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Spirituality Expressed by Caregivers of Stroke Survivors

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Abstract

Thirty-six caregivers of stroke survivors who are new to that role participate in a Web-based support and education intervention over the course of a year. The authors use a secondary analysis of a total of 2,148 e-mail messages that these caregivers posted to the intervention's discussion group. Rigorous content analysis is used to analyze the narrative data coded to spirituality ($n = 230$ e-mails). Four themes emerge and are drawn to Friedemann's (1995) framework of systemic organization: (a) feeling the presence of a greater power, (b) practicing rituals, (c) being one with nature, and (d) interacting with family and friends. Spirituality gives these caregivers hope and sustenance, but it also helps them express themselves more fully during a difficult time of change. The e-mail discussion data presented here highlight the importance of increased awareness of addressing spirituality in nurse–client encounters and designing interventions to support the caregivers.

Keywords

caregivers; population focus; spirituality; health behavior and symptom focus; community; location of care; narrative review; methods; qualitative; stroke

Stroke is the leading cause of disability in adults in the United States (American Stroke Association, 2006). This event is a crisis that not only affects the individual but also touches everyone involved, creating role changes for survivors and caregivers. When faced with too much change or stress, a caregiver's well-being can be altered. As time moves forward, these caregivers' ability to provide necessary care may become weakened if they do not have enough personal support (Kuo & Fisher, 2004; Thompson et al., 2004). In trying to deal with the impact of stroke, the caregivers may turn to spirituality to reduce their own fears of isolation, find comfort, and feel connected during difficult times. Spirituality can be an important aspect of caregivers' ability to connect with the self, stroke survivors, and others.

Description of the Problem

Spirituality is an essential component of being human (Rieg, Mason, & Preston, 2006). Many definitions of spirituality exist; however, key aspects of spirituality include transcendence and value, as well as meaning, connecting, and becoming (Coyle, 2002; McEwan, 2004). Researchers, focused on spiritual needs, have found that spirituality often helps caregivers of persons with chronic health diseases cope with daily living processes and feelings of being overwhelmed with the physical and emotional aspects of caring (Jones-Cannon & Davis, 2005; Murray, 2004; Paun, 2004; Pierce, 2001; Sawatzky & Fowler-Kerry, 2003; Taylor,

2003, 2006; Theis, Biordi, Coeling, Nelpka, & Miller, 2003). The caregivers in these reports were caring for disabled elders or people with Alzheimer's and heart disease, cancer, acquired AIDS or HIV, or stroke. One exemplar is the descriptive study by Paun (2004) that explored the experience of 14 older women (9 Caucasians and 5 African Americans) caring for persons with Alzheimer's disease. Going to church or watching spiritual programs on television helped many of these women cope. Prayer was mentioned as the second most frequently used coping strategy. Even though these women endured many losses, all of them were grateful for their lives. They reported living day by day and shared realistic hope for the future.

We completed an exhaustive review of the literature and discovered that research on the meaning that spirituality may have for caregivers of persons with stroke remains limited. Pierce's (2001) qualitative interview study serves as an example in which she explored the spirituality of urban caregivers ($n = 24$) in African American families. For these caregivers, their values allowed them to accept life after the stroke occurred, 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 the stroke survivor. For all participants, a family piety or togetherness and Christian piety existed, and as they became overwhelmed, they pulled together and turned to God for strength. Satisfaction with spirituality gave them a sense of balance in their lives (Pierce, 2001). More recently through focus groups and surveys, Jones-Cannon and Davis (2005) found that spiritual or religious involvement helped caregivers of people with stroke and dementia cope with their situation. These results are similar to Paun's (2004) study on five female African American caregivers of persons with Alzheimer's disease. Due to the small number of studies, it would be useful to learn more about spirituality and stroke caregivers.

Web-based discussion groups are one source of support where caregivers come together and express their spirituality as a means of coping. Several studies have been found pertaining to Web-based support of caregivers for adults with chronic illnesses such as cancer (Klemm & Wheeler, 2005), dementia (Beauchamp, Irvine, Seeley, & Johnson, 2005), Alzheimer's disease (Glueckauf, 2003; White, 2000), mental illness (Perron, 2002), neurodegenerative disease (Marziali & Donahue, 2006), and heart disease (Dew et al., 2004). Web participants describe the emotional roller coaster associated with caregiving. The emotional, physical, and psychological responses included anger, weakness, exhaustion, grief, and sadness (Klemm & Wheeler). A study by Marziali, Donahue, and Crossin (2005) found that 90% of caregivers reported that the Web-based group experience had been positive and that the group had helped them cope with the stresses of caregiving. Finally, Beauchamp et al.'s (2005) research findings indicate improvement in depression, anxiety, frequency of stress, caregiver strain, self-efficacy, as well as perceptions of positive aspects of caring. These studies focused on outcomes of the Web-based support, not on the content of the discussions.

Purpose and Design

The purpose of this descriptive qualitative study was to explore expressions of spirituality that caregivers communicated in free-flowing dialog in an e-mail discussion group during the first year of caring for a stroke survivor. This study provides an in-depth, theory-based description of these expressions. It was framed within Friedemann's (1995) framework of systemic organization that views people as open systems that strive for well-being. Spirituality, a component of well-being, is based on values concerning commitment, love, affection, and togetherness. Spirituality allows persons—in this case, caregivers dealing with stroke—to uncover ideas about life and seek personal growth. Spirituality is or should be a part of religion (i.e., doctrinal framework that guides beliefs and practices sanctioned by a broader faith community; Torosian & Biddle, 2005), but it can also be achieved in other ways. For example, in Friedemann's (1995) terms, spirituality encompasses accepting or getting in touch with

oneself, finding fulfillment and peace, doing good deeds, and finding meaning in life. In addition, 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” (p. 24). For this study, *spirituality* is defined as the beliefs and practices that connect people with sacred or meaningful entities and give purpose to life.

Friedemann’s Framework of Systemic Organization

According to Friedemann (1995, 2007), behavior patterns acted out in daily life to strive toward congruence or balance, known as health or well-being, can be observed and organized into four process dimensions: system maintenance, coherence, individuation, and system change. System maintenance in caregiving situations involves the tasks of caring for the stroke survivor and the organization of tasks, time schedules, work assignments, communication patterns, and procurement of outside help. Maintenance also includes those actions caregivers undertake to maintain their own well-being, such as rest and sleep, social contacts, good nutrition, and recreation. Coherence signifies being at peace with oneself or feeling as one unified self. Coherence can be achieved by caregivers through a variety of actions leading to renewed energy and a positive attitude. These actions prevent anxiety, depression, exhaustion, or feelings of inadequacy. The third process dimension is individuation, a process of self-development through learning, experiencing, and finding purpose in one’s situation and life in general. Caregivers learn by giving care, exploring facts about stroke, interacting with others, or finding value in their caring through religion or spirituality. Individuation leads to a system change as caregivers become conscious of the impact of their new responsibilities and make changes in their priorities, attitudes, and values, and as a result, assume new behavior patterns (Friedemann, 1995, 2007).

Method

Procedures

The current study was part of a year-long study (referred to as the parent study hereafter). After receiving university and hospital institutional review board approval, we explored the experience of caring for new caregivers of stroke survivors. These caregivers were recruited from May 2002 to December 2004 for the parent study from four urban inpatient rehabilitation treatment programs in northern Ohio after the person with stroke was discharged home (Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007). Inclusion criteria were the following: (a) an adult (more than 21 years of age) responsible for providing day-to-day care in the home for a person with a first-time stroke; (b) the ability to speak, write, and understand English; (c) a novice computer user who did not use the Internet or had limited experience with it; and (d) a telephone and television to facilitate MSN/TV™ and Internet access. There were no exclusion criteria. Caregivers in the parent study were randomized into an experimental group ($n = 36$ Web users) and a control group ($n = 37$ non-Web users). For this study, we included those caregivers from the experimental group, as only they had access to Web-based support and education.

E-mail Discussion Group

Caretalk is a nonstructured, asynchronous e-mail discussion group that is part of Caring~Web®, an intervention of support and education that was designed for and used in the parent study (Steiner & Pierce, 2002). Caretalk connects a caregiver with other caregivers and a nurse specialist via the Internet 24 hours a day, 7 days a week. With a username and password, participants logged on to their e-mail account to read and send messages. E-mail messages sent from one group member were automatically mailed to the entire group, as well as replies to these messages. The nurse specialist facilitated the discussion and furnished educational

information, answered questions, and provided support for the participants. Some participants used a personal computer, but most used MSN/TV™, a service system that provides access to the Internet on a television. A computer technician installed the MSN/TV™ equipment and provided training for all participants. A training manual was made available to the participants to familiarize themselves with MSN/TV™ and Caretalk. The computer technician was accessible to the participants over the telephone for daily assistance with technical difficulties (Pierce, Steiner, & Govoni, 2002).

Data Collection

We used a secondary data analysis of a total of 2,148 e-mail messages posted to the discussion group, Caretalk, to describe these caregivers' expressions of spirituality. This method allowed us to examine a question that was not originally posed in this parent study.

Data Analysis

The data from Caretalk (2,148 archived e-mail messages) were entered as text files into QSR N5 (Richards, 2000), a qualitative software management program. These data were then analyzed using Norwood's (2000) rigorous process of content analysis that consists of three phases: deductive, inductive, and integrative. The deductive phase entailed converting the data from a narrative form to more manageable units. The researchers for the parent study, including a qualitative research consultant and the nurse theorist, Friedemann, first read the e-mail messages (uncoded) that were posted to the Caretalk discussion. This enabled them to acquire a sense for the participants' descriptions of caring. Next, a category scheme was used and data were coded and sorted. The category scheme was framed within Friedemann's (1995) framework of systemic organization and developed by the researchers from the larger parent study (Pierce et al., 2004). Two hundred-thirty e-mail messages were coded to three items that represent spirituality. These included the role and practice of religion, the impact of religion on the self, and the meaning of caring.

Then, the inductive and integration phases of analysis began (Norwood, 2000). In the inductive phase, we individually labeled themes that emerged from these coded spirituality data. These themes were then discussed as a group until consensus was reached, which helped to establish credibility of the findings. In the integration phase, relationships between themes and variations within themes are identified and woven together into an integrated whole such as a theory. For the current study, themes were drawn, as appropriate, to Friedemann's (1995, 2007) process dimensions.

With over 200 e-mail messages analyzed pertaining to spirituality, these data were saturated and expanded the knowledge about spirituality for caregivers during their first year of caring for a stroke survivor. Having the researchers involved in content clarification, refinement, and consensus strengthened the data interpretation and further enhanced the trustworthiness of the findings.

Results

Sample

The 36 Web users recruited from northern Ohio lived there or in southern Michigan. Their ages ranged from 31 to 80 years, with the highest percentage (30.6%) being 51 to 60 years. Most were females (69.4%), Caucasian (86.1%), and wives of a stroke survivor (41.7%). The majority of the Web users had a college education or higher (58.4%). Fifty-six percent were employed. Due to the rolling enrollment, there was a usual group of 11 to 13 participants who were concurrently active in the e-mail discussion group.

Themes

We discovered that of the 36 caregivers who participated in the year-long e-mail discussion group, 25 (69%) of them had responses that were coded to spirituality. Four themes emerged from these data: (a) feeling the presence of a greater power, (b) practicing rituals, (c) being one with nature, and (d) interacting with family and friends. The caregivers' names are pseudonyms, but the following quotes are the caregivers' words taken from the Caretalk e-mail messages.

Feeling the presence of a greater power—The caregivers felt the presence of a greater power, and this affected their life and the life of the stroke survivor 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”:

The funny thing though, God must be really watching us, because knock on wood, I have been pretty alright We both have said that we feel the power of God is what sees us through. (Sarah)

I know that God doesn't give us more than we can handle. (Eileen) 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. (Gene)

We have come to grips with the disability and hope that God will favor us. [We have] more faith in God, I guess. (Lauren)

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 [husband] 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, whereas others made reference to a “Higher Power or Somebody.” They shared that this greater power provided them with support and a sense of not being alone.

Practicing rituals—A second theme that arose was the importance of spiritual practices or rituals in their lives. This consisted of attending church, praying, 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 them in the caring experience. For example, Lauren stated, “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.” 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. Beth shared, “the power of prayer is very much in use in this household these days. It keeps us going!” Michael noted that prayer “helped to understand the changes that we are facing.” Some caregivers seemed very sincere about praying for others, and 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.”

Although many caregivers mentioned the importance of prayer, the church for others seemed to be a source of strength. Due to the limitations the stroke had on both the caregivers and stroke survivors, neither was able to attend church as much as they would have enjoyed. 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 and me kind of hope, and some is better than none.

Likewise, Roger said that he was thankful that his wife was “even going to play the organ for church this Sunday.” Eileen said that her husband “has done exceptionally well, and he has been able to attend church the past two Sundays, and plans on going tomorrow.” 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.”

Being one with nature—The caregivers’ sense of connectedness with nature or the environment was another theme that was revealed. 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’s statement was typical,

I know I need that special time each day (as hard as it is to find); 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!

In a similar manner, Mike stressed the importance of getting a change of scenery (i.e., going to the park seemed to provide a good outlet for caregivers and the stroke survivor). Other caregivers mentioned the change of the seasons and nice weather bringing a sign of hope and revival. Jennifer noted, “the sunshine and warmer weather today helps keep spirits up.” Alice stated, “I’m glad spring and its new beginning is just around the corner.” Kristi’s comment captured the majority of caregivers’ statements when she 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!”

Interacting with family and friends—The final theme that came to light was that it was impossible to overestimate the impact that family and friends had on the stroke survivors and their caregivers. During times of tremendous need, the emotional and tangible interactive support of these individuals made an impossible situation bearable. 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 that he received, including many meals and the time others spent caring for his wife. He said that it took some of the “burden of caregiving off of [his] shoulders.” Roger seemed to sum it up when he said that a combination of prayer, nice weather, and social support gave him strength as a caregiver.

Discussion

One of the reasons that this study is unique is that it is theory driven and combines inductive and deductive approaches within the same qualitative study. Using Friedemann’s (1995, 2007) framework allowed us to not only identify expressions of spirituality from caregivers of stroke survivors, but it also provided a greater understanding of how spirituality is a dynamic force in the first year of caring and helps caregivers achieve balance or well-being in their lives. The four themes were drawn to or placed within three of Friedemann’s process dimensions: coherence, individuation, and system maintenance (see Table 1). According to Friedemann, the areas of solitude, prayer, enjoyment of nature, attachment to objects and symbols, social relationships or mutual togetherness, and an emphasis on spiritual life fall under the process dimension of coherence. Thus, every theme that resulted from this study was related to Friedemann’s process dimension of coherence. Other areas, including family responsibilities,

service to others, human relationships (friendships, marriage, parent–child and/or caregiving relationships), exploration of nature, and pursuit of God or another being are components of the process dimension individuation. As a result, the themes of feeling the presence of a greater power, being one with nature, and interacting with family and friends are connected to the process dimension of individuation. In Friedemann's framework, religious practices grounded in church, mosque, or temple visits; prayer or meditation; and religious holiday rituals are part of the process dimension of system maintenance. Therefore, the theme of practicing rituals was placed in that dimension. The process dimension of system change was not represented by these caregivers' expressions of spirituality. The participants were only followed for 1 year, and this may not have been enough time for true change to occur.

This study's findings highlight that spirituality is a way that the majority of these caregivers coped with the day-to-day aspects of caring. Although spiritual needs are part of a basic assessment, the topic of spirituality is not always addressed. Setting time and workload factors aside, nurses need to focus on short, client-centered assessments to get at the heart of spiritual needs. Of course, there are other factors that may impinge on such an assessment. For example, some nurses may not be comfortable discussing spirituality. Other nurses may not have come to terms with how they feel about their own spirituality, or they may not fully understand what spirituality encompasses. For the caregivers in our study, spirituality was not synonymous with religion, as it included being one with nature and interacting with family and friends. Diversity training for nurses would increase their knowledge about different religions and cultures and make them more open to discussing spiritual practices with clients. Assessment is a two-way event: a nurse–client encounter. Some clients may not welcome a spiritual discussion of their needs or feel that it is not the function of the nurse to address spirituality. Although caregivers of those with stroke need to take responsibility for making their care needs known, nurses need to give them the opportunity to indicate the degree to which they want to discuss spirituality and to specify with whom they feel comfortable talking. Knowing which areas of spirituality are most important to caregivers may aid nurses in developing supportive interventions that specifically focus on caregivers' needs. Each of the four themes relating to spirituality identified in this study requires a slightly different approach. Interventions recommended for each theme relate to the same process dimensions (see Table 1).

Caregivers perceive a connection to sacred sources (Pierce, 2001). To address the theme of feeling the presence of a greater power, nurses need to identify the caregiver's level of spirituality to connect, build trust, and ultimately help the caregiver relax. Providing an opportunity for the caregiver to openly talk about his or her relationship with a greater power may provide comfort and alleviate stress. Practicing rituals, the second theme, was important to these caregivers and an emphasis on them such as prayer, church attendance, and meditation were also helpful strategies in dealing with their situation (Sawatzky & Fowler-Kerry, 2003). To identify practices or rituals important to caregivers, nurses need to be cognizant of the caregiver's person and 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 may allow for meaningful and needed spiritual discussions with the caregiver. The healthcare provider could also offer to pray with the caregiver, contact a chaplain or pastor, or provide other spiritual resources, as appropriate.

The third theme, being one with nature, helps to understand that caregivers may find comfort through nature or may be more relaxed in natural settings. Encouraging outdoor activities, change of scene, and vacations or time away may provide therapeutic distractions and provide personal time for these individuals to recharge. The final theme, interacting with family and friends, highlights the caregivers' ability to strengthen their connectedness or relatedness to others and may produce the happiness and energy needed to provide good care (Pierce, 2001). Strategies to help caregivers positively interact with family and friends may include

helping family and friends communicate with one another to provide support and encouraging people to seek physical and emotional support, as circumstances warrant.

The conclusions of this study are limited, in that all caregivers were from the same geographical area in the Midwestern United States; most were wives and Caucasian. Some caregivers did not discuss spirituality on the e-mail discussion group. Thus, the sample may not provide an accurate representation of all caregivers that provide assistance to stroke survivors. In addition, this study was a secondary analysis of data; therefore, there was no opportunity to ask more questions or prompt caregivers to explore spirituality more in-depth. These issues may limit transferability of the findings.

The findings from this study have important implications for caregivers and nurse–client encounters. This study contributes much needed information about spirituality and caregivers of stroke survivors, which is an outcome of their participation in the e-mail discussion group. This is a distinction between this study and others reported (Jones-Cannon & Davis, 2005; Murray, 2004; Paun, 2004; Pierce, 2001; Sawatzky & Fowler-Kerry, 2003; Taylor, 2003, 2006; Theis et al., 2003), as messages were most often unsolicited and arose from the caregivers or in response to the nurse specialist facilitator and other caregivers, providing an indication of what was meaningful to them during the first year of caring. Spirituality, which gave caregivers of stroke survivors hope, sustenance, and a chance to express themselves more fully, enabled them to cope during a time of change.

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Table 1

Themes Drawn to Friedemann's (1995, 2007) Framework of Systemic Organization

Themes	Process Dimensions
Feeling the presence of a greater power	Coherence Individuation
Practicing rituals	Coherence System maintenance
Being one with nature	Coherence Individuation
Interacting with family and friends	Coherence Individuation