Expressions of Spirituality by Caregivers of Persons with Stroke in a Web-based Discussion

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DEDICATION

I would like to dedicate this thesis to my family and friends who have supported me throughout this process. I am thankful my parents taught me the values of self-motivation, determination, and hard work at a young age. I am very appreciative of everyone’s assistance, patience, and love throughout this endeavor.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEDICATION</td>
<td>i</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>ii</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>iii</td>
</tr>
<tr>
<td>LIST OF FIGURE AND TABLES</td>
<td>v</td>
</tr>
<tr>
<td>CHAPTER I: Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Statement of Purpose</td>
<td>2</td>
</tr>
<tr>
<td>Identification of Nursing Theoretical Framework</td>
<td>2</td>
</tr>
<tr>
<td>Research Question</td>
<td>4</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>4</td>
</tr>
<tr>
<td>Significance</td>
<td>5</td>
</tr>
<tr>
<td>Assumptions</td>
<td>6</td>
</tr>
<tr>
<td>Limitations</td>
<td>7</td>
</tr>
<tr>
<td>Summary</td>
<td>7</td>
</tr>
<tr>
<td>CHAPTER II: Literature</td>
<td>9</td>
</tr>
<tr>
<td>Nursing Theoretical Framework</td>
<td>9</td>
</tr>
<tr>
<td>Review of the Literature</td>
<td>13</td>
</tr>
<tr>
<td>Summary</td>
<td>28</td>
</tr>
<tr>
<td>CHAPTER III: Method</td>
<td>29</td>
</tr>
<tr>
<td>Design</td>
<td>29</td>
</tr>
<tr>
<td>Subjects</td>
<td>29</td>
</tr>
</tbody>
</table>
LIST OF FIGURE AND TABLES

FIGURE

Figure 1: Friedemann’s (1995, 2005) Concepts Related to this Inquiry on Spirituality ................................................................. 12

TABLES

Table 1: Demographics of caregivers of persons with stroke (n = 20) ............... 36

Table 2: Themes caregivers expressed about spirituality within Friedemann’s (1995, 2005) framework of systemic organization ........................................ 46
CHAPTER I

Introduction

Many people suffer from the devastating effects of stroke. Stroke has been found to account for 1 in every 15 deaths in the United States. It is the third leading cause of death, and the leading cause of disability in adults in the United States (National Institute of Neurological Disorders and Stroke [NINDS], 2005). When a person suffers a stroke, it not only affects the individual, but also affects his/her loved ones and the caregivers involved. When faced with too much change or stress, a caregiver’s wellbeing can be altered. In times of hardship, such as after a stroke, a caregiver’s ability to provide maximum care may become weakened if a caregiver does not have enough personal support.

Caring-Web©, a web-based intervention, was created by researchers in collaboration with experts from the Center for Creative Instruction from a Midwestern medical university to provide support and education for first-time caregivers of patients who suffered a stroke. The caregivers then were followed for 1 year. Caring-Web© provides caregivers support in four ways: (1) it offers an opportunity to Ask the Nurse questions and talk about issues of caring, (2) it provides an email discussion called Caretalk for caregivers to talk amongst themselves and/or the nurse, (3) it includes a Tip of the Month with educational information, and (4) it also provides educational links to other helpful web-based sources (Steiner & Pierce, 2002).

Spirituality is an important issue that may be frequently addressed by caregivers in such an intervention. In trying to deal with the stresses accompanying a stroke,
caregivers may turn to spirituality to find comfort, to relax, to cope, or to take blame off themselves. Spirituality can be an important aspect of a caregiver’s ability to connect with the care recipient and provide optimum care. Much research has been done to explore spirituality among caregivers (Chang, Noonan & Tennstedt, 1998; Sawatzky & Fowler-Kerry, 2003; Theis, Biordi, Coeling, Nelpka, & Miller, 2003), and some information targeting spirituality in caregivers of stroke patients has been collected (Pierce, 2001). However, there has not been any research conducted utilizing a web-based support system to examine spirituality among caregivers of persons with stroke.

Statement of Purpose

Few studies have specifically analyzed the effect spirituality has on caregivers of persons with stroke. Little is known about the effect of a web-based intervention to provide support to caregivers of persons with stroke. This study examines the caregivers’ spirituality while participating in Caretalk, the web-based discussion group.

Identification of Nursing Theoretical Framework

The theory that was used to conceptualize this analysis of spirituality in caregivers of persons with stroke is Friedemann’s (1995, 2005) framework of systemic organization. This theory focuses on families, individuals, and other social systems. It includes not only the typical nursing metaparadigm of environment, person, and health, but also encompasses the dynamic concepts of family and family health. Moreover, the environment, people, and families strive toward congruence, or common energy. Health is defined as congruence between a system and its environment, but it can never completely be achieved. An individual can reach optimal health by having a balanced
systemic life process. Conversely, physical disease results when there is a disturbance in the system. Anxiety is the main determinant that causes a person to have a health deficiency.

A family consists of individuals who interact with the environment, serve a function in the family, and are emotionally connected. Family members do not have to be biologically related or living under the same roof. There are family behaviors or strategies that help regulate space, time, energy, and matter so the system is balanced. These strategies are found in four process dimensions, which include system maintenance, system change, coherence, and individuation. There are also four systemic targets including stability, growth, control, and spirituality, which interact with one another to move towards health. Some of the ways spirituality can be expressed are as follows: exploring nature, seeking God or a greater power, searching for meaning/explanations, sharing views about ideologies, or discussing religious views (Friedemann, 1995). Spirituality is rooted in values such as love, affection, commitment, and togetherness, which are vital components of family culture. Spirituality allows not only individuals, but families, to share ideas about life and seek personal growth. Moreover, family health is a dynamic process that attempts to reestablish congruence by utilizing strategies, satisfying family members, providing positive feedback about members’ roles in community systems, and maintaining low anxiety in the family. The purpose of nursing is to support individuals and families so that optimal health is achieved (Friedemann, 2005).
Research Question

What expressions of spirituality do caregivers of persons with stroke relay on a web-based discussion group?

Definition of Terms

Conceptual definition of a caregiver – Friedemann (1995) does not specifically define a caregiver but the term family can be used interchangeably. “The family satisfies its members’ needs for control over their environment and guides them in finding their place in the network of systems through spirituality” (Friedemann, p. 17). Moreover, “The family is a system with interpersonal subsystems of dyads, triads, and larger units defined by emotional bonds and common responsibilities” (Friedemann, p. 18).

Orientational definition of a caregiver – For this study, a caregiver is someone over the age of 21 years who cares for someone with stroke and participates in the Caretalk discussion.

Conceptual definition of spirituality – According to Friedemann (1995), “through spirituality the human organism attunes the rhythms and patterns of physical, emotional, and ideological subsystems to a unified entity. In light of frequent disappointments, setbacks, uncertainties, and conflicts in life, the striving toward a spiritual entity continues though a person’s lifetime. Actions leading to coherence differ greatly among humans. Examples include reducing tension through exercise, enjoying the beauty of nature, cultural and artistic activities, listening to music, meditation, religious worship, practicing body awareness, finding oneself in sharing thoughts with others, enjoying life through the senses, and so on” (Friedemann, p. 12). Additionally, Friedemann states,
“spirituality encompasses all that binds family members emotionally and encourages
them to seek personal growth outside the family. Through spirituality, family members
reduce their fear of isolation, feel connected, and find comfort and help in difficult times”
(Friedemann, p. 24).

Orientational definition of spirituality – For this inquiry, spirituality relates to the
soul, spirit, and/or religious or sacred item that affects the mind or spirit for the caregiver,
as learned through the Caretalk discussion.

does not specifically mention the concept of a web-based discussion group in her theory.
However, this would be considered a nursing intervention aimed at promoting mutual
growth through spirituality and supporting the clients’ systemic processes leading to
health (Friedemann).

Orientational definition of web-based discussion group – Caring~Web© is a
support intervention, using WebTV™ and the Internet, to support caregivers of persons
with stroke. Caregivers participated with other caregivers in an email discussion called
Caretalk and asked questions or expressed their ideas.

Significance

Spirituality may be interpreted in various ways. The significance of this study is
that it provides a better description of the components of spirituality that caregivers
express in caring for someone with stroke. The creation of a web-based group for
caregivers to discuss anything that encompasses spirituality may potentially decrease a
caregiver’s level of stress and ultimately impact his or her health. Exploring spirituality
among caregivers may prove to be beneficial in enhancing their self-care deficiency and alleviating anxiety.

Assumptions

In this study, several assumptions are made. According to Friedemann (1995), humans have the capability to realize they are dependent on natural forces and can often foresee death. This may cause disturbances in a person’s system processes that lead to incongruence, which a person then experiences as anxiety. Stroke is usually unexpected so caregivers also lack much control over their given situation. According to Friedemann, spirituality, stability, growth, and control are four targets that interact to maintain equilibrium, so that congruence is achieved between each person’s system and the environment. Spirituality is becoming more important again in today’s world because it helps a person connect to something and find order. It seems that people are becoming more spiritual, but less religious. According to the theory, “spirituality does not signify resignation but is an active pursuit that employs the intellect and the emotions. Through spirituality humans adjust their own rhythm and pattern to render them congruent with chosen systems of contact: a person, an organization, nature, or the universe” (Friedemann, p. 9).

Caregivers are considered part of a person’s family even if they are not biologically related or live in the same household. As a family member, a caregiver has the duty to guide the care recipient to find his or her place through spirituality. Additionally, through spirituality caregivers are able to reduce their own fears of isolation, find comfort, and feel connected during difficult times. This reduces anxiety
and allows both the caregiver and the care recipient to find balance within their systems (Friedemann, 1995, 2005). Having a web-based intervention for caregivers to explore spirituality may greatly reduce caregivers’ anxiety and positively influence their caring role.

Limitations

Lack of a clear definition of spirituality may be a limitation. This study uses Friedemann’s (1995, 2005) theoretical definition of spirituality. However, there are differences in how people view spirituality. Friedemann’s framework of systemic organization refers to spirituality as a system target and core necessity to maintain congruence within the life processes of the human system. Friedemann does not specifically define all the components of spirituality. Instead, the theory suggests that individuals strive toward a spiritual entity throughout life. Spirituality is an abstract term that cannot be fully measured, seen, or felt. Additionally, the targets of stability, growth, control, and spirituality are not tangible. This may make it difficult for some people to conceptualize how system targets interact with process dimensions so an individual can find congruence.

Summary

Changes occur as the result of stroke which may alter the life of the caregiver and his or her ability to provide assistance. Caregivers in this situation often need to find support and often explore components of spirituality to find peace. It is beneficial for caregivers to have an outlet, such as Caretalk, to discuss topics such as spirituality. This study describes the expressions of spirituality in caregivers of varying ages.
Friedemann’s (1995, 2005) framework of systemic organization was applied to this topic to enhance a caregiver’s ability to maintain congruence and provide support.
CHAPTER II

Literature

In this chapter, Friedemann’s (1995, 2005) framework of systemic organization is described and related to spirituality in caregivers of persons with stroke. An extensive literature review also is presented with respect to what knowledge and research has been done in similar studies analyzing caregivers, stroke, spirituality, and web-based interventions.

Nursing Theoretical Framework

As previously mentioned, the theory used to conceptualize the analysis of spirituality in caregivers of persons with stroke is Friedemann’s (1995, 2005) framework of systemic organization. According to this theory, human system processes are organized in such a way to reduce anxiety and find congruence. Four targets, including stability, growth, control, and spirituality interact with one another to maintain equilibrium and to establish congruence between the human system and the environment.

The target of stability addresses traditions and cultural differences that provide families with a sense of identity, safety, and belonging (Friedemann, 1995, 2005). Stability includes a person or family’s character, personality, and identity as well as basic values and beliefs. Through stability, the family passes on traditions from generation to generation to protect the system from extinction. The target of growth occurs when family members gain new ideas, realizations, or knowledge that changes the system (Friedemann). This change forces the family to readjust its structure. Growth also is needed when a person’s stability loses congruence with the environment and leads to
unwanted behaviors. Through good communication and acceptance of change, the family can buffer anxiety and find congruence within their system. The targets of stability and growth are interrelated and both are needed for the system to survive. The target of control includes the organizational structure of the family that is able to be regulated by its members (Friedemann). This might include each person’s role, autonomy, or rules each family member follows. Control attempts to reduce anxiety within the family system which may be caused by vulnerability or helplessness. According to the theory, the target of control needs a basis of spirituality in order to be effective (Friedemann).

The target of spirituality is explored the most in this study. The target of spirituality is not only an important aspect of family culture, but it also binds family members emotionally and encourages them to personally seek growth (Friedemann, 1995). People often use spirituality as a defense against helplessness. According to the theory, “healthy spirituality results in congruence or unity with other systems and is experienced as a sense of belonging, acceptance, respect, wisdom, and inner peace” (Friedemann, p. 9). A person’s life experience, age, culture, or patterns may vary, and each target may gain or lose importance as process dimensions change.

As aforementioned, the four process dimensions include system maintenance, system change, coherence, and individuation (Friedemann, 1995, 2005). In the human system, both coherence and individuation target spirituality. Coherence results when a person’s subsystems unite to become whole. This can be accomplished through effective communication, sharing of experiences and feelings, affection, acceptance of differences,
appreciation of others, expression of sexuality, and caring. Its outcome is a sense of unity, belonging, and commitment to the family from all of its members in order for the system to survive (Friedemann). Individuation occurs when the human entity becomes attuned to other systems. Bonds are formed between members of the family and the environment. A family that utilizes individuation supports its members’ desire to seek personal growth and to be unique. According to the theory, “As subsystems of environmental systems, humans will adjust their own rhythm and patterns and feel connected to other units of their choice, be it a friendship system, a workplace, an ethnic group, an ideology, a religious community, nature, or the universe” (Friedemann, 1995, p. 13). All of these open systems are connected and work together to reach a state of congruence with one another and the environment (Friedemann).

Figure 1 shows how the system targets interact along the periphery as well as with certain process dimensions so that the system can find congruence. This conceptual level can be applied to this study. When a caregiver is able to find congruence within his or her system, health is achieved. Interventions to support caregivers, such as a web-based discussion group, can allow caregivers to express themselves freely. Discussing spirituality may bring comfort and provide strength for caregivers, which ultimately may positively impact the health of both them and their care recipients.

<table>
<thead>
<tr>
<th>CONCEPTUAL LEVEL</th>
<th>APPLIED LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friedemann’s framework of systemic organization</td>
<td></td>
</tr>
<tr>
<td><strong>PROCESS DIMENSIONS</strong></td>
<td><strong>SYSTEM TARGETS</strong></td>
</tr>
<tr>
<td>System Maintenance</td>
<td>Control</td>
</tr>
<tr>
<td>System Change</td>
<td>Stability</td>
</tr>
<tr>
<td>Individuation</td>
<td>Growth</td>
</tr>
<tr>
<td>Coherence</td>
<td>Spirituality</td>
</tr>
</tbody>
</table>

CONGRUENCE

Health: Caregiver of Person with Stroke

Expressions of Spirituality

Web-based Discussion Group
Review of the Literature

The purpose of this study was to describe expressions of spirituality by caregivers of persons with stroke who have participated in a year long web-based discussion group. In the next section, studies are examined for integrity in sampling and methods, significant findings, implications for providing further support for caregivers, idiosyncrasies or limitations, and any other pertinent information related to definitions of spirituality and health, as well as caregivers.

Definitions of Spirituality

Many definitions of spirituality exist. A broad knowledge of possible meanings of spirituality could be beneficial in interpreting the responses regarding spirituality by caregivers of persons with stroke. Coyle (2002) suggested that spirituality enhances health, but that no clear definition of spirituality exists. The purpose of her study was to develop a conceptual framework to explore the relationship between spirituality and health. Coyle utilized the concept-indicator model, initially created by Glaser (1978), to analyze spirituality in the literature. Three approaches exist when analyzing spirituality, which include the transcendent approach, the value guidance approach, and the structural-behaviourist approach. While these approaches may not be mutually exclusive, key aspects of spirituality include transcendence, meaning and purpose, connectedness, hope, faith, work to produce health benefits in terms of prevention, recovery from illness, and coping with illness. This framework can be of use to practitioners so they are better able to understand the connection between spirituality and health and actively explore beliefs for their clients.
McEwan (2004), in a similar study, attempted to define spirituality and apply how it relates to nursing practice. This author provided examples, concentrating on aged individuals, and explained why spiritual care is problematic in British healthcare. It is conceptually difficult to clarify the true definition of spirituality, but definitions of spirituality often contain one or more of the following: meaning, value, transcendence, connecting, and becoming. McEwan stated that it is possible to have a belief in God without being particularly religious, because religion often binds a person to rules and regulations, but does necessarily lead a person closer to God. This was similar to the findings by Torosian and Biddle (2005) and Stuckey (2001) which also made the differentiation between religion and spirituality.

Previous research also has shown many negative reports of how nurses fail to offer spiritual care to their patients. McEwan (2004) suggested that raising awareness of religious pluralism should be a part of nursing education programs and that one of the goals of nursing should be to facilitate spiritual harmony, so an older person can realize the nature of his or her own healing power. Even though the concept of spirituality is not concretely defined, nurses and practitioners need to personally identify what spirituality means to them and attempt to address the spiritual needs of those they are caring for (McEwan).

Faver (2004) studied 50 female service providers and social reformers and their views on relational spirituality. The concept of relational spirituality is that strengthening one’s relatedness to others and to sources of meaning produces joy and vitality when providing care. Spirituality is defined as coming to reality while relational spirituality is
having the insight to be interconnected (Faver). Faver described these women’s motivation for caregiving and explored the role of spirituality in their lives and work. A purposive sample was collected through a “call for participation” to female clergy and lay leaders in Protestant churches in a southeastern state who were active in social caregiving. The women in this study were 40 to 60 years, with 47 of them being Caucasian and only 3 being African American. Each respondent had an audiotaped interview that lasted approximately 1 hour. Probes were used to obtain information about each woman’s type of work or volunteer experiences, as well as all topics in the interview guide. The findings of this study by Faver displayed four common areas including perceived connection to the sacred source (prayer, meditation, and church attendance), work-related factors (connectedness to one’s work, sense of calling, and importance of work), connections to supportive communities (coworkers, friends, and church communities), and relationships with clients. These supported the concept of relatedness, which is the key attribute of relational spirituality. The findings propose that connecting through spiritual practices and experiences can be a great source of support for caregivers. In addition, students and practitioners need to consider how their spiritual paths may help them in their work (Faver).

Caregivers and Spirituality

Several studies primarily researched spiritual wellbeing and coping in caregivers. Sawatzky and Fowler-Kerry (2003) explored the wellbeing of informal caregivers. The purpose was to describe and classify the effects of caregiving on the health and wellbeing of 11 urban female caregivers in a mid-western Canadian city. The care recipients had a
medical diagnosis of Alzheimer's disease, cancer, multiple sclerosis, cardiac problems, stroke, arthritis, cerebral palsy, or autism. Two in-depth semi-structured interviews were conducted and audiotaped to collect data. The first interview focused on the statement, “Tell me about the impact of your caregiving experience on your health and wellbeing” (Sawatzky & Fowler-Kerry, p. 289). In the second interview, the informants were asked to read through transcripts of their first interview to clarify and elaborate on certain issues. The interviews then were transcribed verbatim and analyzed. Three dominant themes revealed were, experiencing loss and grieving, adapting and coping to the new reality, and the short-term and long-term impact of caregiving. Under the theme of adapting and coping, the sub-themes of support systems and spirituality were explored. Seven of the 11 caregivers belonged to some sort of support group. Nine of 11 caregivers stated that their spiritual beliefs and practices were very important and enabled them to cope better. These women emphasized prayer, church attendance, God, meditation, and Reiki when speaking about spirituality (Sawatzky & Fowler-Kerry). Healthcare professionals and society need to change to improve support for this population.

Theis et al. (2003) conducted a qualitative, descriptive study which focused on spirituality in caregiving and care receiving and used respite as a form of self-care. Moberg’s definition of spirituality was utilized in the study, “Spirituality is the totality of man’s inner resources, the ultimate concerns around which all other values are focused, the central philosophy of life that guides conduct, and the meaning-giving center of human life which influences all individual and social behavior” (Theis et al., p. 48). The participants included 60 caregivers and 60 care receivers, which were equally divided
among Caucasians and African Americans. They were recruited through local churches, healthcare agencies, newspaper advertisements, and word of mouth, and then interviewed for 1-2 hours. Care receivers were screened using the Katx Index of Independence in Activities of Daily Living (ADLs), the Lawton Instrumental IADL Scale, and the Short Portable Mental Status Questionnaire. They ranged from 53-98 years old and had the diagnosis of a chronic illness, including congestive heart failure, stroke, or arthritis. Caregivers, ranging from 24-84 years included spouses, children, siblings and others. One researcher interviewed the caregiver while the other researcher interviewed the care receiver in a separate room. The interviews were audiotaped and then transcribed verbatim later. The data were analyzed using grounded theory (Theis et al.).

Two overarching themes of coping and meaning emerged from these data (Theis et al., 2003). Not all participants mentioned spirituality, but those who did mostly made positive comments. Sub-themes for coping included social support and formal religion, and sub-themes for meaning included positive attitude, retribution or reward, and all encompassing. Most of the responses pertaining to spirituality resulted when subjects were asked how they coped with caregiving or care receiving. The needs of caregivers and care receivers included having the opportunity for formal religion including communion and prayer, social support, and interactions to help find meaning (Theis et al.).

In another study, 131 informal caregivers of community-residing disabled elders were interviewed by telephone to see how religious/spiritual coping was related to specific conditions of caregiving and distress (Chang et al., 1998). The authors
hypothesized that religious/spiritual coping would indirectly affect psychological distress
and quality of relationship between caregivers and care receivers. Data for the study
were collected during Wave 4, the last wave of Phase II of the Massachusetts Elder
Health Project (MEHP), which was a longitudinal study from 1984 to 1996 evaluating the
process of caregiving. The elders in the study were primarily white (99%), female (79%)
and had the following denominational preferences: Catholic (52%), Protestant (39%),
Jewish (4.6%), and Orthodox (3.1%). Due to the majority of caregivers being either
offspring (55%) or spouses (17%) of the elders, their demographics are most likely very
similar. The degree of religious/spiritual coping was measured using one item from the
Meaning in Caregiving scale in which caregivers were asked to rate how much they
agreed with the following statement, “My religion or spiritual beliefs have helped me
handle this whole experience” (Chang et al., p. 466). Path analysis then was used to test
the conceptual model and the hypothesis, and regression coefficients were estimated
using ordinary least squares (OLS) linear regression models. It was found that caregivers
using religious or spiritual beliefs to cope with the strain of caregiving were more likely
to have a better relationship with the elders (beta = .24, p<.01). This was associated with
less depression and lower levels of role submersion (beta = -.30, p<.01). However, none
of the three stressors (level of disability, presence of cognitive impairment, and problem
behaviors) in the conceptual model were related to religious/spiritual coping. The
findings by Chang et al. were much like those in the qualitative studies by Sawatzky and
Fowler-Kerry (2003) and Theis et al. (2003) that found spiritual coping was important
and beneficial to caregivers.
Caregivers and Chronic Diseases

Research regarding expressions of spirituality of persons with stroke is limited. Pierce (2001) explored expressions of spirituality in urban caregivers of African American families in northwestern Ohio. Spirituality is a component of wellbeing and is based on values of commitment, love, and affection. The theoretical framework in this study was based on the framework of systematic organization by Friedemann (1995). Eight primary caregivers and 16 secondary caregivers, ranging from ages 26-76 years, participated in three semi-structured interviews and one short fourth meeting to confirm data. The researcher kept a personal journal as well. Eight caring expressions of spirituality were described including a filial ethereal value, self-contemplation, motivation for a philosophical introspection, filial piety, living in the moment and hoping for the future, purpose, motivation for approval by recipients of care, and Christian piety. For these caregivers, their values allowed them to accept life after the stroke, find reward by being in the caregiving situation, find an intrinsic goodness with peace of mind and love from God, and have the support from God necessary to care for persons with stroke. For all participants, a Christian piety existed and as they became overwhelmed, they turned to God for strength. Satisfaction with spirituality gave them a sense of congruence. This was also true of the 5 African American women in a study by Paun (2004). Pierce suggested that nurses should focus on spirituality when caring for families of persons with stroke.

More research has been conducted on spirituality in caregivers of patients with dementia and cancer. Meller (2001) conducted a study to investigate the differences in
wellbeing between caregivers of older patients hospitalized with dementia versus those caregivers of older patients hospitalized with physical impairments. A total of 107 caregivers, between the ages of 26 to 90 years, of patients in two geriatric hospitals in central Israel filled out a questionnaire that included 90 questions measuring wellbeing, identity accumulation, and religious faith. Forty-six percent of the caregivers were assisting patients with physical impairments (including stroke, hip fractures, Parkinson’s disease, diabetes, heart disease, and lung disease) while the other 54% were caring for patients with dementia. The wellbeing of caregivers was examined by physical health, mental health, financial resources, and social participation. Eight questions specifically examined religious faith with the caregivers being asked to mark “believe,” “doubt,” or “don’t believe” next to the statements concerning spiritual contexts. Results were analyzed using multivariate analysis of variance. Caregivers of physically impaired patients were found to report significantly higher synagogue and club attendance. Also, there was a significant correlation between the number of each caregiver’s social roles and his or her level of wellbeing. On further examination of the relationship between religious faith and the wellbeing indicators, it was found that the stronger the caregiver spouses’ faith was, the worse their physical and mental health was, but the opposite was true of the caregiver children’s faith. Additionally, participation in religious activity had the potential to enhance a caregiver’s wellbeing through social integration and support as well as through establishing a personal relationship with the Divine (Meller).

In a descriptive study by Paun (2004), the experience of 14 older women caring for patients with Alzheimer’s disease was explored. A specific focus on spiritual and
religious aspects of the participants was examined. A total of 5 African American women and 9 Caucasian women were selected through purposive sampling from 3 referring agencies in a large Midwestern metropolitan area. The author conducted 1 in-depth, open-ended, tape-recorded interview lasting 45-90 minutes with each caregiver. A single question pertaining to spirituality and religion was, “Have religious or spiritual values played a role in your decision to take care of your husband?” in an attempt to explore each caregiver’s motivation (Paun, p. 13). The investigator collected ample data, kept a journal, and took contextual field notes. The following 4 themes were identified: taking charge, adjusting/coping, making sense of the situation, and looking into the future. One of the major subthemes, under the theme of taking charge, was the caregivers’ efforts to preserve normalcy and dignity. To help cope, many of these women went to Mass, watched spiritual programs on television, or stayed up-to-date through a church’s newsletter. Prayer also was mentioned to be the second most frequently used coping strategy. Even though these women endured many losses, all of them still found aspects of their lives for which they were grateful, and they did not take their lives for granted. All 5 of the African American caregivers expressed deep trust in God, and their beliefs were deeply rooted in religious faith. Conversely, 2 of the Caucasian women indicated their commitment transcended religious beliefs and was based on values such as altruism or caring. All participants reported living day-to-day and shared realistic hope for the future (Paun).

Similarly, Stuckey (2001) interviewed 20 Catholic and Protestant older adults, half of which were caregivers of a spouse with Alzheimer’s disease and half who were
noncaregivers, to explore their views on religion, spirituality, and integrated faith in their lives. First, like Torosian and Biddle (2005), the author defined the difference between religion and spirituality. Religion is a doctrinal framework that guides beliefs and practices sanctioned by a broader faith community. Spirituality, then, refers to the beliefs and practices that connect people with sacred or meaningful entities and give purpose to life. The study utilized the Reconciled Life Perspective (RLP) to explain the connection between religion, spirituality, and wellbeing in persons with adverse events in their lives. It also proposed that strong religious and spiritual beliefs allow for effective adaptation resources in persons with a strong RLP. Participants for the study were drawn from the Caregiving Core of the University of Alzheimer Center at University Hospitals and were evenly matched into the two groups by gender, age, and marital status. Religious and spiritual beliefs and practices as well as RLP were assessed using a Life Reflection Interview (LRI) with questions such as, “What words come to mind when I say religion?” or “What words come to mind when I say spirituality?” (Stuckey, p. 74). Interviews lasting 45 minutes to 1 hour were tape recorded and transcribed. This was very similar to the previous study by Paun (2004) in which the caregivers were presented with a question pertaining to spirituality to explore its meaning.

In most cases, the data in Stuckey’s (2001) study were transcribed verbatim, coded, and categorized into common themes. Data analysis using a qualitative thematic design was used to allow informants to freely express their views in the study by Stuckey. Four themes were highlighted including the following: church or synagogue being utilized for a support network, use of religion or spirituality for coping, personal accounts
of spiritual growth, and transcending loss to find meaning. From these four themes, five patterns then were identified including attributes of God and faith, spiritual growth, values, definitions and details, and caregiving or other significant life events. Major differences in the themes expressed by caregivers versus noncaregivers did not emerge. However, the two themes expressed slightly more by caregivers were, “God has a plan” and “prayer for coping and for comfort” (Stuckey, p. 81).

Three studies were identified that deal with spirituality in caregivers of persons with cancer. First, Weaver and Flannelly (2004) attempted to show how religiosity and spirituality significantly contribute to psychological adjustment in both patients suffering from cancer and their caregivers. Several key points were made including the following: faith can give a person with cancer or their loved one a framework for finding meaning and purpose; qualitative research indicates that religion provides hope for oncology patients; prayer can act as a form of self-soothing to reduce negative emotions such as anger, depression and fear; and, caregivers who are more religious feel more positively about their role and get along better with those for whom they care. Physicians and nurses need to acknowledge that spiritual practices can be beneficial for many patients with cancer and their caregivers (Weaver & Flannelly).

Similarly, Torosian and Biddle (2005) stressed the importance of spirituality in improving healing from cancer and promoting positive coping responses of caregivers and health professionals. Significant life changes occur on a personal, familial, social, psychological, and spiritual level when the diagnosis of cancer is made. Spirituality is distinctly different from religion. Spirituality provides hope, faith, love, prayer, purpose
in life, and is a unique and dynamic part of every individual whereas religion promotes a set of beliefs, principles, doctrines, and behaviors. These researchers conducted clinical studies to show that spiritual integrated therapy, which is an innovative treatment approach that combines spirituality/religion with clinical psychotherapy, is beneficial. During spiritual integrated therapy, the patient is able to identify his/her strengths and weaknesses, allowing him/her to spiritually connect to God. This therapy has successfully helped patients with cancer, depression, anxiety, post-traumatic stress disorder, and other physical and mental diseases (Torosian & Biddle).

Out of the three studies regarding spirituality in caregivers of patients with cancer, the study by Taylor (2003) was the most organized and was the most applicable to nursing practice. Taylor studied what patients with cancer and their caregivers expect from nurses regarding having their spiritual needs addressed, as well as descriptions of their perceptions of what constitutes spiritual care. A descriptive, cross-sectional, qualitative study was conducted in which 28 African American and Euro-American adult patients with cancer and their primary caregivers participated in a tape-recorded interview. The interview began with the open-ended question, “Are there any spiritual needs that you may have had since being diagnosed with cancer (or your loved one was diagnosed)?” (Taylor, p. 587). The data were transcribed verbatim and analyzed. Some respondents indicated their spiritual needs should be taken care of through friends, family, and priests and not a nurse. Conversely, the way other responders replied created six categories of nursing approaches for addressing spirituality including kindness, respect, talking and listening, prayer, connecting, quality of nursing care, and mobilizing
religious or spiritual resources. Patients and caregivers want kindness, warmth, respect, to share conversation, prayerfulness, authenticity, presence, and symmetry in relationships. Furthermore, patients and caregivers often misinterpret what the definition of spirituality is and confuse it with religiosity (Taylor).

Caregivers and Web-based Discussion Groups

Several studies have been found pertaining to caregiver interest and participation in web-based support. However, no studies have specifically explored caregivers of persons with stroke and web-based support regarding spirituality. Monnier, Laken, and Carter (2002) sought to identify the need for, interest in, and feasibility of implementing Internet-based services for cancer patients and their caregivers. In this descriptive study, a convenience sample of 319 cancer patients and caregivers from a southeastern medical university completed a 44-item questionnaire that assessed demographics, interest in Internet-based healthcare services, interest in online conversations with healthcare professionals, and Internet use. Of the sample, 195 were patients with cancer, 54 were caregivers, 11 were neither patient nor caregiver, and 59 did not give their status. Respondents rated questions using a four-point Likert scale indicating how interested they were with each item. Chi-square analyses and \( t \) tests were used to compare responses with variables and across ethnic groups. The results of the study indicated that the majority of patients and caregivers alike were interested in using the Internet for services such as conversations with a physician or a nurse, online support groups, development of communication skills, and access to online resources. Interest in these services was the same across ethnic groups. However, Internet use and knowledge differences were
identified. For example, individuals with less education and those who were older tended to have less knowledge and access to the Internet (Monnier, et al.).

In another study by Dew et al. (2004), a web-based intervention was created for patients having undergone heart transplantation and their caregivers. The sample was taken from the 82 heart recipients at the University of Pittsburgh Medical Center who were 6 to 36 months post-transplant as of December 1999. The patients were mailed a letter from the transplant team asking if they had Internet access. The 29 patients who had Internet access, as well as their caregivers, then were asked to participate in the study. Twenty-four patients and 20 caregivers enrolled in the intervention. A group consisting of 40 heart recipients and caregivers who did not have access to the website was used as a control. The control group was selected from a larger pool of heart recipients and their caregivers. Individuals for the comparison group were chosen to match the intervention patients based on age, education, and income (Dew, et al.).

Dew and associates (2004) intervention subjects were contacted by telephone and were interviewed to collect the study measures. They were instructed how to access the website, how to select a user name and password, and were asked to use the website at least weekly for 4 months. A brochure summarizing these instructions was mailed to participants and a 10-minute follow-up phone call 2 weeks later was done to answer any additional questions. After the 4 month intervention, follow-up interviews were conducted to assess the success of the intervention. The comparison group also received two interviews approximately 4-6 months apart. The intervention contained a HeartNet Home Page describing the website and its purpose, Post-Transplant Skills Workshops
designed to improve psychological adjustment and quality of life, Discussion Groups for both patients and caregivers to voice their concerns, Ask an Expert – a module whereby users could submit non-emergency questions to the transplant team and receive answers within 48 hours, a Question and Answer Library, Healthy Living Tips, and a Resources and References Library. The researchers were able to monitor when and how often each user accessed the site as well as how much each participated. At the 4 month follow-up interview, subjects were asked to report how frequently they used the site, to rate its ease of use, and to rate (on a 7-point scale) how helpful and encouraging each module was (Dew, et al.).

Descriptive information was examined based on accessibility and opinions from the users (Dew, et al., 2004). McNemar’s chi-square statistics for paired proportions was done to look for differences between patients and caregivers. Although two patients and two caregivers did not use the website, the majority thought the website was easy to use and participated in the modules. Patients tended to use the website more frequently than the caregivers. The modules most frequently visited and favored were the Discussion Groups and Ask the Expert. It also was found that among the patients, there was a significantly greater reduction in depression and anxiety symptoms with more intervention exposure. Among the caregivers, only anxiety symptoms were reduced with greater intervention exposure. Although limited sample size and quasi-experimental design, this study provided the first empirical evaluation of an internet-based intervention for heart recipients and their caregivers (Dew, et al.).
Summary

Utilization of Friedemann’s (1995, 2005) framework of systemic organization as a conceptual framework enhanced this study is several ways. One of the key components of this model is the belief that all things are organized as open systems of energy and matter that are in constant motion to find congruence and ward off anxiety. Each system attempts to target stability, growth, control, and spirituality. Behavior patterns are based on multiple factors, such as beliefs and cultural patterns. As the four targets interact and connect to the environment, movement toward health is slowly achieved. This model encourages clients to create their own goals, utilizes strategies congruent with clients’ family system processes, and focuses on strengths instead of weaknesses. This model works well for caregivers of persons with stroke because they play a vital role in the family system yet struggle for support of their own. Spirituality, as well as nursing, may enhance caregivers’ health and wellbeing.

The literature addressed many important aspects regarding the importance of spirituality to many caregivers. There is limited nursing and medical literature regarding the meanings of spirituality specific to caregivers, especially those caring for persons with stroke. Consequently, research that addresses spirituality in caregivers of patients with other diseases was presented as well. Spirituality seemed to be a significant help in coping for most individuals. There is also limited data on the use and success of web-based interventions for caregivers and their care recipients.
CHAPTER III

Method

The purpose of this study was to examine expressions of spirituality from a web-based discussion group by caregivers of persons with stroke. The design of the study, the setting, the sample, inclusion criteria, materials for the study, data collection procedures, limitations, and data analysis are discussed.

Design

The research design for this study utilized descriptive narrative analysis using Norwood’s (2000) eclectic approach for qualitative data. A secondary analysis of data taken from a larger stroke study (ROINR07650) was conducted. Secondary analyses reexamine data previously collected in another study with the use of different organization techniques or analyses. This method allows the researcher to examine data in a differing way or to examine questions not originally posed in the study (Burns & Grove, 2005).

Subjects

Setting and Sample

Caregivers of persons with stroke in the original study were recruited from rehabilitation facilities in northern Ohio and southern Michigan. The original study recruited caregivers over 3 years, including both a control group and an experimental group. The experimental group was exposed to the web-based intervention; the control group was not. For this study, only those caregivers from the experimental group who
completed the entire 1 year of the intervention, from May 2002 to June 2004, were used. At the time of this study, this resulted in 20 caregivers.

**Inclusion Criteria**

Each of the participants was a first-time caregiver of a person suffering from an initial stroke. Caregivers had to be able to speak, write, and understand English. Caregivers had to be part of the experimental group, which was given the opportunity to participate in the web-based intervention, Caring~Web©. They had to have a telephone and a television, and they were trained to use this intervention that provided Internet access through MSN/WebTV™ or their own computer. The caregivers were not required to participate on the discussion board, but they were encouraged to do so.

**Materials**

Caring~Web© has several features including Ask the Nurse, Caretalk, Tip of the Month, and educational links (Steiner & Pierce, 2002). During this time, caregivers were able to converse freely, ask questions of one another or a nurse specialist, share experiences, follow educational links, and hopefully gain support. The data for this current study consisted of email messages in Caretalk. Caretalk is an electronic mailing list, similar to a discussion board, which was created to allow caregivers to communicate to others about their experiences and ask questions to caregivers in similar situations. The nurse specialist was included in the mailing list so she could send messages or probe caregivers regarding their caregiving experiences. All caregivers were automatically put on the mailing list, although they had the option to actively participate in the discussion or simply read what others wrote. After the participants utilized Caring~Web© for 1 year,
all of the email data obtained from Caretalk were uploaded. The data relevant to spirituality were used in this current study.

Data Collection

As discussed previously, the data for this current secondary analysis came from a larger stroke study at a Midwestern university. The participants were caregivers of persons affected with stroke for the first time and were part of the experimental group of the original study. This experimental group was randomly selected to participate in the web-based discussion group on Caring~Web©. The data consisted of all email messages posted in Caretalk that were automatically saved and archived. These data were analyzed and coded by the larger research team. The labels of the codes on spirituality included the following:

1.5 Role and practice of religion
3.13 Impact of religion on self
4.11 Impact of caregiving on religious or spiritual feelings

These codes were only used to obtain data pertinent to this current study, which included all statements the selected 20 caregivers made about spirituality. The data relevant to spirituality then were analyzed in-depth to determine how various caregivers expressed spirituality throughout the year-long intervention.

Protection of Human Rights

Institutional Review Board (IRB) approval for this current study was obtained as an amendment to a larger stroke study so that a secondary analysis could be done (Appendix). Caregivers’ complete names and personal identifiers were removed from the
data, and each caregiver was assigned an identification number and first name. All data used in this study were kept anonymous to protect the caregivers from any violation of their personal rights.

Limitations

There were several limitations to this study. All caregivers were taken from the same geographical area in northern Ohio and southern Michigan, and most caregivers were Caucasian. The sample may not provide the most accurate representation of all caregivers who have provided assistance to persons with stroke. This also may limit transferability of the findings. The study was a secondary analysis. Therefore, there was not an opportunity to ask more questions or prompt caregivers to explore spirituality more in-depth. There was no manipulation of variables. The current researcher did not collect the data. All of the caregivers were trained how to use the web-based discussion group, but not all of the caregivers may have fully understood the intervention or felt comfortable using it. Additionally, the definition of spirituality used in this study may be different from what others view as spirituality, since multiple meanings exist.

Data Analysis

A preliminary coding rubric for the qualitative data was created by the larger research team and was based on the framework of systemic organization by Friedemann (1995, 2005). Codes were grouped according to concepts of the framework. A research team, a qualitative consultant, and the theorist conducted a data review and analysis of exemplars, and they reached consensus on the coding scheme.
To answer the research question of this study, an in-depth qualitative analysis was done using Norwood’s (2000) eclectic approach. Data that were already pre-coded into spirituality using Friedemann’s (1995, 2005) framework of systemic organization were analyzed in an attempt to discover themes. The research question this study answered was as follows: What expressions of spirituality do caregivers of persons with stroke relay on a web-based discussion group?

Norwood’s (2000) approach blends together deductive and inductive analytic processes to reduce and interpret qualitative data. This eclectic approach has three phases including a deductive phase, an inductive phase, and an integrative phase. First, during the deductive phase, the data were converted into manageable units by creating category schemes where data were coded and sorted into similar categories. This phase was completed prior to this current study. In the inductive phase, each category was examined individually. This investigator looked for themes within the data. After themes were identified, they were defined and labeled for clarity. For example, themes could be named with indigenous concepts (key words), sensitizing concepts developed from the literature review or conceptual framework, or metaphors. Finally, the integration phase searched for links or relationships between themes and pieced together data into a conceptual pattern drawn to Friedemann’s (1995, 2005) framework of systemic organization. Everything then was woven together to form an integrated whole. Using these techniques, the investigator analyzed data about spirituality in caregivers of persons with stroke and reached a consensus with the larger research team regarding the themes using Friedemann’s framework.
Summary

A qualitative design was used to explore expressions of spirituality in caregivers of persons with stroke. The study was a secondary analysis of data from an existing stroke study. The setting, sample, materials, and inclusion criteria were outlined. Specific data collection procedures as well as limitations of the study were listed. The chapter concluded with ways an in-depth data analysis using qualitative methods was conducted.
CHAPTER IV

Results

This chapter includes results from the data collection and qualitative analysis using Norwood’s (2000) eclectic approach. It contains descriptive statistics of the demographics of both the caregivers of persons with stroke and their care recipients. This descriptive data helps identify the types of caregivers in the study, and who they were caring for, so one can better understand the caregivers’ perceptions of spirituality in the discussions.

Sample

Data for this current study were taken from email messages in Caretalk that pertained to spirituality. Postings from 20 caregivers over the year-long intervention were analyzed. The caregivers’ ages ranged from 32-77 years. Of the 20 caregivers, the majority were females and wives of the person with stroke. Table 1 is a more detailed report of caregiver demographics.

Each of the 20 caregivers assisted and cared for a person with a stroke. The care recipients ranged in age from 33-83 years. Of the care recipients, 6 had strokes that occurred on the left side of the body, 11 occurred on the right side of the body, 2 had both sides of the body affected, and 1 was unsure which side of the body was affected. Limited demographic information is given about the persons with stroke, since the emphasis of this study was on the caregivers’ expressions of spirituality.
Table 1

Demographics of caregivers of persons with stroke (n = 20).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>70</td>
</tr>
<tr>
<td>Relationship to Person with Stroke</td>
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<td></td>
</tr>
<tr>
<td>Wife</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Husband</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>Daughter</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Son</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Friend</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Ethnic Background</td>
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<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
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<td>0</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
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<td>0</td>
</tr>
<tr>
<td>Black, not Hispanic origin</td>
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<td>0</td>
</tr>
<tr>
<td>Hispanic origin</td>
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<td>5</td>
</tr>
<tr>
<td>White, not of Hispanic origin</td>
<td>19</td>
<td>95</td>
</tr>
<tr>
<td>Other or unknown</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Level of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>High School Graduate</td>
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<td>40</td>
</tr>
<tr>
<td>College +</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Employment Status</td>
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<td></td>
</tr>
<tr>
<td>Works full-time</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>Works part-time</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>Does not work</td>
<td>9</td>
<td>45</td>
</tr>
</tbody>
</table>

Findings

During the year-long participation on the Caretalk discussion board, caregivers relayed varying expressions of spirituality. The data used in this study were originally coded into spiritual domains using Friedemann’s (1995, 2005) framework of systemic organization. Next, these coded data were re-analyzed in an attempt to discover themes. There were 145 entries pertaining to spirituality posted by the caregivers. Analysis of
these data revealed four main spiritual themes. The themes that emerged included the following: (1) feeling the presence of a Greater Power, (2) practicing rituals, (3) being one with nature, and (4) interacting with family and friends. The themes that became evident after analysis of the data then were drawn back to Friedemann’s framework of systemic organization. The data revealed several references that were not particularly spiritual in nature. Instead, individuals used these terms in a socially acceptable way. Each of these four themes and additional references are discussed in the following section and supported with excerpts from the data.

Feeling the Presence of a Greater Power

The most prevalent theme expressed in the data consisted of statements caregivers made about feeling the presence of a Greater Power. The caregivers felt this Greater Power was truly present and affected their own life and the persons with stroke for whom they cared. They stated that this Greater Power was watching over them, giving them strength, providing meaning to life, and working in mysterious ways. One of the caregivers, Sarah, said, “The funny thing though, God must be really watching us, because knock on wood, I have been pretty alright.” She also made the comment, “We both have said that we feel the power of God is what sees us through.” Eileen repeatedly said, “I know that God doesn’t give us more than we can handle.” Similarly, caregiver Linda stated, “I’m always thankful to God each day for helping me get through it!” It was possible that this Greater Power provided the caregivers with a sense of not being alone or gave them purpose. The thought of this Greater Power being there provided a great deal of hope and comfort to caregivers at a time when their lives were significantly
changed. Caregiver Lauren said, “We have come to grips with the disability, and hope that God will favor us. [We have] More faith in God I guess.” Another caregiver, Jennifer, said that only her faith in God got her through a great loss. She later went on to say, “I am sure it is his young age that has helped so much and faith in a higher power helps us all through our struggles.” Many caregivers specifically stated that God, Lord, or He was that Greater Power while others made reference to a Higher Power or Somebody.

The topics of receiving one’s reward, grace, peace, and free will also were brought up in the discussions. Caregiver Gene said:

You know God didn’t put this burden on us. He gave us choices on how to live this life. He said we can or can’t, will or won’t, do or don’t. . . . He works in mysterious ways, but He always gives us the chance to rise above all the detours in life.

Interestingly, Gene, when referring to his ungrateful step-children in a later posting, changed his terminology and said, “I know that Somebody with unknown power and salvation is watching our every move. When the time comes, I hope the kids can look Somebody in the eye.” It is evident that caregivers as well as the ones they cared for found comfort and felt the presence of a Greater Power.

Practicing Rituals

Another theme in the data occurred when caregivers mentioned spiritual practices or rituals important to their lives. This consisted of attending church, praying, celebrating the holidays, and participating in various other common religious practices. Out of all the
spiritual terms used in the discussions, the word prayer was repeated the most frequently. Many caregivers expressed how much prayer seemed to help their caregiving experience. One of the caregivers, Lauren said:

I’m not very religious, although I do believe in the power of prayer and had [a] lot of prayer chains going for my husband. That is probably the only practice I have, and is easy to keep up. . . . Prayer chain is w[h]ere you ask people to pray in groups! You ask a church (who will start the prayer chain) and those people will say to the other people and they go to other people to pray; it’s like a pyramid, that just keeps growing. And the more you have praying, they say, the more God will hear.

As evidenced by this caregiver, Lauren did not view herself as a particularly religious person, but she strongly believed in the spiritual practice of prayer. Another caregiver Linda said, “The power of prayer is very much in use in this household these days. It keeps us going!” Caregiver Sarah said, “I suppose I missed the entire power of prayer discussion. We attend church weekly and my husband served before his stroke.” Many of the caregivers mentioned the significance of prayer, but one caregiver specifically said a prayer for another caregiver during at difficult time at Thanksgiving. Kristi said:

I will pray for you and am praying now. I pray that you will be comforted, that God will use his hands and arms and mouth on earth (people) to hug you and hold you and be with you during this difficult, painful time. I also pray that God himself will be especially near to you, holding you with one arm, protecting you
with his other and constantly whispering in your ear and heart how much you are loved.

While a couple of the caregivers seemed very sincere about praying for others, many of the caregivers simply ended their discussion postings with comments such as “my thoughts and prayers are with you”, “I will keep you in my prayers” or “prayers are with you.” In today’s society, this phrase seems to be more habitual or socially-appropriate than meaningful.

While many caregivers mentioned the importance of prayer, the church body for others seemed to be a source of strength. Due to the limitations the stroke had on both the caregivers and care recipients, neither was able to fellowship at church as much as they would have enjoyed. Caregiver Lauren commented:

Hubby didn’t even think about going to church until after his stroke, but now he wants to go, but since it is so cold and he walks so slow, we haven’t been going lately (that was my request). But [it] gives him some kind of hope, and some is better than none.

Similarly, Roger said he was thankful that his wife was “even going to play the organ for church this Sunday.” Eileen said, “He has done exceptionally well, and he has been able to attend church the past two Sundays, and plans on going tomorrow.” Other caregivers made arrangements with family or friends to take care of the person with stroke so they could continue to go to church. Jennifer said, “On Sunday a.m. I go to church and my 81 year old stepfather stays with him.” Eileen, in another posting, commented that “through it all I had meetings for my church (5 meetings in 2 weeks)” and that she was able to
make it to them. In addition to the loss of the spiritual element, extroverted caregivers probably felt trapped without the social network a church could provide. A couple of the caregivers also made references to religious formalities. Gary said, “She was so proud last week, she was able to make the sign of the cross.” Caregiver Gene said, “We all get down on bended knee and give thanks for our very being.”

Many holidays have religious traditions and formalities that also were evident in the data. Holidays such as Thanksgiving, Christmas, and Easter, were perhaps more fully celebrated the year the stroke occurred. Caregiver Mandy made the most references to the significance of the holidays. Mandy said, “Today is the day we all sit and say ‘What we are thankful for’. Well I thank God everyday Dave wakes up and pray no seizures.” She later stated, “My homeless will have a nice Christmas. 10 [thousand dollars] off the top will go to help them. That I made a promise to God.” She also mentioned her husband wanted to go to New Hampshire to spend Easter with family and beautiful surroundings. Another caregiver, Gene said, “We wish all of you and yours the most blessed Christmas. . . . After all, tomorrow is a birthday we shall never forget.” It seemed that holidays immediately following a family crisis caused some of the caregivers to treasure life and to recognize there was something bigger out there. This made the religious significance of the holidays more meaningful.

**Being One with Nature**

Another spiritual theme identified in the data was that caregivers found a sense of connectedness with nature or the environment. Taking time for oneself seemed to
provide an outlet to relieve stress from the caregiving experience. Caregivers stated that nature also helped the person with the stroke recover. Sarah said:

I know I need that special time each day (as hard as it is to find most day’s) that’s what keeps me going! Finally my husband and I were able to get away for a few days last week. We went up north to visit our daughter and son-in-law in their new log home. Such a wonderful place to relax and enjoy the surroundings. So quiet and peaceful. We love it there!

Mike stressed the importance of getting a change of scenery. Going to the park seemed to provide a good outlet for caregivers and persons with stroke. Caregiver Patricia said, “My husband loves going to the park. We drive thru about every week, but one of these days we are going to stop and go for a walk.” Similarly, Mandy said, “It’s suppose[d] to be nice tomorrow so we are going to take him for a ride and go sit by the water in th[e] park.” Other caregivers mentioned the change of the seasons and nice weather bringing hope and revival. Jennifer said, “The sunshine and warmer weather today helps keep spirits up.” Finally, Kristi said, “We will be leaving for a week’s vacation in Florida. . . I pray that this will be a time of emotional renewal for my husband and that our time together will be filled with peace and joy!” The busyness of the caregiving process often prevented caregivers from rejuvenating themselves outdoors.

*Interacting with Family and Friends*

It was impossible to overestimate the impact family and friends had on the persons with stroke and their caregivers. During times of tremendous need, the
emotional and tangible support of family and friends made an impossible situation bearable. Caregiver Sarah made the comment:

Although I cannot say that I am glad for the stroke, we have truly seen the blessings that we have been given. Our family and friends have been wonderful. I always knew that we had many wonderful people in our lives, but I never could have imagined their outpourings.

Gary was very appreciative of the help he received, including many meals and the time others spent caring for his wife. It took some of the burden of caregiving off his shoulders. He said:

I have been very fortunate with the amount of help I’ve gotten from family and friends, some friends are from the church, so I lump the church help as friend’s help. . . With the support and prayers of my family and friends we will get through this little setback and I [k]now it will make me a more caring person. My family and my self realize that a good healthy life is a gift, and we should treat it as such.

Roger said that a combination of prayer, nice weather, and social support gave him strength as a caregiver. He stated:

Thoughts and prayers from all helped support me and her in this part of our life. Things that help me are getting out to my therapy (Bridge), and now that I am not breathing ice, outside task[s] help with the thought that things are starting anew again and that is what we all have to do.
Other caregivers made short and direct comments about who they found to be supportive in their lives. Patricia said, “Our neighbors are not neighborly so that leaves the church.” Mandy said the nuns helped her a lot. Ola said, “Friends are one of the blessings we can be truly thankful for.” Caregiver Kristi stated that she did not think that God gave people more than they could handle but encouraged individuals to lean on one another for support. She also stated:

As my year is ending here, I am filled with thanksgiving: thankful for how far my husband has come physically; thankful for the support I received and continue to receive from family, friends and from the stories of those on this caring web; thankful for my life!

Many of these caregivers recognized the indispensable value their friends and family provided in a severe time of need.

Summary

After analyzing caregivers’ comments posted on the Caretalk discussion, four themes emerged from the data. These included (1) feeling the presence of a Greater Power, (2) practicing rituals, (3) being one with nature, and (4) interacting with family and friends. Many caregivers expressed faith in some kind of Greater Power. They realized there was something bigger than themselves that operated in their lives. The various caregivers demonstrated uniquely individual evidence of spirituality through traditional expressions of religion as well as oneness with nature. The recognition of this, as well as assistance from family and friends, gave comfort to many. The caregivers in this study found support, hope, and peace by connecting with something outside of them.
CHAPTER V

Discussion

The findings that emerged from the data are discussed in this chapter. The themes found in the study are related back to Friedemann’s (1995, 2005) framework of systemic organization. The findings are compared and contrasted to findings from the literature review. Limitations of the study and implications for nursing practice, education, and theory are drawn from the results of the study. Finally, the chapter concludes with recommendations for future research and a summary.

Findings

The four themes pertaining to spirituality that emerged from the data included the following: (1) feeling the presence of a Greater Power, (2) practicing rituals, (3) being one with nature, and (4) interacting with family and friends. All of the themes fit into three of the four process dimensions of Friedemann’s (1995, 2005) framework of systemic organization.

Relationship to Friedemann’s Process Dimensions & System Targets

The four spiritual themes applied to three of Friedemann’s (1995, 2005) process dimensions including (1) coherence, (2) individuation, and (3) system maintenance. The process dimension of system change was not represented by the caregivers’ expressions of spirituality. The participants were only followed for 1 year, and this may not have been enough time for true change to have occurred. Additionally, all four of the system targets (spirituality, control, growth, and stability) interacted within the process
dimensions. Table 2 displays each theme and which process dimensions and system targets were involved.

Table 2

*Themes caregivers expressed about spirituality within Friedemann’s (1995, 2005) framework of systemic organization.*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Process Dimensions</th>
<th>System Targets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling the Presence of a Greater Power</td>
<td>Coherence &amp; Individuation</td>
<td>Spirituality &amp; Stability</td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td>Practicing Rituals</td>
<td>Coherence &amp; System Maintenance</td>
<td>Spirituality &amp; Stability</td>
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<tr>
<td></td>
<td></td>
<td><strong>Spirituality is not a direct target</strong></td>
</tr>
<tr>
<td>Being One with Nature</td>
<td>Coherence &amp; Individuation</td>
<td>Spirituality &amp; Stability</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interacting with Family and Friends</td>
<td>Coherence &amp; Individuation</td>
<td>Spirituality &amp; Stability</td>
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</tbody>
</table>

According to Friedemann (1995), the areas of inner peace (solitude, prayer, meditation, morals), relationships with the environment (enjoyment of nature, attachment to objects/symbols), social relationships (mutual friendships, acceptance of social roles), and values and attitudes (emphasis on spiritual life) would fall under the process dimension of coherence. Therefore, all four of the themes in this study relate to coherence. Depending on the client or caregiver’s situation, certain areas take on importance and others may be skipped entirely according to Friedemann’s theory. Other areas, including achievements (family responsibilities, community involvement, service to others), human relationships (social roles, friendships, partnerships/marriage, parent-
child relationships, work relationships, and caregiving relationships), environmental interchange (travel, exploring nature, seeking God or a greater power), and philosophy and ideologies (search for meaning, testing of values, involvement or opposition to ideologies, belonging to a religious organization) are components of the process dimension individuation (Friedemann). Consequently, the themes feeling the presence of a Greater Power, being one with nature, and interacting with family and friends have connections to the process dimension of individuation. One of the areas of the process dimension system maintenance is religious practices. This includes church/mosque/temple visits, prayer/meditation, religious holiday rituals, and social involvement (Friedemann). Therefore, the only theme in the study that would fit in this process dimension is practicing rituals.

The process dimensions include the behaviors that are necessary to strive toward the abstract targets of spirituality, stability, growth, and control. These system targets were previously defined. Each caregiver emphasized these targets in a unique way, and balancing of the targets occurred on an abstract level through subconscious behaviors of the caregivers. Behaviors and actions used to meet the targets were observable and could be assessed within the nursing process. The four targets interacted with one another along the system periphery to maintain equilibrium and to find congruence (Friedemann, 1995, 2005). Table 2 displays which of the system targets interacted within each of the process dimensions in relation to the four identified spiritual themes. For example, the process dimension of coherence targets both spirituality and stability. Spirituality helps a person, such as a caregiver, experience connectedness and a sense of belonging. Stability
addresses a person’s core identity, character, and personality and includes one’s values, attitudes, and rules of life. The target of growth requires reorganization of a person’s basic values and priorities to overcome resistance. Together, these targets join a person’s subsystems into a unified whole.

Findings Related to the Literature

Several similarities and differences were found between this study’s findings and the existing literature. The terms spirituality and religiosity are often thought to have the same meaning. In the study by Coyle (2002), the author stated that no clear definition of spirituality exists. However, several of the components of spirituality included transcendence, meaning and purpose, connectedness, hope, and faith. These descriptions were all mentioned at one point by various caregivers in this current stroke study. McEwan (2004) made the comment that it is possible to believe in God without being religious. Several caregivers of persons with stroke made similar references. They said they did not necessarily view themselves as religious even though they believed in God or participated in practices such as prayer. The study by Taylor (2003) found that patients and caregivers often confused the terms spirituality and religiosity. The participants in this study indicated that they considered kindness, respect, talking and listening, prayer, connecting, quality of nursing care, and the mobilization of spiritual resources as ways spirituality were addressed by nurses.

The theme interacting with family and friends that emerged from this study was similar to Faver’s (2004) concept of relational spirituality. Faver defined relational spirituality as one’s ability to strengthen his or her connectedness or relatedness to others,
which can produce the happiness and energy needed to provide good care. This same concept was termed filial piety in the study by Pierce (2001). The study by Faver found four spiritual themes that were similar to the themes found in this current study. However, Faver’s study seemed to have more of an emphasis on relationships. The themes included the following: work-related factors, connections to supportive communities, relationships with clients, and perceived connection to the sacred source.

The theme perceived connection to the sacred source was similar to the themes feeling the presence of a Greater Power and practicing rituals in this current study. The emphasis on rituals such as prayer, church attendance, and meditation were also very apparent in the study by Sawatzky and Fowler-Kerry (2003). Caregivers sometimes get too busy meeting the needs of others; this prevents them from enjoying the rituals or activities in which they participated before the stroke occurred.

In many of the studies, spirituality was only brought up when caregivers were asked how they coped with the caregiving process. This was different from the current study. Some caregivers said they used spirituality to cope but others expressed spirituality as a part of their daily lives even before they became a caregiver. In the study by Theis and associates (2003), social support and formal religion (communion and prayer) were sub-themes that developed after caregivers were asked about coping. Similarly, in the study by Chang et al. (1998), caregivers who used religious or spiritual beliefs to cope with the difficulties of caregiving were found to have better relationships with their care recipients and had less depression. The study by Paun (2004) found that many caregivers had ritualistic practices like going to Mass, watching spiritual programs,
and praying to help them cope. Interestingly, the 5 African American caregivers in the study by Paun expressed more than just taking part in spiritual practices but possessing a strong trust in God and having deep roots in the religious faith. This concept was termed Christian piety in the study by Pierce (2001). As African American caregivers in Pierce’s study became overwhelmed with caregiving, they turned to God for strength and guidance. This feeling of presence with God was also evident in the current study. Many of the caregivers of persons with stroke found strength, meaning and purpose, and a sense of a greater power watching over them. The two most prominent themes that emerged in the study by Stuckey (2001) were “God has a plan” and “prayer for coping and for comfort.” Moreover, the theme of prayer was repeatedly identified in many of the studies, including this current study. An example was the finding by Weaver and Flannelly (2004) that prayer brought not only a source of hope but also acted as a form of self-soothing for caregivers of persons with cancer. Many caregivers found peace and comfort through both prayer and meeting the needs of someone else.

Most of the caregivers in the literature expressed spirituality or religious preferences when talking about the caregiving process. However, two of the Caucasian caregivers in the study by Paun (2004) stated that their commitment to the care recipient was not based on religious or spiritual beliefs but instead on values such as altruism and caring. This was different from the current study because all of the caregivers made some reference to spirituality; that is why they were included in the current study.
Conclusions

The four spiritual themes caregivers of persons with stroke relayed on the Caretalk discussion included the following: (1) feeling the presence of a Greater Power, (2) practicing rituals, (3) being one with nature, and (4) interacting with family and friends. These themes developed from expressions caregivers made pertaining to spirituality. For example, they spoke of strength in God watching over them, the power of prayer, church attendance, the peacefulness of nature and traveling, and the support of family and friends. All of these data were pieced together into a conceptual pattern drawn from Friedemann’s (1995, 2005) framework of systemic organization. Spirituality not only gave the caregivers a sense of comfort and hope, but also it helped them express themselves more fully during a difficult time of change.

Study Limitations

There were several limitations to this study. One limitation was that all but one of the caregivers of persons with stroke was Caucasian, and the majority of the caregivers were women, which does not make a very heterogeneous sample. This may limit the ability to transfer results to the population. Another limitation was that all of the participants in this study were chosen because they mentioned something pertaining to spirituality on the Caretalk discussion. The amount of participation varied from caregiver to caregiver, but all were part of this study because specific statements they made were originally coded using three spiritual categories from Friedemann’s (1995, 2005) framework of systemic organization.
Implications for Nursing Practice, Education, and Theory

There are many useful ways to apply the results of this study. It would be beneficial for nurses to include caregivers as a plan of care is developed. Caregivers are often overlooked when they may require a great deal of support. Providing educational materials, creating and maintaining web-based interventions, and making follow-up home visits or telephone calls are just a few ways nurses or advanced practice nurses (APNs) could offer assistance to caregivers. The topic of spirituality is not always addressed even though good nursing care should include the assessment of physical, psychological, emotional, and spiritual needs. This may be due to the fact that many healthcare providers are not comfortable discussing spirituality. Also, they may not have come to terms with how they themselves feel about spirituality, or they may not fully understand what spirituality encompasses. Diversity training for healthcare providers might make them more knowledgeable about different religions and cultures and more open to discussing spiritual practices with clients. It might benefit many caregivers if part of the nursing assessment included spirituality. The caregivers then could indicate the degree to which they wanted to discuss spirituality and specify with whom they felt comfortable talking.

This study identified four spiritual themes common to caregivers of persons with stroke. Knowing which areas of spirituality are most important to caregivers may aid a nurse or practitioner in developing supportive interventions that specifically target caregivers’ needs. For example, some people may not view nature or the support of friends and family as being spiritual, yet this study showed how important these two
themes were to caregivers. The role of the advanced practice nurse is to advocate not only for the person who had the stroke but also for the family as well. Spirituality also needs to be incorporated into the curriculum at schools of nursing. As nursing students are trained in the clinical setting, they could begin to address spirituality in their assessments and plans of care. This could best be done after the students explored their own inner beliefs and values. For example, students could write a paper examining their views of spirituality, they could interview fellow students, and then compare and contrast their findings.

Many people during midlife go through a period of reexamining the meaning of life and values. This is often initiated due to responsibilities not only for caregivers’ children, but also for their chronically ill or frail parents (Friedemann, 1995). The nurse or practitioner could facilitate discussion of these changes and what is going to support and comfort caregivers. It takes a great deal of intuition and sensitivity on the part of the nurse or practitioner to determine the extent of involvement and level of interaction the client would need in these areas. The nurse or practitioner would additionally need to assess not only the developmental needs of the caregiver but also the family’s history, pattern of functioning, and environment situation (Friedemann). The healthcare provider could provide comfort and hope at a time when the lives of both the caregiver and the person with stroke have been changed dramatically. Several nursing interventions could be applied to the four spiritual themes identified in this study.

Each of the four themes relating to spirituality would require a slightly different approach from nursing. To address the theme of feeling the presence of a Greater Power,
the nurse or practitioner would need to identify the caregiver’s level of spirituality in order to connect, build trust, and ultimately help the caregiver relax. It could be a great comfort to the caregiver to openly talk about his or her relationship with a Greater Power, and it may alleviate stress. In order to identify practices or rituals important to caregivers, the nurse or practitioner would need to be cognizant of his or her surroundings. For example, the caregiver may be wearing a cross, carrying a Bible, or displaying other religious symbols in the home or on the body. Making comments about these items could bring up spiritual discussions with the caregiver. The healthcare provider could also offer to pray with the caregiver, contact a chaplain or pastor, or provide spiritual resources.

Some caregivers may find comfort through nature or may be more relaxed in certain settings. While doing a home health visit, the nurse or practitioner could offer to do the assessment outdoors. They could also investigate the caregiver’s hobbies; these activities might be a good distraction and provide personal time for the individual to recharge. Interventions to help caregivers positively interact with family and friends could include the following: assessing support systems and relationships with others, suggesting hiring a home health aide, or providing a list of community resources including local senior centers or support groups. The goal of all of these interventions would be to support the caregiver spiritually. Friedemann’s (1995, 2005) framework of systemic organization may be helpful in research studies to arrange themes using concepts of the theory and to explain the nursing process.
Recommendations for Further Research

The literature review identified gaps in current research regarding spirituality and a nurse’s role. For example, nurses and other healthcare practitioners can play an important role by increasing support and exploring spirituality in client encounters. However, the needs of both the care recipient and the caregiver need to be addressed. Often, only the needs of a person with a physical disability, such as a stroke patient, are addressed by the medical community. However, primary prevention is vital in promoting health and wellbeing, especially to caregivers who are faced with much change and stress. Perhaps future studies could explore other aspects of the caregivers, such as selecting caregivers from different geographic locations, or using a more ethnically diverse sample. In addition, not much research exists on the use of web-based interventions for support, especially ones focusing on caregivers of persons with stroke.

Summary

This qualitative study explored expressions of spirituality that caregivers of persons with stroke relayed on a web-based discussion group. Findings from this study, including four spiritual themes, were presented and supported by the available literature and drawn to Friedemann’s (1995, 2005) framework of systemic organization. Conclusions and limitations of the study were identified. Finally, implications for nursing practice, education, and theory, as well as recommendations for future research were presented.
REFERENCES


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


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

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

2. Comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information and security of protected health information.

3. Promptly notify the MUOT IRB at (419) 383-6796 of any untoward incidents or unanticipated adverse events that develop in the course of your research. Please complete and submit RGA Form 317 for ALL SUCH REPORTS for this protocol. The Principal Investigator is also responsible for submitting to the MUOT IRB reports of adverse events that occur at other sites conducting this study and for maintaining an up-to-date cumulative table of adverse events (RGA Form 316) and submitting it to the MUOT IRB for each research project. The Principal Investigator is responsible for reporting adverse events to the appropriate federal agencies and the sponsor (when one exists).

4. Report promptly to the MUOT IRB any deviations or violations from the MUOT IRB approved protocol in accordance with the procedures outlined in RGA Form 309. In your report include the protocol number and title, the subject’s initial/specimen identifier (as appropriate) and study I.D. number, date of the event, a brief description of the occurrence and a description of any corrective actions taken. The Principal Investigator is responsible for reporting deviations, violations and participant non-compliance to the appropriate federal agencies and the sponsor (when one exists) in accordance with federal regulations, institutional policy and any other legal agreements with these organizations.

5. Obtain prior MUOT IRB review and approval for changes in study personnel and for any and all changes/new information that may require additional information be provided to participants.

6. Report promptly to the MUOT IRB, sponsor (if this research is sponsored) and all other required federal and state agencies all new information affecting the risk/benefit ratio and obtain prior MUOT IRB approval for any changes in the study documents that may be required by the new information.

7. Obtain prior MUOT IRB review and approval for all modified and/or added incentives going to the P.I., study coordinator, other study personnel, and/or the institution. These incentives may be in the form of money or other...
items of value, including, but not limited to, equipment, such as computers, and intangibles, such as frequent flyer miles.

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

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

Additional Information:

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

- **Required Procedure to Request Review and Approval for Changes/Updates to MUOT IRB Approved Research:**
  Please complete and submit the Request for Amendment/Changes/Updates (RGA Form 314 found at <http://www.medunohio.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 MUOT IRB to stamp. Please remember that all changes and correspondence submitted to the MUOT IRB (regardless if they are generated by a sponsor, the P.I. or requested by the MUOT IRB) must be in writing, signed and dated by the Principal Investigator.

- **Federally Mandated Continuing Review:**
  MUOT IRB protocols must be reviewed and reapproved not less than once per year. The Institutional Review Board will try to remind you when reapproval is due. However, it is the responsibility of the Principal Investigator to have his/her own reminder system in place to initiate the re-approval process at least a month prior to the expiration date shown above. Please note that Federal Regulations prohibit the extension of this expiration date. Please see the Application for Continuing Review (RGA Form 319 found at <http://www.medunohio.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.medunohio.edu/research/rga_frms/rga320.doc>) to the MUOT IRB for review.

MCO Amendment #010
ABSTRACT

Few studies have specifically analyzed the effect spirituality may have on caregivers of persons with stroke. The purpose of this qualitative study was to explore expressions of spirituality caregivers of persons with stroke relayed on a web-based discussion group. A sample of 20 caregivers from northern Ohio and southern Michigan was included in this study. Norwood’s eclectic approach for qualitative data was used to analyze the data in this secondary analysis. Data extraction revealed four themes, which were drawn to Friedemann’s framework of systemic organization, and included the following: (1) feeling the presence of a Greater Power, (2) practicing rituals, (3) being one with nature, and (4) interacting with family and friends. These findings can be used to design interventions to support caregivers and to increase awareness of the importance of addressing spirituality in client encounters.