from email discussions between caregivers and a nurse specialist on Caretalk, as well as from the Ask the Nurse forum for confidential questions caregivers may have had related to caring for a person with stroke.

Data Analysis

After obtaining Institutional Review Board approval for secondary analysis (see Appendix B), questions emailed to the Caretalk or Ask the Nurse components of Caring~Web, were reviewed and analyzed. To assist in understanding the role of caring for a person with stroke, data were analyzed by this investigator using Norwood's (2000) eclectic approach for qualitative analysis. Questions asked and answers recorded were read to get an overall sense of the types of questions asked of an on-line nurse specialist and other stroke caregivers within the group. Next, sub-categories of gender were established. Within each of the two sub-categories, main themes and recurrent significant phrases were extracted. The main themes and significant phrases for each gender were described to formulate the specific meanings and root of the need of the

caregiver. Data were reviewed as they were stated on the Web-based postings, but also grouped within overall themes expressed. These specific meanings were described, thus allowing the investigator to compare and contrast the root of the caregiver needs from both male and female caregivers of persons with stroke as well as over time. These themes were reviewed with members of the larger study until consensus emerged.

Summary

This study used a descriptive design to analyze data from caregivers of persons with stroke during their first 12 months of caregiving. Data were collected from questions asked within the Caretalk and Ask the Nurse components of Caring~Web[®]. The plan for analysis of the data was described and the results are presented in the next chapter.

CHAPTER 4

Results

The results of the data analysis of the questions asked in the Web-based discussions by male and female caregivers of persons with stroke are presented in this chapter. A demographic profile of the participants is provided. The perceived themes related to the questions asked of men and women in the first year of caring for a person with stroke are identified. Analysis of these themes is described within Friedemann's (1995, 2005) framework of systematic organization. A summary concludes this chapter.

Sample

The sample consisted of 6 male and 6 female caregivers. The six female caregivers in the sample were Caucasian with ages ranging from 32-71 years. Four females cared for their spouse, one for her father, and one for her life partner within the home setting. Education of the female caregivers ranged from 12-21 years of schooling. Over half (67%) of the female caregivers were employed. Only one of these caregivers used paid help in caring for the person with stroke. Demographic profiles of the female caregivers are shown in Table 1. The real names of all caregivers and their care recipients were not used to preserve privacy. Fictitious names were assigned to each of the participants and care recipients to aid in the ease of reading the demographic profiles and subsequent data.

Table 1

Demographic profiles of the female caregivers of persons with stroke (n = 6).

Caregiver	Relationship to Care Recipient	Age	Ethnicity	Years of Education	Employed	Paid Help
Sandy	Spouse	32	White	15	Part-time	No
Cathy	Daughter	60	White	12	No	No
Ann	Spouse	71	White	12	No	No
Margie	Spouse	60	White	21	Part-time	No
Rose	Spouse	68	White	15	Part-time	No
Barbara	Life Partner	39	White	12	Full-time	Yes

The 6 male caregivers in the sample were Caucasian with ages ranging from 34-77 years. Five male caregivers were caring for their spouse and one provided care for a friend within the home setting. Education of the male caregivers ranged from 12-17 years of schooling. One male caregiver was employed. None of the male caregivers used paid help in providing care. The male caregivers' demographic profiles are provided in Table 2.

Table 2

Demographic profiles of the male caregivers of persons with stroke (n = 6).

Caregiver	Relationship to Care Recipient	Age	Ethnicity	Years of Education	Employed	Paid Help
Jeff	Spouse	34	White	13	Full-time	No
Don	Spouse	35	White	13	No	No
Jim	Spouse	77	White	17	No	No
Jerry	Spouse	62	White	12	No	No
Russ	Spouse	55	White	14	No	No
Harry	Friend	62	White	14	No	No

Findings

There were a combined total of 816 email entries with 95 questions asked by all the caregivers during the year of their participation in the Caring~Web[®]

intervention. Female caregivers posted a total of 370 email entries to the Caretalk or Ask the Nurse components of Caring~Web. A total of 52 questions were asked either of each other in the open forum or to the on-line nurse specialist by the female caregivers. The male caregivers in this sample had a slightly higher entry rate, with 446 email postings to the Caretalk or Ask the Nurse components of Caring~Web. They asked a total of 43 questions. Table 3 displays the number of questions asked and email entries made by the male and female caregivers. A total of all entries and questions per subject are provided.

Table 3

Email entries and questions for female and male caregivers.

Female Caregivers	Entries	Questions	Male Caregivers	Entries	Questions
Sandy	28	6	Jeff	5	3
Cathy	89	6	Don	10	0
Ann	5	1	Jim	63	11
Margie	88	23	Jerry	43	7
Rose	154	16	Russ	199	12
Barbara	6	0	Harry	126	10
Total:	370	52	Total:	446	43

Themes

Within the first year of caring, a variety of topics were revealed through questions asked and statements made by both the male and female caregivers. The topics of frequent discussion were often found to develop into a question, which then were posed to either the group or to the on-line nurse specialist. Analysis of the questions asked revealed the expression of three main, but somewhat different, themes for both groups of male and female caregivers. It was

found that gender did affect the outcome of expressed themes. The themes that emerged from these data were placed within Friedemann's (1995, 2005) framework of systematic organization.

Questions posed by the female caregivers were more likely to be vague or seeking advice. Questions were expressed while sharing personal experiences and looking for mutual support. Themes expressed by the females included: 1) validating caregiving efforts, 2) socializing in a group, and 3) changing roles. Questions asked by male caregivers of person with stroke were often task oriented and were more likely to be direct and looking for a specific answer. Themes expressed by the males included: 1) asking questions related to medical care, 2) socializing in a group, and 3) giving advice. A difference in two of the three main themes of the questions asked of male versus female caregivers was revealed. Within the 12 months of caring, the main themes for male and female caregivers did not change. Each of these themes is discussed and supported with excerpts from the data.

Female Caregivers

Validating caregiving efforts was the most prevalent theme expressed through questions asked of the six female caregivers. This theme was expressed in several ways, generally after making a statement of fact then reflecting upon that fact with uncertainty. For example, Sandy, when speaking about her husband not needing a medical procedure, stated "... we are taking this as good news. Should we?" Validation, which can be an act of seeking a state to withstand criticism, also was expressed through statements such as "Does this sound

familiar, or am I just imagining it?” (Sandy), or “Have others experienced this?” (Margie). Margie later goes on to express this theme more thoroughly in the following posting:

I think caring for Lloyd and never really knowing what is going to cause an impatient or critical response, makes me more tired than before...it is so hard emotionally to be on guard all the time, and to have to try to edit things. As a result, I seem to be more distracted...it seems as if my thinking is not as sharp, [is] anyone else feeling the same way?

What can be derived from these statements is that the caregivers are asking, “Am I okay?” By expressing these questions to the group, female caregivers sought acceptance on a personal and emotional level. The seeking of validation and support can be expressed within Friedemann’s process dimension of coherence. Coherence is expressed in this respect through the females striving for emotional bonding with the group, sharing of experiences, and mutual concern and respect.

This differs from the second main theme, socializing in a group, due to the intimate nature of the questions asked. The questions asked related to group socialization were less emotional in nature, overall lighthearted, and were generally asked of new caregivers to the group. After a general welcome to a new caregiver, one or more of the current caregivers would ask personal profile type questions related to the condition of the person he/she was caring for, what the caregiver does in his/her free time, and how he/she is doing overall in the role of caregiver. Margie often took the role of welcoming newcomers and encouraging them to use the on-line support. She stated, “We need all the help we can get,

right?” Rose often encouraged other members to open up and share their stories, asking questions like, “How are you and yours?” or “What’s your stress reliever?” Cathy asked one caregiver “How do you manage your children, do you get help from your family?” Questions categorized within the theme of group socialization fall within Friedemann’s process dimension of coherence. Caregivers, in pursuance of balance within their personal health system, use socialization and seeking of advice to measure and contrast their system against others within the group. By learning from other caregivers of persons with stroke, female caregivers are attempting to reach congruence that will lead them, eventually, to system change.

The last theme of female caregiver questions, changing roles, was expressed through questions related to changes in day-to-day life. Margie asked:

[In the past] I have valued time to myself...but Lloyd’s new talkative personality... I get really desperate for peace and quite. How do you handle togetherness vs. time alone...?

Rose, after talking about her role as “...chauffer, shopper, cook, maid and bottle washer, oh yes, don’t forget the housecleaning, garbage out, and the list goes on and on...” asks the question “What if I were in his shoes? I am hoping he would care for me as good as I care for him.” Later in the postings she admits, “My biggest complaint is doing all the driving. I just wish someone would take me somewhere, anywhere... I guess I am dreaming, right?”

Questions posed by the female caregivers can be interpreted as their questioning of the future and reflecting on the past. Within the process dimension

of coherence, stability and spirituality are targeted; in system maintenance, stability and control are targeted. Female caregivers, through asking questions related to their role changes and seeking of information related to how others are handling their roles changes, are attempting to reduce anxiety, maintain control, and strive for congruence. In Table 4, the emerged themes of the female caregivers within Friedemann's (1995, 2005) framework are displayed.

Table 4

Emerg ed themes of female caregivers within Friedemann's (1995, 2005) framework of systemic organization.

Themes	Process Dimensions	Systemic Targets	Congruence
Validating Caregiving Efforts	Coherence	Stability, Spirituality	Pursuit and Balance of: Process Dimensions & Systemic Targets
Socializing in a Group	Coherence	Stability, Spirituality	
Changing Roles	System Maintenance	Stability, Control	

Male Caregivers

Male caregivers posed questions with a different goal and overall tone. The questions were task oriented and straightforward in nature. The men's questions usually centered upon asking questions related to medical treatment, seeking information related to personal care or asking for a specific answer for a targeted problem. A few examples of the questions are "What are the chances of

my wife having another stroke?” (Russ), “What is a good way to overcome emotional stress?” and “What is a good antidepressant?” (Jeff). Several of the men seemed to be looking for dates when recovery would be complete. For example, caregiver Jim asked, “[Therapy] progress has been slow, is it her or her therapy?” A month later he asks, “Isn’t it about time she is getting a little more pep?” With disruption of family dynamics, such as with the impact of stroke, seeking of factual information is comforting for certain individuals. Within Friedemann’s (1995, 2005) process dimension of system maintenance, male caregivers sought to provide stability and control in their daily routine.

The second theme that emerged, socializing in a group, was similar to the females in that the males also participated in personal recounts of activities, holidays, and family events. The male caregivers asked more frequently if the group should get together and meet face-to-face than the females. Jim asked “I would like to put a face to the names in this group...any ideas?” Russ, having responded the most frequently of all participants, exhibited value in the Web-based support and socialization. After giving a recount of the activities of the day, he asks the group:

How does one keep from thinking of their patient responsibilities even when you’re not there? I realize you can get someone else in to sit, but I keep going over schedules and thinking ‘Is there anything else I should be doing?’

By reaching and connecting on a social level, the male caregivers demonstrated coherence, using the group as a source of stability. Accepting the new experience

of caregiver was met in a more direct manner for the male caregivers and the method in which they socialized reflected this.

The third main theme of the questions, giving advice, falls under the process dimension of system maintenance. Male caregivers frequently interjected advice to both female and male caregivers in ways to help others improve their situation or resolve a particular issue. Four of the 6 caregivers had questions within this theme. Providing advice can place an individual in a position of dominance, allowing for a feeling of control in a situation. A natural result of incongruence is for an individual to attempt to increase control of a situation (Friedemann, 1995, 2005). When a female caregiver was discussing the lack of time off Jim asked, "Have you tried to get some type of hardship leave?" Russ asked another female caregiver:

Would it help if she got one of her hubby's friends that could sit and chat with him and casually bring up the changes that she has had to do to help him? Just a thought.

By offering advice, caregivers were able to feel the value of what they learned from their role as caregiver. Using this knowledge in a positive manner allows them to feel the value of their learned experiences (Ponton, Derrick, & Carr, 2005). Validating what they have learned and experienced was demonstrated to provide a conduit towards congruence for a majority of the male caregivers. The male caregivers' emerged themes are presented in Table 5.

Table 5

Emerg ed themes of male caregivers within Friedemann's (1995, 2005) framework of systemic organization.

Themes	Process Dimensions	Systemic Targets	Congruence
Asking Questions Related to Medical Care	System Maintenance	Stability Control	Pursuit and Balance of: Process Dimensions & Systemic Targets
Socializing in a Group	Coherence	Stability, Spirituality	
Giving Advice	System Maintenance	Stability Control	

Summary

The caregivers in this study asked questions on a variety of topics throughout their year with the Web-based intervention. Three main themes for both male and female caregivers were revealed and discussed, and examples from the data were provided. Analysis of these themes was described within Friedemann's (1995, 2005) framework of systematic organization.

CHAPTER 5

Discussion

In this chapter, the themes demonstrated in the data are discussed. The themes revealed are further drawn to Friedemann's (1995, 2005) framework of systematic organization. The themes are compared and contrasted to the existing literature. Limitations of the study are included within the chapter. Implications for nursing practice, education, and administration are drawn from the findings. Recommendations for future research and a summary conclude the chapter.

Findings Related to Friedemann's Framework

In the analysis of questions asked of male and female caregivers of persons with stroke, several themes emerged and are presented in Tables 4 and 5. Male and female caregivers both used and actively participated in the Web-based support group. Drawing the themes to Friedemann's (1995, 2005) framework of systematic organization, demonstrated that the female caregivers asked questions geared toward personal understanding of their new role, as well as internal reflection of positive achievement (or lack thereof) within the role (see Table 4). Two of the three themes expressed, validating caregiving efforts and socializing in a group, fall with Friedemann's process dimension of coherence. Friedemann described the process dimension of coherence as targeting stability and spirituality within a family. Coherence relates to the relationships between family members, using a regulation of time, space, and matter to connect individuals through affection. Female caregivers asked questions while at the same time, shared experiences and expressed feelings. One question demonstrates this clearly: "Am

“Am I doing this right?” The female caregivers in the study, through the dimension of coherence, seemed to be asking, “Am *I* doing this right?” The female caregivers were questioning themselves, their role, and the personal consequence of their actions.

This can be contrasted to the male caregivers of persons with stroke. Two of the three themes expressed by male caregivers, asking questions related to medical care and advice giving, fall within the dimension of system maintenance (see Table 5). Friedemann (1995, 2005) defined system maintenance as behavior strategies that relate to tradition, structure, and running the family business. Friedemann used the word “strategy (p. 24)” to collectively sum the tasks family members take to achieve congruence within this dimension. Behaviors expressed within this dimension include time management, energy regulation, family function and control. To use the above example, “Am I doing this right,” the male caregiver would ask, “Am I doing *this* right?”, thus taking emphasis off of himself and placing it on the task (caregiving) that needs to be accomplished.

Two of Friedemann’s (1995, 2005) process dimensions, individuation and system change, were not expressed in the questions asked by either male or female caregivers. Individuation is expressed through spiritual and personal growth. Seeking new knowledge is present within this dimension, however, the caregivers in this study asked questions on a more rudimentary level, adapting to the change in the primary family structure. This is similar to the fourth process dimension of system change. Friedemann states that system change occurs after a family integrates new knowledge, adapting wholly to the new behaviors, values,

and structure, leading to a family transformation. Friedemann entitles this process, “morphogenesis (p. 27).” For a person with stroke and their caregiver, the first 12 months of caregiving is a time of rehabilitation, new information, triumphs, and setbacks. The upheaval experienced in the months post stroke for both the caregiver and recipient can be tumultuous (Bakas, et al., 2002). System change is not likely to be achieved, but the groundwork can be laid for its obtainment.

Findings Related to the Literature

The questions asked and themes expressed by male and female caregivers of persons with stroke are supported by the literature. Male and female caregivers adapt to the role without formal training and perform the role by incorporating life experiences into the role (Coe & Neufeld, 1999). Several studies have shown that male caregivers assimilate becoming a caregiver similar to their traditional work approach: out of duty, love, and teamwork (Harris, 1998; Neal et al., 1997). Lauderdale & Gallagher-Thompson (2002) further expressed this in their study of seven male caregivers involved in a support group for family members with Alzheimer disease. These researchers reported that male caregivers preferred a “skills-based approach” (p. 53) to handling stress as well as felt a benefit from sharing experiences in the group and passing along advice (2002).

Females exhibited incongruence in their role change on a more emotional and personal level than their male counterparts as was supported in the literature (Coe & Neufeld, 1999; van den Heuvel et al., 2001). Although this emotional response to caregiving has been labeled “emotion distress” (Lidell, 2002, p. 150),

a majority of females in this study found the Web-based support group a positive outlet to express concerns and air frustrations.

Conclusions

The questions asked of male and female caregivers of person with stroke in the first 12 months of caring demonstrated a difference in themes expressed between men and women. Male caregivers asked questions in a task oriented manner and sought to organize care by asking questions related to time management, skill achievement, and levels of expected recovery. Female caregivers asked questions related to caregiving while at the same time reflecting upon personal values and feelings. The themes can be drawn to Friedemann's (1995, 2005) framework of systematic organization. Men, through the dimension of system maintenance, and women through coherence, were striving to achieve congruence within their family relationships.

Credibility of these data was bolstered by several factors. The investigator set aside preconceived notions, in that the literature review done prior to the initiation of data analysis was accomplished without prior knowledge of subjects or potential gender themes. The prolonged engagement of the subjects' participation in the Web-based discussion group for 1 year, as well as the high volume of the 816 email entries made during this time period also helped to demonstrate the trustworthiness of these data. Additionally, credibility of the findings was established as the themes of the questions asked in the discussion group were discussed at length with the team of experts from the larger study.

Limitations

There were several limitations to this study. First, contributing to the Web-based discussion group, while encouraged, was not mandatory. Several of the caregivers had minimal entries and one female and one male caregiver asked no questions. It cannot be assumed that they were completely comfortable in the role of caregiver and all of their care needs were met. Second, one of the female participants was caring for a same sex partner. This individual had minimal entries after her initial introduction. Fear of nonacceptance may have hindered her ability to express needs in an honest and safe manner. Finally, all participants of this study were Caucasian and from either Ohio or Michigan, thus cross-cultural generalizability cannot be assured. These findings can only represent the caregivers in this study and their questions. The reader must decide if these findings have applicability to their caregiver populations.

Implications

By using what was expressed in the questions asked by male and female caregivers of person with stroke in the first 12 months in the caregiving role, unique and helpful implications for nursing practice can be proposed. With 2.4 million persons with stroke residing in the home (American Heart Association, 2005), gender-based caregiver needs should be considered from the moment a person with stroke enters the medical system. Nurses should anticipate that a person with stroke will eventually be cared for by a friend or family member who lacks medical or nurses training. Nurses should enact measures that encourage hands-on caregiver teaching as soon as it is medically feasible, approaching

teaching with gender-based considerations. Male caregivers would benefit from a task-oriented method of teaching, allowing them to feel useful and connected with their friend or family member. Allowing female caregivers to express personal and emotional reservations about their new role as caregiver may enable them to move through the experience more smoothly. By creating an environment of supportive transition, nursing can foster communication, teach hands-on care, and provide emotional support to individuals learning the role of caregiver.

Educators need to be attuned to the difference in gender needs for caregivers of stroke survivors. By incorporating gender awareness into teaching plans, future nurses will be made more aware of distinct male and female caregiver needs from the initiation of acute care after the onset of stroke. By anticipating specific care needs that will be required upon discharge from the inpatient setting, costly and stressful rehospitalization can be reduced.

Nurse managers are aware of the need for patients to be discharged from the hospital in a timely and cost effective manner, however, relying on caregivers to provide continued care at home without providing adequate teaching can lead to an unsafe situation. The encouragement of nurse managers to address gender specific caregivers' needs may not seem like a priority during a time of intensive teaching, however, information that is presented, but not relevant to the caregiver, will not be incorporated into his or her knowledge base. If a caregiver is not as secure as possible in his or her role, this can lead to strain on him or her as well as the care recipient. Educating the caregiver can be done through hands on training for the non-medical person. Setting specific goals while teaching new tasks to

male caregivers might be useful, whereas allowing female caregivers to verbalize reservations of the new role could promote increased assimilation of demonstrated skills.

Recommendations for Further Research

This current study opens many venues for further research, and replicated studies are needed to confirm and expand upon the themes identified in this study. Qualitative studies examining the motivation for asking certain questions would be interesting. By allowing the caregiver to verbalize why they felt the need to ask a certain question, it could help to identify deficits in discharge teaching and preparation measures given to a new caregiver when first assuming the role. An in depth case study of one of the individuals who did not actively participate in the Web-based support group could help to identify other outlets needed for individuals to feel comfortable expressing needs and sharing concerns.

Summary

The purpose of this study was to explore the differences between the questions asked of male and female caregivers in a Web-based support group in the first 12 month of caring. Main themes emerged from both the male and female questions. The male themes were primarily drawn to Friedemann's (1995, 2005) process dimension of system maintenance and to a lesser degree, coherence. In contrast, the female themes were primarily drawn to the process dimension of coherence, and system maintenance secondarily. There was no change over time in questions asked and how they related to the themes for either men or women.

Limitations, implications and recommendations for further research also were discussed in this chapter.

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Appendix A

Institutional review board approval form for larger study.

	<p>Medical College of Ohio INSTITUTIONAL REVIEW BOARD Department for Human Research Protections Block Health Science Building – Room 140 3035 Arlington Avenue, Toledo, Ohio 43614-5504 Phone: 419-383-6796 Fax: 419-383-3248 (FWA00007382)</p>
MEMORANDUM	
TO:	Linda Pierce, Ph.D., R.N. MCO Department of School of Nursing
FROM:	Eric Schaub, M.D., M.P.H. <i>Eric Schaub</i> Chair, Institutional Review Board
DATE:	April 4, 2005
SUBJECT:	IRB # 103261 – The Caring-Web: Web-based Support for Stroke Caregivers
<p>The above project was reviewed and re-approved by the Chair of the Institutional Review Board as an <u>expedited review</u> (category #7). The full board will review it at its meeting on 05/19/2005. The Chair noted that enrollment is closed at this site but the research intervention continues. This review and approval includes the amendment (delete Lori Flick Beluens, Candace Tavormina and Kathleen Mitchell as study personnel).</p>	
RE-APPROVAL DATE:	4/4/2005
EXPIRATION DATE:	4/3/2006
<p>It is the Principal Investigator's (P.I.'s) responsibility to:</p>	
<ol style="list-style-type: none"> 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 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 HIPAA Privacy Rule and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information. 3. Promptly notify the MCO 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 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 MCO 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 MCO IRB any deviations or violations from the MCO 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 ID 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 MCO 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 MCO 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 MCO IRB approval for any changes in the study documents that may be required by the new information. 7. Obtain prior MCO 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. 	
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Appendix B

Institutional review board approval form for secondary analysis.

Medical College of Ohio
INSTITUTIONAL REVIEW BOARD
 Block Health Science Building – Room 140
 3035 Arlington Avenue, Toledo, Ohio 43614-5804
 Phone: 419-383-6796 Fax: 419-383-3248
 (FWA00007382)

MEMORANDUM

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

FROM: Eric Schaub, M.D., M.P.H., Chair *Eric Schaub*
 MCO Institutional Review Board

DATE: December 29, 2004

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

Your amendment (add Bridget Wicks as study personnel to conduct secondary analysis of de-identified data) to the above protocol was reviewed and approved by the Vice-Chair of the Institutional Review Board. This amendment does not change the previous determination that Consent/Authorization for Use and Disclosure of Protected Health Information is required for the initial collection of data from participants. This action will be reported to the committee at its meeting on 01/20/2005. Thank you for your notification.

PROTOCOL EXPIRATION DATE: 4/4/2005

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 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 HIPAA Privacy Rule and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information.
3. Promptly notify the MCO 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 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 MCO 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 MCO IRB any deviations or violations from the MCO 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 MCO 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 MCO 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 MCO IRB approval** for any changes in the study documents that may be required by the new information.
7. Obtain **prior MCO 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

ABSTRACT

Adult caregivers of persons with stroke [n=12] from northwest Ohio and southeast Michigan were enrolled for 48 weeks in a study that examined the experience of caring after discharge home. A secondary analysis was used to examine questions asked by male and female caregivers in a Web-based support group. Narrative content analysis of a combined total of 816 email entries, with 95 questions asked by the subjects during their participation in the Web-based discussions, resulted in emerged themes that were drawn to Friedemann's framework of systematic organization. A difference between the themes expressed in the questions asked by male versus female caregivers was revealed. *Coherence*, in Friedemann's terms, emerged as the most prevalent theme for the female caregivers, and *system maintenance* was the predominant theme expressed by the male caregivers. There were no notable changes in the themes expressed by the male or female caregivers over time.