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A male caregiver's perceived experience of caring for a wife with stroke

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Graduate School
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FINAL APPROVAL OF THESIS
Master of Science in Nursing

A Male Caregiver's Perceived Experience of Caring for a Wife with Stroke

Submitted by


Judith A. Dawson-Weiss

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

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Date of Defense: April 29, 2005

A Male Caregiver's Perceived Experience of Caring for a Wife with Stroke

Judy Dawson-Weiss, RN, BSN

Medical College of Ohio

2005

DEDICATION

I would like to dedicate this work to my memory of Mary Beth Hayward.

Mary Beth made a difference in my life. Mary Beth was an Associate Professor in the School of Nursing at the Medical College of Ohio. She was kind, encouraging, helpful, empathetic, enthusiastic, and caring. Mary Beth instilled confidence with each step I took, cheered with my successes and heard my frustrations. It is my prayer that I can follow her example of what a true mentor really is.

ACKNOWLEDGEMENTS

I recognize my husband, Dave for all his patience, love, support, and encouragement.

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CHAPTER 1

Introduction

Stroke is the leading cause of long-term disability in the United States. Approximately 700,000 people experience a stroke each year and, of these, about 76% survive the stroke. More than a million American adults have survived stroke with impairments. Impairments include hemiparesis, inability to walk without assistance, dependence in activities of daily living, aphasia, and depressive symptoms (American Heart Association, 2005). Additionally, approximately 23% of survivors have multi-infarct dementia, resulting in other concerns such as cognitive impairment and personality changes (Han & Haley, 1999). Eighty percent of stroke survivors return home after hospitalization and rehabilitation (Thibodaux Regional Medical Center, 2005). Many survivors who return home require long-term care (Anderson, Linto, Stewart-Wynne, 1995).

Caregivers of persons with stroke often suffer with increased burden because of the involvement of care and how this affects their lives. The increased burden felt by caregivers was caused by feelings of increased responsibility, uncertainty about the survivor's care needs, constant worries, restraint in social life, and feelings that the survivor relies only on their care. Studies indicated that unmet needs for psychosocial care, emotional distress, and severe disability of the person with stroke further increased the level of burden felt by the caregiver (O'Connell, 2003, & Scholte op Reimer, de Haan, Rijnder, Limburg, & van den Bos, 1998).

Family members provide most of the care for persons with stroke (Scholte op Reimer, et al., 1998). Current statistics revealed that men make up 44% of the

caregiving population. Sixty-one percent of family caregivers that provided care for greater than 21 hours a week have suffered from depression. As many as seventy-five percent of these spousal caregivers did not receive any assistance from family members (National Family Caregivers Association, 2002).

Caregivers need information and support to decrease stress (Anderson et al, 1995). Mant, Carter, Wade, and Winner (2000) found that providing an increase in social activities improved the quality of life for the caregiver. Caring~Web[®], a web-based in-home support and education site for caregivers of survivors of stroke, is an example of support and education that is available (Steiner & Pierce, 2002).

Statement of the Problem

Little information exists on the experience of male caregivers. Houde (2002) found evidence that male caregivers report fewer negative emotional responses to caregiving than females. What contributes to the difference between genders is not well understood. Longitudinal studies would be beneficial in analyzing the changes that occur in the lives and needs of male caregivers. It is not well understood whether male and female caregivers benefit from the same interventions.

Statement of Purpose

The purpose of this study was to describe a male caregiver's perceived caring experience in the first year of caring for a wife with stroke. This experience was identified by his participation in a web-based support group. Through his electronic messages to other caregivers and the nurse, his experience of caring became known.

Nursing Conceptual Framework

The conceptual framework chosen to guide this study was Friedemann's (1995, 2005) framework of systemic organization, which is a midrange family theory. According to Friedemann (1995), "The nursing metaparadigm – environment-person-health-nursing – has been expanded to include the dynamic concepts of family and family health to guide the explanation of systemic functioning of individuals, social and environmental systems, and interactions between them" (p. ix - x).

Persons with stroke and their families continue to live with the sequellae of their stroke injury. These persons attempt to find congruence and ward off anxiety or stress (Friedemann, 1995, 2005). Individuals and social systems are connected and they interact together. The result is caregivers may be in a state of incongruence or out of balance. The goal of the caregiver and the person with stroke is to reestablish stability, growth, control, and spirituality in their lives. Friedemann's framework was chosen as the foundation for this study because the person with stroke, caregiver, and environment, all interact together as a system and the individuals attempt to find congruence or balance in adjusting to the changes in their lives. The emphasis on the family system is what makes Friedemann's framework an excellent choice for understanding a male spousal caregiver's perceived experience of caring.

Research Question

What is the perceived experience of caring for a wife with stroke by a male caregiver, as learned by a year of participation on Caretalk, a web-based support group on the Caring~Web site?

Orientational Definitions

Orientational definitions are presented to define the main concepts of interest in this study.

Perceived Experience of Caring

The perception of events related to caring for a wife with a stroke, as describe by the male caregiver experiencing these events.

Male Spousal Caregiver

This caregiver is defined as a husband who lives with and provides assistance to his wife who has some degree of disability and needs help in recovering from stroke.

Caring~Web[®]

A web-based intervention of support and education for caregivers of persons with stroke (Steiner & Pierce, 2002).

Caretalk

A web-based discussion group for caregivers of persons with stroke available on Caring~Web (Steiner & Pierce, 2002).

Significance

Gender and family relationships bring about different needs for male and female caregivers (Houde, 2002). The perceived experience of male caregivers is not well understood. Male caregivers report fewer negative emotional responses to caregiving than females. The significance of why male caregivers report differences is not understood (Houde). Research (Lauderdale & Gallagher-Thompson, 2002) has shown that male caregivers benefit from support groups. This was evidenced by decreased stress and increased competence. Male caregivers benefit from social interaction and

support from other male caregivers living similar experiences (Lauderdale & Gallagher-Thompson). Consequently, in understanding the experience of caring from a male spousal caregiver, new intervention strategies may be identified that may be beneficial to this population. These interventions may help the caregivers to provide better care to both themselves and their spouses, increasing their quality of life.

Summary

The need for describing the perceived experience of caring by male spousal caregivers was presented in this chapter. The conceptual framework was identified. Research questions and orientational definitions were discussed, as was the significance of the perceived experience of caring and support.

CHAPTER 2

Review of Literature

The framework of systemic organization by Friedemann (1995, 2005) was the underlying conceptual base for this study to describe a husband's perceived experience of caring over the first year following his wife's rehabilitation for stroke. Discussed in this chapter is how Friedemann's framework of systemic organization applies to this study. Examination and evaluation of literature is also summarized for the purpose of identifying what is known and unknown about caregivers of persons with stroke, spousal caregivers, and web-based support for caregivers.

Nursing Conceptual Framework

Friedemann's (1995, 2005) framework of systemic organization was used in this study. Friedemann's framework is a conceptual approach to working with individuals, families, and social systems. This framework is based on a systemic and holistic view of people (Friedemann), in this instance, a person with stroke, caregiver, their family, and the environment and people around them, as an open macrosystem that strives toward congruence.

Congruence refers to free flowing energy between systems that are compatible in patterns, rhythms, and attuned to each other. Discord and stress are part of life in any system and congruence remains an ideal, not a certainty (Friedemann, 1995, 2005). Health is congruence within the system and between the system and the environment. Complete achievement of health never occurs. Optimal health is due to a balanced systemic life and is subjected to personal experience (Friedemann).

Within this environment, culture includes the person and/or families' systemic life processes. Culture maintenance are processes that assist in the preservation of traditions, values, beliefs, ideals, and behaviors that result and define the person or families basic nature (Friedemann, 2005).

Systemic Targets

Four systemic targets exist and are used by the organism to attempt to reestablish congruence (Friedemann, 1995, 2005). These four targets include control, spirituality, growth, and stability. The targets interact with each other to form a self-motivated balance that is used assist the organism in finding congruence between it's self and the environment.

Control. This is the aspect of the system that serves the purpose of reducing anxiety or stress induced by vulnerability and helplessness (Friedemann, 1995, 2005).

Spirituality. Spirituality is a defense against helplessness. Healthy spirituality results in a sense of belonging, acceptance, respect, wisdom and inner peace (Friedemann, 1995, 2005).

Growth. Growth requires reorganization of values and priorities. Growth is necessary to regain stability to become congruent. The growth process often comes with resistance and is painful. Growth is needed for system survival (Friedemann, 1995, 2005).

Stability. Stability addresses the inner person. It signifies the person's identity and is surrounded in values, attitudes, and rules of life. The person follows the rules to ward off influences that challenge traditional life processes. Stability is necessary for system survival (Friedemann, 1995, 2005).

Process Dimensions

Family style is defined by its importance on four process dimensions (Friedemann, 1995, 2005). Process dimensions include the actual behaviors needed to attempt to move toward the abstract systemic targets. Process dimensions include system maintenance, system change, coherence, and individuation.

System Maintenance. The goal of system maintenance is to maintain stability and control. System maintenance involves maintaining and protecting the system from threatening changes. The actions implemented in system maintenance involve meeting physical, emotional, and social needs of the system (Friedemann, 1995, 2005).

System Change. System change, an independent dimension, occurs when a person experiences pressure from within or from the environment. Tension or unhappiness is what compels the person to test values and set new priorities in his/her life. This is where a person decides to integrate information, change, or to replace attitudes or old values. Actions in system change result in growth or control (Friedemann, 1995, 2005).

Coherence. All behaviors needed to maintain unity compose coherence. The most stable parts of a person including, the body, personality, self-system, self-esteem, body image, personality, personal identity, self-confidence and sexual identity are all parts of the coherence dimension. A coherent person feels secure and is at peace within. Coherent persons will access weaknesses and acknowledge abilities and talents that they bravely change into achievements. Coherence refers to emotional bonding and caring relationships among people and targets the spirituality and stability of the family (Friedemann, 1995, 2005). For example, the family may share concerns,

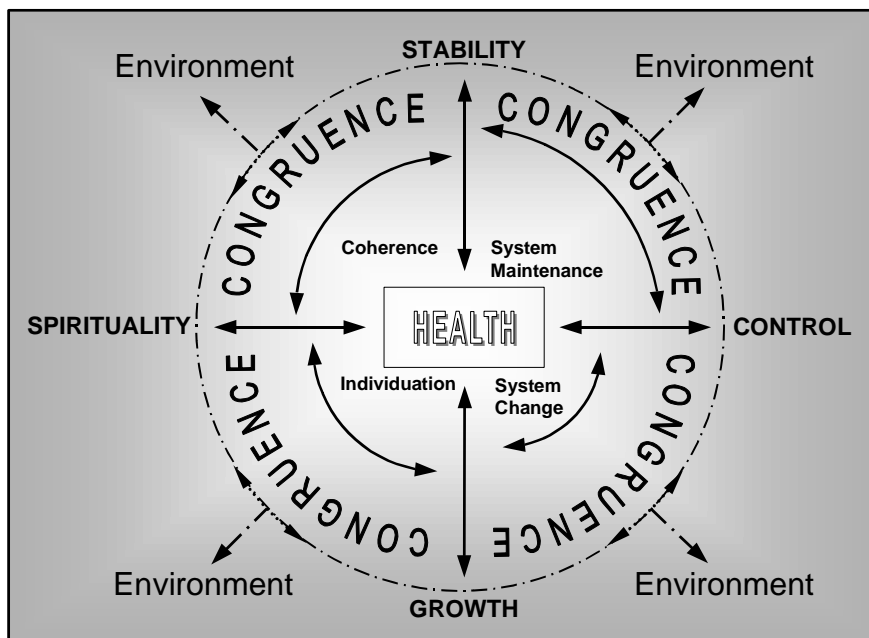
participate in joint activities, and provide mutual support for one another.

Individuation. Coherence is essential for individuation. This is because people need to have inner security to venture out and assert themselves in their environment. Individualization also targets spirituality by adjusting the person to other systems. It is through individualization that a person will develop talents, ideas, and gain knowledge and understanding. Individualization leads to growth. Growth cannot occur in isolation (Friedemann, 1995, 2005).

In Figure 1, the components of Friedemann's (1995, 2005) framework of systemic organization are displayed. The goal of the system is to eliminate anxiety or stress by seeking congruency by pursuing the systemic targets of stability, growth, control, and spirituality. Systems are differentiated by the degree in which they emphasize the targets and by the behaviors they use to pursue the targets. The four targets of stability, growth, control, and spirituality interact with each other. There is movement along the margins of the system to the outside of the system connecting to the environment, and to the inside of the system connecting its parts. The outcome of this movement is health. The four process dimensions are observable and measurable patterns. Systems regulate time, space, energy, and materials through four process dimensions: system maintenance, coherence, individuation, and system change. System maintenance and system change direct to the target of control; coherence and individuation to spirituality; system maintenance and coherence to stability; and individuation and system change to growth. Behavior patterns are based on cultural values and beliefs and they are designated as pertaining to a specific dimension based on the motivation that results in the behaviors (Friedemann, 2005).

Figure 1

Friedemann's framework of systemic organization (1995, 2005).



In Figure 2 on the next page, Friedemann's concepts are linked to the domain of interest: male spousal caregiver and his perceived experience of caring ascertained from the Caretalk discussion.

Review of the Literature

Literature review allows the researcher to identify, analyze, and synthesize the results from independent research studies and use that information to determine the current knowledge that is known about the topic being studied (Burns & Grove, 2001). The purpose of this review is to discuss, evaluate, and critique literature to support this study of a male spousal caregivers of persons with stroke involved in a web-based support group.

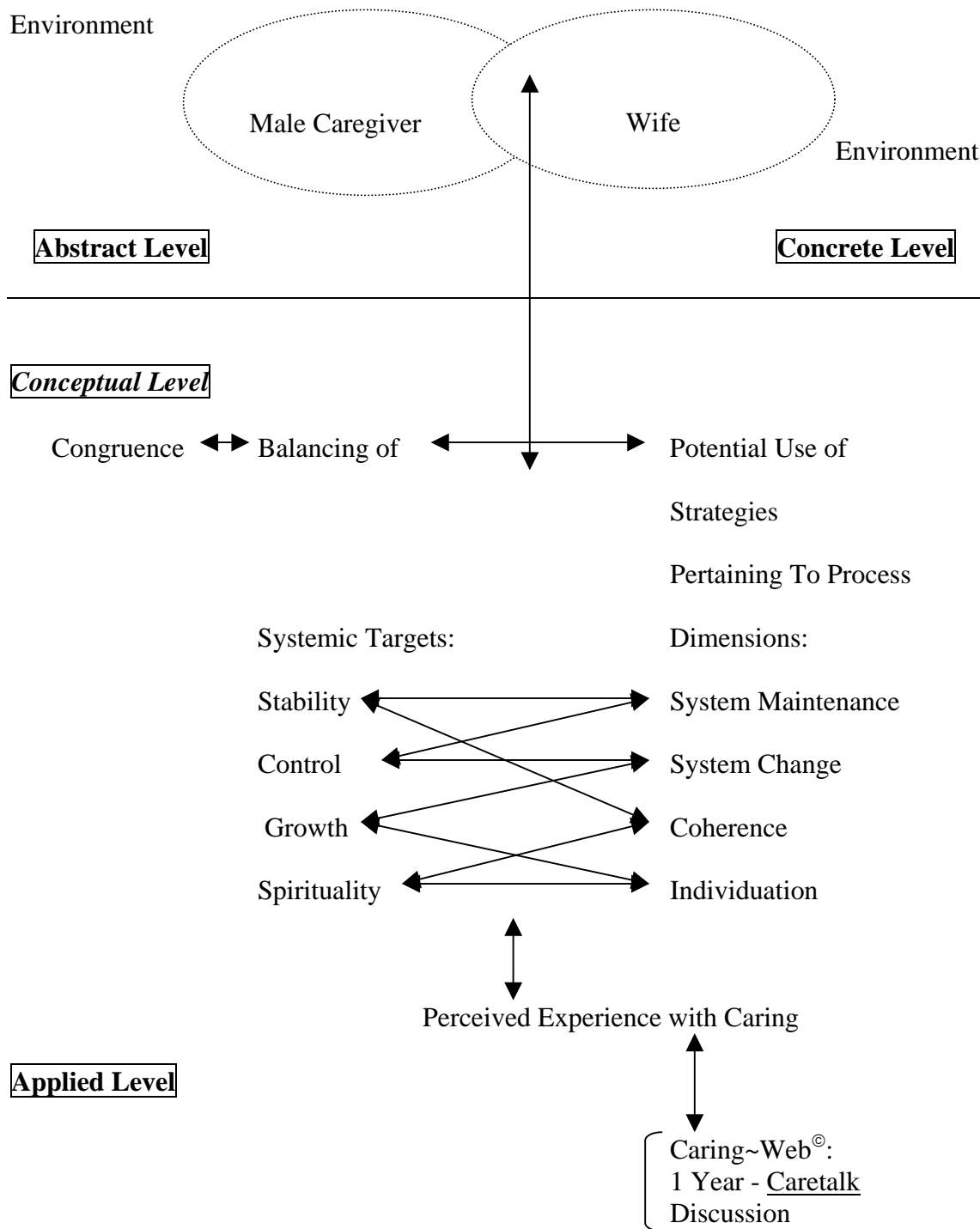


Figure 2

Perceived experience of caring by male spousal caregiver related to Friedemann's (1995, 2005) framework of systemic organization.

Note: Adapted from Pierce, L. (1998). *The experience and meaning of caring for urban family caregivers of persons with stroke*. Unpublished doctoral dissertation, Wayne State University, Detroit, Michigan.

Caregivers of Persons with Stroke

There is a large amount of research on caregivers of persons with stroke. Han and Haley (1999) evaluated caregiver well-being through the review of 20 previously published studies and identified what causes difficulties for caregivers. The study revealed that older caregivers are less likely to have depression at 6-9 months post-stroke. Those caregivers with higher incomes were also less likely to be depressed at 6-9 months post-stroke. Caregivers concerned for the future, before the chronic phase of the stroke, were found to have higher levels of depression. Caregivers had greater depression with symptoms of their own illness, the depression of the person with stroke, and the perception of the survivor's cognitive hassles, such as disruptive or inappropriate behavior. Dennis, O'Rourke, Lewis, Sharpe, and Warlow (1998) identified many of the same causes of depression in caregivers of persons with stroke (n=231). Female caregivers noted higher levels of anxiety than did male caregivers. Dennis and associates' also identified that if the person with stroke was dependent before the stroke, the caregiver suffered greater emotional distress.

Secret (2000) investigated the quality of life of caregivers of survivors of stroke (n=10). This qualitative research revealed themes of fragility, vigilance, and loss/responsibility due to the transformation of the relationship with the survivor. Caregivers perceived life as fragile. This awakening occurred with the spouse's stroke. The caregivers reported a heightened sense of vigilance, because they felt a need to watch over the survivor and felt responsible for the survivor's well-being. Caregivers also felt a sense of loss/responsibility that was defined by the caregiver as a loss of an

aspect of the person they love, loss of time and social activities, or they felt responsibility for memories, care, and chores (Secrest).

Research by Bakas, Austin, Okonkwo, Lewis, and Chadwick (2002) identified concerns expressed by caregivers of persons with stroke (n=14). These concerns were broken down into five areas. The five areas included information, emotions and behaviors, physical care, instrumental care, and personal response to caring. This information was used to create a checklist for nurses to identify caregiver needs and allowed the needs to be anticipated in the home. These authors chose to exclude male caregivers from this study, because their needs and concerns were thought to be different from female caregivers (Bakas, et al.). No follow-up research was identified to measure the difference that this checklist made for caregivers of persons with stroke after the checklist was implemented.

Hanger, Walker, Paterson, McBride, and Sainsbury (1998) identified many of the same concerns expressed by caregivers as Bakas et al. (2002). Hanger and associate's longitudinal study listed initial concerns having to do with the disheartening nature of the stroke and the lack of information. After two-years, most caregivers' inquires related to communication difficulties, balance, vision problems, dysphasia, and dysarthria due to disruption in relationships. These researchers found that caregivers asked more questions when the survivor of stroke had more disability.

Anderson et al. (1995) described the health and social consequences of caregiving for survivors of stroke with long-term handicaps one-year post stroke. This study included 84 caregivers, 49 of which were spouses. The findings indicated that caregivers must overcome the shock of the stroke, reassess their values, and readjust

their lives and the lives of their families, so they can provide extraordinary care.

Emotional illness among the caregivers was positively correlated with dementia and behavior abnormalities of the person with stroke. Concerns for caregivers relate to age, being middle-aged to elderly, preexisting illness, and functional limits. These concerns related to the management of the physical aspects of caregiving (Anderson, et al.).

Periard and Ames (1993) identified themes that caused stress for the caregivers (n=24). The three themes listed were: 1) life style changes, 2) developmental age differences (less of a problem for spouses), and 3) time and confinement. Lindgren's (1990) study looked at caregiver burnout (n=51). Lindgren found that there was a lack of social support that left these caregivers exhausted. In agreement with Periard and Ames, Lindgren found that caregivers that had the most difficulty were confined to their homes without a chance to have a social life.

Mant and associates (2000) found that family support significantly increased social activities and improved quality of life for the caregiver (n=323 persons with stroke, n=267 caregivers for persons with stroke). The interventions of information, emotional support and home visits, telephone contact, information leaflets, and setting up local stroke clubs improved quality of life and psychological outcomes for the caregiver.

Spousal Caregivers of Persons with Stroke

Male and female spousal caregivers. DeLaune and Brown (2001) studied (n=17) spousal responses to role changes after stroke. The participants in the study were comprised of eight husband and nine wife caregivers. The spouse had suffered a stroke within the past three months and was discharged home from a rehabilitation

hospital. Consequently, this study was limited to the acute phase and rehabilitation phases of a stroke, however, DeLaune and Brown found many role changes to which the spouses needed to adjust. Both husbands and wives reported decreased social functioning post stroke. Wives reported decreased enjoyment with fixing things, driving, lost family income, and making decisions on family matters. Husbands reported less enjoyment with household tasks such as meal preparation, house cleaning, shopping, paying bills, and handling the checking and savings account. The role of the husband/wife changed after a spouse's stroke (DeLaune & Brown).

Blake and Lincoln (2000) selected 222 spousal caregivers of stroke survivors. Although 74 participants were male, the study did not separate out differences in the results related to gender. This study did examine spousal caregiver strain and identified that strain is strongly associated with caregiver mood and the degree of the survivor's disability. Findings also indicated that strained caregivers have a significantly lower self-esteem, negative outlook, and lower levels of optimism (Blake & Lincoln). This study was conducted in England and cultural differences may have played a role in the findings. It was the hope of these authors that this information may help with early identification of caregivers who are at risk of strain, thus, allowing intervention to assist in the prevention of undue stress (Blake & Lincoln).

Scholte op Reimer and colleagues (1998) explored what caused burnout in 115 partners of persons with stroke. Factors that contributed to stress included feelings of heavy responsibility, uncertainty about the survivor's care needs, constraints in social life, feelings of caring for a partner that is dependent on them, unmet demands of assistance with activities of daily living (ADLs), and unmet demands for psychosocial

care (Scholte op Reimer, et al.). The results of this Holland-based study may also reflect cultural differences. Han and Haley's (1999) review of literature indicated that spousal caregiver were more likely to be depressed during the acute phase of stroke.

Male caregivers and male spousal caregivers. Limited research exists about male and male spousal caregivers. One in-depth study about male spousal caregivers of wives with dementia (n=26) was identified (Cahill, 2000). This study took place in Australia. The purpose was to understand the experiences of male spousal caregivers with regard to their motivation to care, caring tasks they had undertaken, formal and informal support they received, and their attitudes toward caring with regard to satisfaction in the caregiver role. All caregivers were married for a minimum of five years, and provided care to their wives for an average of four years. The disability of spouses ranged from moderate to severe. Two-thirds of the caregivers provided care seven days a week, the remaining one-third provided care for 4-6 days a week. Ninety percent of the caregivers were responsible for managing household finances and housework, including meal preparation. Eighty percent of the caregivers were responsible for medication administration and supervision of their wives. Between one-quarter to one-half of the caregivers were responsible for delivering hands-on personal care. Fifty percent of the caregivers provided incontinence care. Seventy-three percent of the caregivers received help from adult children on an intermittent basis. All but three caregivers reported satisfaction with their caregiving role in keeping their wives healthy and happy looking. The elderly male spousal caregivers took on more tasks than they did when they were employed. They reported enjoying providing care to their spouse. Cahill found that male spousal caregivers were less likely than females to seek help

through support groups and they were less anxious than female caregivers. Cahill noted that the men seemed to enjoy the new role of providing care to their wives and managing both of their lives.

Houde (2002) looked at issues related to gender of caregivers. Houde found that male caregivers report fewer negative emotional responses than did female caregivers. This supported the findings of Cahill (2000). Lauderdale and Gallagher-Thompson (2002) reported results opposite that of Houde and Cahill. Lauderdale and Gallagher-Thompson reported that male caregivers of persons with dementia (n=11) had greater emotional distress and poorer health. The study compared male caregivers to non-caregiver males. Nine male spousal caregivers and two caregiving sons were part of the study. These findings revealed that male caregivers benefited from support groups by increased social interaction, support from other male caregivers and by decreased stress and increased competence. While this study was very in-depth, stroke survivors were not part of the study. However, persons with dementia may be similar to persons with stroke in the aspect that they require a long-term commitment to care.

In another work, Pierce and Steiner (2004) analyzed data from five male caregivers dealing with stroke on a web-based support group for three months. Caring~Web provided these male caregivers living in rural settings with interactions with other caregivers and informational support. The research was conducted within Friedemann's (1995, 2005) framework of system organization. The findings within the framework included identification of role changes (*system change*), promotion of closer family ties (*coherence*), improvement of the care the caregivers gave (*individuation*),

and acknowledgement that at times the caregivers were unable to find balance in their lives and therefore sought balance through spirituality (*congruence*).

Web-based Support Groups

Zrebiec and Jacobson (2001) addressed what attracted diabetic patients (n=47) to a web-based support group. They found that professionally moderated health focused web-based support groups were visited by over 47,000 patients and families. The information and emotional support that was available at this web site provided information exchange for a large number of patients and families related to care, diet, and support issues. Ninety percent of all participants reported that discussions were helpful in managing their diabetes. Many of the people with diabetes reported greater adherence by taking their medications more regularly after visiting a disease-specific web site. It is unknown as to whether the on-going information and support resulted in behavior modification and what long-term health outcomes occurred because of the support provided. This literature indicated that web-based support groups benefit from web-based education (Zrebiec & Jacobson).

Govoni, Pierce, and Steiner (2003) reported pilot work from a web-based in-home support intervention for caregivers dealing with stroke, Caring~Web. The web site allowed the caregiver to ask the nurse questions about care, concerns, and needs. The site provided information about support systems and education on the most common questions that concern caregivers. There was an opportunity to share experiences with other caregivers. The results of sharing provided support, socialization, and information to other caregivers. Web links were provided on the Caring~Web site to take the caregiver to other web sites with information about stroke,

as well as games, and news. These web sites provide distraction and an opportunity for the caregivers to relax without leaving their home (Govoni, et al). This information supported the finding of Zrebiec and Jacobson (2001) in that these caregivers found the web site helpful in managing care for a person with stroke.

Miller, Miller, Burton, Sprang, and Adams (2003) found that web-based support was useful to decrease isolation, increase access for clinical consultation and health education, and increase speed in providing information and guidance. Perron (2002) investigated self-help groups for caregivers of persons with mental illness (n=33). The research indicated that more females than males are caregivers. Most frequent themes noted in discussion are disclosure, providing information and advice, empathy or support, and requesting information or advice. For mental health, online support option was a viable option for support for families with mental illness. The author recommended providing education to potential online participants regarding Internet etiquette, maintaining anonymity, and considering using online support as a supplement to face-to-face interactions (Perron).

Glueckauf and Loomis (2003) found that a web-based support was helpful in increasing a sense of effectiveness in performing caregiving tasks and also decreased the caregivers' sense of burden (n=18). Rotondi, Sinkule, and Spring (2005) investigated web-based interventions for families (n=19) of persons with traumatic brain injury. Caregivers in this six-month study found web-based interventions helpful in receiving information, guidance, and social support. Kelly (2003-2004) looked at caregiver satisfaction surveys from the web-based support intervention for caregivers. Link2Care targeted isolated and over-burdened caregivers of dementia patients

(n=700). Caregiver satisfaction surveys indicated that the participants found the web-based intervention to be helpful in gaining knowledge about caregiving issues, decreasing isolation, and coping with caregiving. The most valued features of this web-based support were news and research updates, information articles, fact sheets, web-based discussions, “Ask the Expert,” and local educational events. Eighty-six percent of the participants would recommend web-based intervention to other caregivers.

Summary

This chapter included identification and description of the theoretical framework underlying this study. The literature revealed stressors, concerns, and needs identified by family caregivers, and the helpfulness of a web-based support and interventions. The literature identified needs of the male caregiver that may be different than the female caregiver. Male caregivers deal with the tasks of caregiving differently than female caregivers. The literature supports the need for further research to identify the perceived caring experience for a male spousal caregiver of a wife with stroke.

CHAPTER 3

Method

This study is a secondary analysis of data collected for a larger National Institutes of Health (NIH) research study [ROI NR007650]. The NIH study investigated the effects of Caring~Web[®], a web-based support intervention for caregivers of persons with stroke. This secondary analysis of data explored a male caregiver's perceived experience of caring for a wife with stroke. Included in this chapter are descriptions of the sample including, how the sample was chosen, the method of data collection, as well as data analysis.

Design

Secondary data analysis was used in this descriptive study to examine a male caregiver's perceived experience of caring for a wife with stroke.

Participant

The targeted participant for this study was a male caregiver caring for a wife with stroke who participated in Caretalk, the Caring~Web discussion group, for one year. Inclusion criteria were: 1) a male spousal caregiver responsible for everyday care and the resources his wife with stroke needed and 2) the caregiver lived with his wife. Six caregivers met these inclusion requirements. The method of selecting the participant was by placing the names of these six male spousal caregivers in a hat and randomly drawing the name of a participant. The sample size of one male spousal caregiver was adequate, as the data are thick and rich in number and content. Spradley and McCurdy (1988) stated that a total of only one person may be used for

qualitative projects as long as every attempt to control for reliability is made. Spradley and McCurdy noted that reliability of the data can be achieved by (a) developing a good rapport with the informant and (b) inquiring about the informant's opinions in an unbiased manner. These strategies were used within the discussion group.

Materials

The caregiver participated in Caring~Web, a support intervention that was web-based (Steiner & Pierce, 2002) for the first year after hospital rehabilitation of his wife with stroke. The spousal caregiver received MSN Web TV™ with the monthly service paid by the investigators (Steiner & Pierce). The investigators also supplied a training manual for orientation and a computer technician was available should the participant have technical difficulties. The qualitative data came from the Caretalk aspect of the Caring~Web. Caretalk was an e-mail open discussion group for caregivers and the nurse specialist. Discussions encouraged caregivers to “chat” with other participant caregivers in the study, as well as the nurse specialist. While only messages from this male caregiver sent to others on the discussion group were reviewed for this study, support and information messages from other participants were sent to him on a regular basis. The nurse specialist facilitated the Caretalk discussion by providing educational information and posting a question of the week based on Friedemann's (1995, 2005) framework of systemic organization (Steiner & Pierce).

Data Collection

The Institutional Review Board approved this secondary analysis of data for Protection of Human Subjects at a Midwestern college prior to data review (Appendix A). The subject's confidentiality and anonymity were protected, as the caregiver's

name and other identifiable information did not appear on any transcript or published data. All e-mail messages from the male spousal caregiver that were posted on Caretalk were collected from October 2002 through September 2003. A group of 11 – 13 caregivers participated in the discussion during this time period.

Data Analysis

For the secondary data analysis, the data were reviewed using a thorough process of chronological steps that yielded descriptions of the perceived experience of caring as identified by a male spousal caregiver. Before analysis of the data, efforts were made by the investigator to reduce the bias of preconceived notions by identifying them prior to reading the data. The bias included that the caregiver would be able to identify and communicate the perceived experience of caring on the Caretalk discussion group. The researcher anticipated that the caregivers' perceived experience would resemble at least one or more theoretical concepts of Friedemann's (1995, 2005) framework of systemic organization.

An eclectic approach was used to analyze these data (Norwood, 2000). This eclectic approach consisted of three phases: a deductive phase, an inductive phase, and an integrative phase. The deductive phase entailed converting the data from narrative form to more manageable words. A category scheme was developed and the data were coded.

The researchers from the larger NIH study developed the coding rubric. The team included the theorist, researchers, nurse specialist, and a qualitative research consultant. These researchers reviewed and edited the rubric for consistency within the theory to achieve consensus. The qualitative research consultant then coded data and

shared this information with two of the primary researchers. The interpretation of the data was confirmed for meaning, use, and to ensure that the codes were sufficient to describe the content within the data that was coded. Again, the full research team met to identify the degree to which the content and coding reflected the meaning of the caregivers' perceived experience. This meeting allowed for further consensus by adding meaning to probes, content, the coding process, and application. A third review refined the coding rubric, displayed in Appendix B, to reflect the perceived experiences of the caregiver. The coding rubric also provided descriptors of the meaning of each code (Pierce, Steiner, Govoni, Hicks, Thompson, & Friedemann, 2004).

For the secondary analysis, this investigator first read the email messages (uncoded data) from the participant that were posted to the Caretalk discussion. This enabled the investigator to acquire a sense for the participant's description of caring. Second, the investigator read the coded data.

Next, the inductive and integration phases of analysis began. In the inductive phase, the investigator looked for themes or recurrent regularities written to emerge from these data. Finally, using Friedemann's (1995, 2005) framework, in the integration phase the emerged themes were drawn to Friedemann's five concepts (system maintenance, system change, coherence, and individuation and congruence), as appropriate, and were labeled.

Summary

This research study examined the perceived experience of a male caregiver providing care to a wife with stroke. The analysis of the data was completed using an eclectic approach for analysis and resulted in identification of themes related to the

perceived experience of caring that were then drawn to Friedemann's (1995, 2005) framework.

CHAPTER 4

Results

The findings are presented in this chapter. The data analysis resulted in themes that emerged from the coding rubric for this male caregiver in the first year of caring for his wife. Friedemann's (1995, 2005) framework of systemic organization was used to organize identified themes into process dimensions.

Participant

This male caregiver was providing care to his wife who was dealing with left sided brain damage and right sided impairment from stroke. The participant and his wife's real name were not used in order to protect their privacy. Fabricated names were assigned to improve the ease of reading these results. Thomas was Caucasian and fifty-five years of age. He was well educated and retired from a being an operations officer at a local bank. Thomas rated his health as good and he lived in an urban setting. On a typical day, Thomas spent two or more hours in performing tasks related to caring for his wife, Ethel. He also provided care to his elderly mother, although she did not live in his home. Thomas was actively involved with the Caring~Web intervention group over the first year after his wife's stroke. Thomas lived with Ethel in their home and did not have outside assistance from children and friends. Thomas did have emotional support from family members and friends.

Ethel was Caucasian and fifty-seven years of age. Her score of 79 on the Functional Independence Measure (Center for Outcome Measurement in Brain Injury, 2002; Granger & Hamilton, 1993) indicated that she was functioning at a moderate

level. However, Ethel's communication and physical function were affected by her stroke, as well her involvement in social activities.

Findings

These Caretalk entries (n=213) were coded and drawn to Friedemann's (1995, 2005) framework of systemic organization. The four targets of stability, growth, control, and spirituality have the potential to be impacted by the process dimensions of system maintenance, system change, coherence, and individuation. These dimensions change as the caregiver strives to obtain congruence or balance in life. In analyzing these data, the process dimensions of system maintenance and coherence were noted as the caregiver strove for congruence over the first year of providing care to his wife. The themes that emerged from the coded data were drawn to Friedemann's framework and presented in Table 1 on the following page.

System Maintenance and Coherence

The process dimension of system maintenance is aimed at stability and control and includes actions that work to maintain the system and protect it from threatening changes (Friedemann, 1995, 2005). The actions taken by this male caregiver are meant to help him meet physical, emotional, and social needs, while maintaining his life. Actions that are included are sleeping, exercising, eating, resting, or recreational activities. These actions are meant to reduce the threats of change. In other words, system maintenance represents a guide in life that allows the person to have a sense of security and autonomy (Friedemann).

Table 1

Themes drawn to Friedemann's (1995, 2005) framework of systemic organization.

Themes	Process Dimensions	Systemic Targets	Congruence
Providing Support	System Maintenance } Coherence }	Stability Control Spirituality Stability	Balance of: Process Dimensions & Systemic Targets
Offering Solutions	System Maintenance	Stability Control	
Taking Control	System Maintenance	Stability Control	

Coherence represents family identity and emotional bonding, behaviors that are necessary to maintain unity. Coherent persons feel secure and are at peace with themselves. They accept their weaknesses and acknowledge their abilities and talents. Coherence targets stability and spirituality (Friedemann, 1995, 2005). This male caregiver was demonstrating coherence in that he interacted with others for support.

The themes that emerged from these data were related to system maintenance, having to do with providing support, offering solutions, and taking control. There was an overlap with coherence in the theme of providing support.

Providing support. Support for the caregiver was noted from the data. Thomas wrote numerous entries providing emotional support to other caregivers. Thomas used encouraging words and humor in supporting and encouraging these caregivers. He also received return messages to him, as evidenced by his message that indicated others' wishes and prayers were helpful for him and his wife.

Thomas offered emotional support to other caregivers on Caretalk, providing humor and support in this way. Thomas complimented other caregivers when he said,

“I vote Jerrold as head spirit lifter. I can tell that you really enjoy life.” He also wished others well. He said, “I hope that yesterday was a good day with family and friends and that soon we can all return to a normal life.” Thomas welcomed others to Caretalk. He shared, “Welcome to our little Caretalk world. Even though the stroke is serious and caregiving is a lot of work. Sometimes we try to lighten up.”

Thomas expressed support for others through prayer. An abundance of references to prayer were in the data. While prayer was mentioned through out the first year of caregiving; only a few references to prayer were made during the first six months of providing care. References to prayer were six-times more common during the second half of the year. The following examples are representative.

Thomas welcomed other caregivers to the group with reference to prayer. He shared, “Welcome to our tale of whoops and then praise to the Lord progress has been made.” Many references to prayer existed in closing such as, “Prayers are with you” and “God bless to all.” Prayers related to closing of each entry increased during the later part of the year of Thomas’ providing care. Thomas made one reference to how important prayer was to him. He shared, “Thoughts and prayers from all helped support Ethel and myself in this part of our life.” Thomas offered prayer to other caregivers during their times of increased stress. He said, “OK, let’s all do the group hug for Mindy and have her in our collective prayers.” He used prayer to encourage and support others. Thomas noted, “My prayers are with you all in the hope that recovery is just around the corner.” Thomas referred to his everyday prayers, when he said, “Julie, I give big hugs or handshakes to all caregivers and victims right along with a short prayer every day.”

Thomas wrote about being thankful for successes and offered words of encouragement to others that encompassed not only spirituality but also growth. He said, "Ethel and I were told that some recovery can take place several years down the road. I just keep praying and am very thankful that she has come back to the point she is at now. Chin up and charge forward." Thomas was satisfied with things going normally. He shared, "I guess all are doing great with things going normally no problems, or wonderful successes. Ethel is keeping busy with the Harry Potter book. She has now stopped using the shower seat and doesn't want the shower head holder."

In summary, the data entries were related to giving support to other caregivers in encouraging them in their role of caregiver and to care for themselves. However, other caregivers responded to him with messages of mutual support. Support was more often given, but was also received.

Offering solutions. While Thomas wrote requesting knowledge from others, he more often wrote to other caregivers and offered solutions based on his experience of caregiving and just trying to be helpful. Thomas more frequently offered advice to other caregivers based on his experience of caring for Ethel. He said,

Jason, I know when Ethel had long therapy sessions she was ready for a nap, her stroke was August 5th. She still gets tired if takes on too many activities. I do not know any special secrets. When she had therapy, which was the only activity for her on those days. Is Jill trying to do something before going to therapy? Maybe on those days Jill should be more restful.

Thomas also offered advice to others by sharing his experience of what

worked for him and what to watch out for. He said, "Ethel would let them skip things (physical therapy), so I had to watch and see that they followed through." Based on Thomas past concerns he offered advice to guide other caregivers when they were not sure what to do. He offered,

Michael, I addressed with Jason that anti-depressants will affect people differently. Ethel was on Celexa and Amantadine for a while. She is now off both of them and is doing fine now. She had her stroke August 5, 2002 and stopped using them by the end of the year. My best advice is contact the doctor and tell him what is going on. Time and patience is also helpful.

Thomas also offered advice to other caregivers to give them another option that they may not have thought about. He suggested, "Maybe the holiday could be delayed until YOU can take time to get things in order, but do not rush it. It is no good if you are too exhausted to enjoy the holiday."

Giving advice was Thomas' way of offering solutions for assistance with caring. Thomas clearly gave more advice than he sought out. The advice offered to other caregivers included suggestions. Thomas offered, "It might help you if you made a diary of Beth's time away then ask what today's therapy is doing to enhance the activities that are on the list, with Beth as part of the conversation." Thomas encouraged other caregivers by congratulating them on their progress and encouraged them to get beyond difficulties. He said, "Glad to hear that progress is still being made with your hubby. Make a flash card that says 'You can only yell at the hired help, I care about you', and then when he starts to yell, hold it up." Guidance for other caregivers included words of encouragement toward helping themselves. Thomas said,

“Lori I think you need to arrange something special for yourself, take a break. You can still be hubby’s everything but a break is in order. You’re in our thoughts.” He also encouraged others to release their frustrations. He said, “Is there a neighbor that might stop in to keep him company while you go screaming through the neighborhood. I can only imagine how tough it must be.” Thomas guided other caregivers by praising their actions when they did care for themselves. He said, “Barb getting out and doing things like you did was worth a whole week of therapy.”

Thomas offered advice about relaxing. He said, “One thing Amy [nurse specialist] didn’t tell you is that sometimes we try to lighten up (can’t be serious all the time or it is the WEIGHT OF THE WORLD) and we have all been there and survived.” He offered his positive attitude to other caregivers. Thomas said,

“Oh, Julie surely something good happens everyday no matter how small it is. But it is the small accomplishments that should be praised everyday. If something did not work out today so what. The failures do not have to come up in conversations, just push the day’s accomplishments. I kept telling Ethel that we are doing this one day at a time. We make it through today and this is wonderful. Then we wait for tomorrow’s accomplishments. Head up and push forward and look for that one good thing that is what it’s all about.”

Thomas used his positive attitude when offering solutions for other caregivers. Thomas focused on the good. For example, in order to evaluate progress, he said, “Remember recovery takes time, it surely isn’t fast. Remember to count the good things and the great progress to this point.” Thomas emitted a positive attitude throughout the year of caring.

Taking control. Thomas spoke frequently about taking control of what was going on with Ethel since the stroke. Thomas's discussions on Caretalk relayed a strong sense of trying to maintain control in their lives. Thomas spoke of all the household chores and the difficulties of maintaining organization in the home. He said, "Even though I did all the laundry Friday, certain things were dirty, so tonight was three more loads." He spoke about how consuming caregiving was for him. He said,

Today it is therapy, nap, lunch, nap for Ethel while I do chores. How does one keep from thinking of their patient responsibilities even when you not right there? I realize you can get someone in to sit, but I keep going over schedules and thinking if there is anything else I should be doing.

Thomas took Ethel to the doctor's office and felt responsible for keeping track of all that was going on with her care. He said, "I feel that part of my caregiving is making all those Doctor visits so that once she leaves the doctors office I know what was said. I sometimes have to refresh the doctor on her condition or what test Ethel had done someplace else."

In an early response on Caretalk, Thomas said, "The show I put on like every thing is under control is just that." Thomas verbalized that he felt it was necessary to protect Ethel. He said, "She knows that the rest of the jobs at church don't belong to her and the word is out if anybody asks her to take something on, they could be smashed like a bug by her mean caregiver (slave)." Thomas verbalized that it was his job to watch over Ethel and decide when she is done taking on more efforts. He acknowledged,

I know Ethel would like to do more but she know that I am watching and ready to flip the limit switch if I feel she would be taking on too much. I think it is wonderful that she wants to do more but I am not looking to start over.

Thomas indicated he preferred being a caregiver over the thought of losing Ethel. He said, "I figure that I like being a caregiver as the other option is my partner is gone, so I make the best of this challenge that has been handed to me." Thomas reflected why he needed control over what happens in Ethel's life. He said,

Your life changes. My life value changes started at the time my father had a massive stroke and died seven years ago. I started thinking about what was more important and when my mom showed signs of needing more assistance three years ago. I decided it was time to quit the rat race and take on the career of caring for her. Ethel had her stroke on August 5th and the burden just tripled. I was able to dial back some when mom was moved in to the nursing section of the home in December. The losing of a parent started me on value change.

Thomas' need to be more in control started with the loss of a parent. He valued caregiving because it meant that he still had Ethel at his side. Thomas displays an attitude of confidence and protection related to caring.

During the first year of providing care, Thomas spoke of the responsibility of providing care to Ethel. He wrote, "How does one keep from thinking of their patient responsibilities even when you not right there? I realize you can get someone in to sit, but I keep going over schedules and thinking if there is anything else I should be doing." He wrote about being there to support her if she needs him, "I can do my best for Ethel, letting her reach out to do things that she is comfortable with and being there

to catch her if something goes wrong.” Thomas feared if he did not limit Ethel’s activities that certain disaster would one again visit them. He wrote,

I am not concerned about Ethel playing the piano. She once did many other tasks as well, including: 1) Once a week after school tutoring, 2) Adult handbell group, 3) Children’s handball group, 4) Bazaar chairperson, and 5) Planning special services for special Sunday’s Choir director. I must be missing at least one thing I think the stress of all of the above raised the blood pressure and BANG strokesville.

Thomas was also frustrated by Ethel’s attempt at drive without him being there. This event left him feeling like he needed to exert more control in Ethel’s life to assure her safety. He wrote,

Jason and Julie, First of all Ethel didn’t hurt herself, other than her pride. But for some unknown reason she just had to get this piece of music. So she got in her car and was unable to reach the pedals very well because she couldn’t figure out how to move the seat forward. Then, she backed out of the garage, missed the house, missed the power pole right next to the driveway, and shot like a rocket across the street over the curb on the other side backing in an arc 180 degrees. In this process, she blew a tire. The force of the back bumper coming up wrinkled the truck lid. Lucky no one was on the sidewalk or coming down the street. I now have her set of keys. This is the first bad problem here at home we have had. Since she was all right and AAA was coming to change the tire I went to play bridge, it was that or try to construct bars over the hall doorway so she could never do this again. The cards were rotten; this was consistent with the rest of the day.

Summary

There were several themes of the perceived caring experience as identified by this caregiver in caring for a wife with stroke. These themes were drawn into Friedemann's (1995, 2005) process dimensions of system maintenance and coherence. This illustrated the caregiver's efforts toward maintaining stability and control of his life and environment as well as his use of spirituality. The themes noted were providing support, offering solutions, and taking control. This caregiver put the greatest amount of energy into maintaining his system and protecting his and his wife's life from the threatening changes caused by her stroke, as he sought to find congruence or balance in life.

CHAPTER 5

Discussion

The findings presented in the previous chapter are discussed. The relationship between the findings and Friedemann's (1995, 2005) framework of systemic organization are described and compared to existing literature. Limitations of the study are presented. Implications for nursing practice are also described. Recommendations for future research and a summary conclude this chapter.

Discussion of Findings

Caregivers provided care to persons with stroke while participating on a web-based discussion group. Each caregiver that participated in the Caretalk discussion group shared experiences, support, and thoughts with other caregivers and the nurse specialist. These data messages from one male caregiver were examined for his perceived experience of caring during the first year after his wife had a stroke. The main themes that emerged from his data included: 1) providing support, 2) offering solutions, and 3) taking control.

Findings and Friedemann's Framework of Systemic Organization

The perceived experiences related to caring by this male caregivers were drawn to Friedemann's (1995, 2005) framework of systemic organization. This caregiver sought to create stability and control in his life. He also sought to maintain spirituality within his new role of caregiving.

The themes of giving support, offering solutions, and taking control were mostly centered within Friedemann's (1995, 2005) process dimension of system maintenance. According to Friedemann, system maintenance comprises roles, rules,

organizational patterns, rituals, decision-making, power structure, and division of labor and targets control and stability. This man was doing everything in his power to preserve his life.

The theme, offering support, was also drawn to the process dimension of coherence that targets spirituality and stability (Friedemann, 1995, 2005). Coherence represents family identity and emotional bonding, behaviors that are necessary to maintain unity. Coherent persons feel secure and are at peace with themselves. They accept their weaknesses and acknowledge their abilities and talents. This experience was represented during the first year of this male caregiver in caring for his wife. Spirituality was present too. In fact, indications of spirituality were found to be six times more prevalent during the second half of the year of providing care to his wife with stroke.

Individuation represents self-growth. Coherence and individuation actually overlap, as persons need to have inner security to be able to develop. Individuation targets spirituality and growth when not inhibited by isolation (Friedemann, 1995, 2005). No themes were identified with respect to individuation. This may be because the discussion shared on Caretalk represented only a segment of this male caregiver's life. Individuation may have occurred, but it was not shared through the discussion with other caregivers or the nurse specialist.

When a person experiences pressure from the environment or from within, system change will eventually occur. System change represents adjustment to harsh changes. Unhappiness or stress induces the caregiver to set new priorities, and may leading to change, and replacement of old values. Taking action in system change

leads to the targets of control and growth (Friedemann, 1995, 2005). No themes were identified in system change. True change was not demonstrated by this male caregiver in his discussion with others on the Caretalk group. System change may have occurred. However, for true system change to happen, it may take years before the change is integrated into life patterns. One year of caring may not have allowed for the system change to be known.

Congruence represents the targets of stability, growth, control and spirituality. Congruence is the pursuit and balancing the targets, which in turn allows for optimal health, whether the health is individual or family health (Friedemann, 1995, 2005). No theme was identified with respect to congruence. However, this male caregiver was striving for congruence in a continuing struggle to find a balance for his life.

Findings Compared to Existing Literature

Han and Haley (1999) identified what caused concerns for caregivers. Concerns for the future existed with chronic conditions (Han & Haley). This male caregiver wrote, "For awhile I accepted the title of SLAVE." This response was during the first year of providing care where he was talking about the frustration and concerns in caring for his wife with a stroke and the need to have control over this situation.

Secrest (2000) found that after stroke the caregiver felt a sense of responsibility for care, chores, and memories. Bakas et al. (2002) found the five areas that caused caregiver the most concern were information, emotions, behaviors, physical care, instrumental care, and physical response to caring. Hanger et al. (1998) had many of the same concerns as Bakas and associates (2002) noting the concern of lack of information about stroke. Similarly, this male spousal caregiver felt responsible for

control of the chores and care of his wife. His concerns were related to providing care. However, he obtained much information on the Caring~Web intervention site, as to questions of providing care and information about stroke. These findings supported those of Anderson et al. (1995) in that this male caregiver reassessed values and readjusted his life to provide care. The male caregiver also strove for closer family ties, improvement of caregiving skills, and balance through spirituality that was similar to the findings of Pierce and Steiner (2004) in the rural male caregiver study. However, there were no reference from this caregiver that indicated concerns about falls, nutrition, staying alive or dealing with emotional changes, as reported by Pierce and associates.

Periard and Ames (1993) identified cause of stress as life style change, developmental age differences, and time and confinement. Lindgren (1990) identified that lack of social support leads to caregiver exhaustion. For this male caregiver, the Caretalk discussion was used as a method of providing support and offering advice. He also made time to get out of the home and did not suffer from exhaustion.

In contrast to the literature from Scholte op Reimer et al. (1998) and Mant et al. (2000) this male caregiver did not suffer restraints in social life, unmet demands even though he had little family support. This caregiver had a positive outlook and did not report burn out, while providing care over the first year of his wife suffering a stroke.

Lauderdale and Gallagher-Thompson (2002) reported that men benefited from support groups, increased social interaction from support of other caregivers, particularly male caregivers. The caregiver represented in this research was an active

member of the support group, and often offered encouragement to other caregivers, thus indicating results that were similar to Lauderdale and Gallagher-Thompson.

Zrebiec and Jacobson (2001), Govoni et al. (2003), Pierce and Steiner (2004), Glueckauf and Loomis (2003), Rotondi and associates (2005), and Kelly (2003-2004) found that caregivers benefit from web-based support groups in meeting educational needs, supporting other caregivers by sharing, socialization, interacting, giving advice, and learning from other caregivers. The male caregiver in this study typed many notes of support to other caregivers, asked question about care, shared thoughts, and offered advice. He had a positive attitude toward caring and made only one comment about feeling inadequate, but this comment was related to providing care to his elderly mother whom did not reside with this caregiver.

Conclusions

The themes identifying the perceived experience of caring for a wife with stroke by a male spousal caregiver from his participation on the Caretalk discussion identified themes of providing support, offering solutions, and taking control. System maintenance dimension was the area that captured most of his experience within the first year of providing care for his spouse. This indicated that this caregiver spent significant amount of his energy in creating control and stability in his environment in order to maintain congruence.

Limitations

There are two very evident limitations to this study. First, this male spousal caregiver made reference to meeting other caregivers involved in the Caretalk discussion group at a restaurant. Because of a potential of an actual meeting, some of

the data may have been lost in the form of face-to-face conversation. Second, this caregiver was Caucasian and lived in the Midwest. Thus, culture and ethnicity may also play a role in the caregiver's perceived experience. These findings can only represent this one male caregiver's perceived experience of caring. The reader must decide if these findings have applicability to their caregiver population.

Implications

There are many useful applications for basic nurses as well as advanced practice nurses in administration, education, and practice roles related to the outcomes of this study. One implication is to have professional nurses include male and female caregivers of persons with stroke as someone who also needs nursing care. Too often caregivers, especially male caregivers, are ignored, and they are crucial to successful home caring. For example, when home health or family focused nurses expand their nursing care to routinely include these caregivers, it could raise the cost of health care, in that there would be time and resources needed to assess, diagnose, plan, and evaluate caregiver interventions in addition to caring for the person with stroke. However, increasing the success of home care giving by male caregivers, and also their family members, would decrease the amount of health care dollars needed for persons with stroke to live at assisted living or extended care facilities.

Advanced practice nurses caring for the caregiver in office or clinic settings must carefully listen to the caregiver's verbalization of complaints and experiences, with attention to voice tone, emotion, and actions concerning their experience. Nurses must use open-ended questioning and excellent listening skills. It is all these actions together that give the best clues as to what experiences, needs, concerns, or difficulties

that caregivers may have. Advance practice nurses then have an opportunity to identify concerns and assist caregivers in maintaining success in the caring experience by providing support and information and/or referrals. For example, support groups, respite care, and educational materials may be an excellent resource for these caregivers.

The male spousal caregiver identified themes that give clues to how he may be further assisted in out-patient settings. The themes of providing support, offering solutions, and taking control persisted over the entire first year of providing care. The theme of providing support found this male caregiver spending much of his time offering help to other caregivers. This theme indicated that men have a need or desire to help others. This information encourages advanced practice nurses to offer male caregivers information regarding support groups for them and their care recipient. Male caregivers can be given a role in the support group to go to the hospital to meet new caregivers to talk about what it is like to provide care. This role would allow male caregivers to support other caregivers and give them an outside activity and additional socialization opportunities.

The theme of offering solutions indicated that this male caregiver frequently offered advice to other caregivers. This theme identified that this male caregiver wanted to help others by sharing his expertise in caring for his wife. Specific advice from male caregivers could be collected by advanced practice nurses and put together in an informational pamphlet for caregivers about common problems incurred and successful solutions tried. For male spousal caregivers this knowledge about what was

helpful for them in caring may also be shared with other caregivers in a support group or within the hospital settings, as other caregivers begin their caregiving roles.

The male spousal caregiver took control of his situation in caring for his wife. This caregiver spent much of his time in trying to control factors that he truly had no control over. His goal was to control his wife's life and decrease her stress. He wanted to allow as little stress as possible into her life in order to stop a feared future stroke. This is a concern for advanced practice nurses, as male caregivers face a potential for burn out when trying to control what they truly do not have control over. Male caregivers would benefit from education about stroke and what causes stroke to allay their fears. Men may benefit from support in out-patient settings by nurses allowing for verbalization of real or imagined fears. Individual or family intensive therapy may benefit these male caregivers, as over time and in a safe setting, they can verbalize fears and work through the life changes that they endure after the stroke changed their lives. Men would also profit from outside diversions such as exercise, hobbies, or community activities to decrease the amount of time and energy they might spend in trying to hold their wives back from returning to functions that they previously maintained.

Advanced practice nurses' knowledge of the male spousal caregivers' perceived experience has other implications for practice. For instance, the findings include the benefit of a web-based support group in providing education, assistance, and socialization to male caregivers that can be accessed at their convenience. This group gives male caregivers an outlet to vent concerns, offer support, and give advice. Advanced practice nurses need to further develop electronic educational materials and strategies that are pertinent to these caregivers, as they start their caregiver role in home

settings. By providing strategies to meet the male caregiver's needs, he may gain knowledge, be more effective in the caring role, receive helpful support, and use the intervention to ease the difficult task of providing care to his wife with stroke.

Recommendations for Further Research

This study could be replicated in order to confirm and expand the themes identified by this study. Recommendations for future research include examining other male spousal caregiver to note the differences that may be related to ethnic and cultural aspects of caring. Geographic settings need to be expanded. Further recommendations include research that looks at differences in caring among male and female caregivers in a variety of settings that would further explain the experience of caring.

Summary

This study identified the perceived experience of caring of a male spousal caregiver as learned from a web-based support group. The overall themes for the entire year were: 1) providing support, 2) offering solutions, and 3) taking control. The perceived caring experience for this male spousal caregiver providing care to his wife with stroke was drawn to Friedemann's (1995, 2005) framework for systemic organization. System maintenance and coherence were the process dimensions related to the themes from this caregiver and they targeted stability, control, and spirituality. Limitations, implications, and recommendations for future research were also discussed in this chapter.

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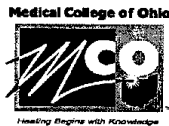
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APPENDIX A



Medical College of Ohio
INSTITUTIONAL REVIEW BOARD
 Block Health Science Building – Room 140
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 Phone: 419-383-6796 Fax: 419-383-3248
 (FWA00007382)

MEMORANDUM

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

FROM: Katherine Sink, Ph.D., R.N., Vice-Chair
 MCO Institutional Review Board *Eric Schaub, Chair
 for Katherine Sink*

DATE: December 14, 2004

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

Your amendment (add Judy Dawson-Weiss, BSN, RN as study personnel) 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

form of money or other items of value, including, but not limited to, equipment, such as computers, and intangibles, such as frequent flyer miles.

8. **Promptly** notify the MCO IRB; other required MCO committees, departments or individuals; the sponsor (if this research is sponsored); and all other required federal and state agencies of all potential conflicts of interest before beginning this research and, during the course of this research report to these committees, individuals and agencies any changes that may affect conflict of interest for any of the study personnel. **Prior MCO IRB approval** must be obtained for any changes in the study documents that may be required by information related to conflict of interest or any changes in this information during the course of the research.
9. **Promptly** notify the MCO IRB of any changes in contracts, budgets, grants or other agreements with sponsors, agencies or individuals regarding the conduct of this research **before** initiating these changes. The IRB reserves the right to review these study related documents and changes to them to verify accuracy and consistency with regard to the research protocol in order to protect the rights and welfare of the study subjects. Changes in these documents that have the potential to affect the rights, welfare or willingness of the study subjects to participate in or continue to participate in this research and changes in subject documents (such as informed consent, assent or authorization for use and disclosure of protected health information forms, etc.) that are a result of these changes **must** be reviewed and approved by the MCO IRB **prior** to being instituted.

Additional Information:

- **Other Required Review(s) or Approval(s)**
Review or approval by the MCO Institutional Review Board/Privacy Board does not take the place of any other review or approval required by the Medical College of Ohio, non-MCO performance sites, the government and/or the study sponsor.
- **Required Procedure to Request Review and Approval for Changes/Updates to MCO IRB Approved Research:**
Please complete and submit the **Request for Amendment/Changes/Updates (RGA Form 314 found at <http://www.mco.edu/research/rga_frms/rga314.doc>)** with a copy of all materials relevant to the requested change (including consent/assent/authorization for use and disclosure of protected health information forms if applicable) with the changes underlined. If you are requesting review and approval of consent/assent/authorization for use and disclosure of protected health information forms, please attach a clean copy of the revised forms for the MCO IRB to stamp. Please remember that all changes and correspondence submitted to the MCO IRB (regardless if they are generated by a sponsor, the P.I. or requested by the MCO IRB) must be **in writing, signed and dated by the Principal Investigator.**
- **Federally Mandated Continuing Review:**
MCO IRB protocols must be reviewed and reapproved not less than once per year. The Institutional review Board will try to remind you when reapproval is due. **However, it is the responsibility of the Principal Investigator to have his/her own reminder system in place to initiate the re-approval process at least a month prior to the expiration date shown above. Please note that Federal Regulations prohibit the extension of this expiration date.** Please see the **Application for Continuing Review (RGA Form 319 found at <http://www.mco.edu/research/rga_frms/rga319.doc>)** for items required for continuing review.
- **Required Final Report Upon Termination of Research:**
When you decide to stop this research, you are responsible for completing and submitting a **Final Report (RGA Form 320 found at <http://www.mco.edu/research/rga_frms/rga320.doc>)** to the MCO IRB for review.

APPENDIX B

Coding Rubric[®] for the Friedemann's framework of systemic organization.

<i>Domain: System Maintenance</i> Code- 1.0	<i>Description: Targets Stability and Control</i>
1.1 Care giver tasks	What instrumental activities of daily living [ADLs] or ADLs that you do?
1.2 Care organization	How do you deal with the work of care; how is it planned and organized?
1.3 Care assistance (people)	What are any activities by others in helping you with care?
1.4 Care decision assistance	Is there any collaboration on care decisions?
1.5 Role and practice of religion	What is the character and custom of spirituality for you?
1.6 Caregiver recreation/exercise	What is your amount of activity?
1.7 Caregiver rest/sleep	What is your amount of repose/slumber?
1.8 Caregiver support – services	What supports do you use?
1.9 Caregiver socialization	How do you get to socialize?
1.10 Caregiver nutrition	What do you do to maintain your nutrition?
1.11 Impact on caregiver previous activities	Are you able to do things you did prior to the stroke?
1.12 Caregiver health maintenance	What is done to manage you health; i.e., doctor's appointments?

<i>Domain: System Change</i> Code: 2.0	<i>Description: Target Growth and Control</i>
2.1 Impact of caregiving on behaviors	What actions have you changed related to caregiving?
2.2 Impact of caregiving on attitudes & values.	What are your feelings related to care?
2.3 Changes made	What are changes in you life since stroke occurred?
2.4 Future Life	What does the future hold for you?
2.5 Caregiver learning impact	What behavior or value changes have you made since beginning caregiving?
2.6 New self perception in this situation	Is there a change in your caregiver identity?

<i>Domain: Coherence</i> Code: 3.0	<i>Description: Targets Stability & Spirituality: Inner Feelings</i>
3.1 Reenergize	What do you do to replenish energy?
3.2 Avoidance of feeling down	What do you do for yourself?
3.3 Happiness contributors	What makes you happy?
3.4 Perception of caring	Does caregiving uplift or discourage you?
3.5 Feelings of inadequacy	Do you perceive a sense of deficiency for self?
3.6 Feelings about giving up	Are you discouraged in caring?
3.7 Care for self	What do you do to care for yourself?
3.8 Overcoming anger or depression	How do you handle anger or depression?
3.9 Care dividend	Do you receive a benefit from caregiving for self?
3.10 energy sources	What increases or decreased your energy?
3.11 Feelings of depression	Do you have a lack of success to fight depression; I.e. I just can't get my act together?
3.12 Loss of control	Is there a perception of yourself falling apart?
3.13 Impact of religion on self	What does your spiritual beliefs mean to you?

<i>Domain: Individuation</i> Code: 4.0	<i>Description: Targets Growth and Spirituality</i>
4.1 Family teaching care giver	Are there approaches to caregiving you have learned from your family?
4.2 Caregiver performance different than family	What are the differences in caregiving between your family and yourself?
4.3 Learning about self and growth	How have you changed as a result of caregiving?
4.4 Learning from the experience	Have there been any changes based on your learning about caregiving?
4.5 Caring as a good experience	Is caregiving a positive experience?
4.6 Burden experience (related to lack of adjustment & care learning)	Is caregiving a burden?
4.7 Feelings about giving up (related to lack of adjustment & care learning)	In relation to caregiving: is there meaning in the caregiving situation for you; futility feelings; difficulty dealing with the situation?
4.8 What keeps you going	What are the new ways that you do things in caregiving?
4.9 Meaning of caring	What does caregiving mean to you?

4.10 New perception of the situations	Are there changes you see in the caregiving situation?
4.11 Impact of caregiving on religious or spiritual feelings	What is the influence of caregiving on you spiritual beliefs?
4.12 Why is caring worth it	Do you search for meaning?

<i>Domain: Congruence</i> Code: 5.0	<i>Description: Pursuit & Balance of Targets: Stability, Growth, Control & Spirituality</i>
5.1 Situation satisfaction	How satisfied are you with your life?
5.2 Ways of feeling happy	What makes you feel happy in caregiving?
5.3 Feelings of fairness	Is there resentment with caregiving?
5.4 Anger about situation	Are you ever disappointed or depressed about family and friend support?
5.5 Depression or disappointment about family or friends	Are you ever disappointed or depressed about family and friend support?
5.6 Upset with self	Is there a state of being; or disappointed in caregiving for you?
5.7 Anxious or inadequate feelings	Is there a state of being anxious and inadequate in caregiving for you?
5.8 Feeling grateful to others for support or experience	Do you feel grateful in caregiving?
5.9 Arguments/disagreement	Are there conflicts and discord between you and care receiver that creates negative feelings?
5.10 Family discord	Does family discord impact on caregiving?
5.11 Caregiver overwhelmed	Do you feel overwhelmed?
5.12 Caregiver frustration	What aspects of caregiving frustrate you?
5.13 Feeling of family/social support	Do you feel you have family/social support?

ABSTRACT

A male spousal caregiver providing care to his wife with stroke was enrolled in Caring~Web[®], a web-based support intervention study. This caregiver's electronic messages posted on Caretalk, the discussion group on Caring~Web, were collected over the first year of caring. These data entries (n=213) were coded, using an established coding rubric based on Friedemann's framework of systemic organization. The themes that emerged were drawn to this framework's concepts. The themes during this year were that of the male caregiver: 1) providing support, 2) offering solutions, and 3) taking control. Friedemann's system maintenance process dimension was the area that captured most of his experience. This indicated that this caregiver spent a significant amount of his energy in creating control and stability within his environment in order to maintain congruence or balance in his life. These findings can be used to identify and design interventions for caregivers that impact the quality of their lives.