Research: Spirituality as a Coping Resource for Family Caregivers Dealing with Cancer

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NUR 416 Honors Directed Research

Dr. Linda Riley, Faculty Advisor

17 April 2008

Research: Spirituality as a Coping Resource for Family Caregivers Dealing with Cancer
Honors Research Project
Approval

Form 3 – Submit with completed thesis. All signatures must be obtained.

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ABSTRACT

The purpose of this pilot study was to explore the meaning of spirituality and its use as a coping mechanism to family caregivers of patients with cancer. Participants were recruited by staff at a community based hospice organization. Eligible participants were 21 years of age or older, the primary caregiver of a cancer patient, and English speaking. Semi-structured interviews using an interview guide were conducted during fall semester 2007 and spring semester of 2008. Interviews were conducted via telephone for convenience and comfort for the participants (N = 7). All information was tape recorded and transcribed verbatim. A sample of participants also completed the Spiritual Well Being Scale (Paloutzian & Ellison, 1991). Because of such a small sample size, the Spiritual Well Being Scales were not able to produce sufficient and valid data for analysis at the current time. However, qualitative interview data was carefully analyzed using content analysis and organized into the following five dominant themes: (a) a time to talk; (b) strengthening relationships; (c) blessed assurance: coping with the uncontrollable; (d) concept of a sacred caregiver; (e) spiritual nourishment vs. starvation of the soul.
INTRODUCTION

When cancer patients and caregivers are faced with an unknown prognosis, they often feel vulnerable and overpowered, and may seek comfort by looking above the materialistic world and turning their face towards the spiritual realm. Spirituality is a broad concept that is as unique and independent as an individual's personality traits. Conceptually, spirituality has complex, personal connotations for every individual. Spirituality has been defined as “a person's sense of being that gives life” (Meraviglia, 2004, p.89). Due to this broad context, spirituality may be seen as an integral part of every person, uniquely defined by the each person.

Conceptualizing spirituality as a light may help clarify some of its unique properties. For example, spirituality may serve as light that provides security in a long tunnel filled with darkness and question that begins at diagnosis for cancer patients and their caregivers. However, spirituality is dynamic, constantly changing and being under construction. From the time of a patient's diagnosis to the time of remission or death, the patient and caregiver may experience different shades of light during the course of the disease. When first told the cancer diagnosis, the light of spirituality may be far away, possibly too far to see. But gradually over time, its light may increase as they see growth and healing taking place. In contrast, for other people, the light of spirituality may be burning bright at the time of diagnosis but becomes dimmer as prayers appear to go unanswered, hope gets smaller, and death approaches.
LITERATURE REVIEW

The concept and definition of spirituality has received much attention in the healthcare setting over the last several years and continues to be a topic of interest and debate. A review of the literature found broad definitions of the term. Theis, Biordi, Coeling, Nalepeka, and Miller (2003) quote Moberg's (1979) definition of spirituality as 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..." (p. 48). More recent definitions describe spirituality as a complex term that holds such depth and greatness that it may not be possible to adequately define or comprehend (Miner-Williams, 2006). Difficulty defining spirituality is enhanced because spirituality is often confused with religious issues or beliefs. For example, Sherman, Ye, McSherry, Calabrese, Parkas, and Gatto (2005) report that religiosity is a way of expressing spirituality. They believe that one's spirit has specific needs that are expressed in specific ways by the individual. Elizabeth Johnson Taylor (2006) elaborates further by stating that spiritual needs are often personal and include concepts of hope, forgiveness, purpose, value, and faith. The statements suggest that spiritual needs may be identified internally on an individual level but can be manifested externally and observed by others through personal relationships, conduct, and demeanor (i.e., optimism, anger, withdrawal).

Spiritual needs have been identified for centuries in religious texts. Biblical writings record numerous examples of individuals who suffer in spirit during times of loss, distress, or physical discomfort. For example, in II Samuel, King David is described as weeping, prostrating himself, and refusing to eat for days because his child was sick (2 Samuel 12.16-17, New American Standard). Job also was portrayed as speaking in the
anguish of his spirit while suffering from boils and the devastating loss of his family (Job 30.16-17). During times of sickness and loss, spirituality and issues of hope and faith may arise and provide a source of comfort and strength rather than increased distress. Therefore, for some individuals spirituality may be viewed a resource for adaptive coping and improved psychological wellbeing when coping with illness related stress (Speck, 2005).

Stefanek, McDonald, and Hess (2004) stated that psychological outcomes of quality of life, self esteem, and depression are associated with and benefited from positive religious coping methods such as finding spiritual contentedness, receiving church support, and looking for spiritual strength. Similarly, Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl, and Prigerson (2006) reported that positive religious coping includes security in God, a sense of purpose in life, and a feeling of being connected. However, negative religious coping, such as feelings of being forsaken and punished by God, may lead to areas of struggle in the spiritual dimension (Tarakeshwar et al., 2006).

Caregiver Needs

The caregiver may experience needs specifically related to their unique situation of providing care for a loved one. They may feel anger, resentment, guilt, or helplessness while they, ironically, are actually trying to provide emotional support to the one with cancer. Some may even neglect their own needs in order to adequately meet the needs of the one receiving care (Soothill, Morris, Harman, Thomas, Francis, & McIllmurray 2002). Their spiritual needs may often go unnoticed and unmet by others because of the focus on the ill person, and consequently, caregivers’ needs sometimes magnify during times of distress (Taylor 2003). To provide optimal support, healthcare providers should
be aware of these issues, learn how to assess for spiritual distress, and how to effectively handle the situation by addressing the needs of the caregiver.

Taylor (2006) conducted a study of the spiritual needs of 156 cancer patients and 68 caregivers. She discovered that the most important spiritual needs of the patients and their families were keeping an upbeat spirit, showing love, finding an understanding, and recognizing and being in harmony with God. These important spiritual needs and associated religious coping strategies took place at different intervals, evolving over the course of the patient's disease process. They were not stagnant but represented dynamic processes and often reflected the prognosis, progress, and treatment of the disease that was continually changing.

This process of change was supported by a study by Abernathy, Chang, Seidlitz, Evinger, and Duberstein (2002) who found that spiritual strength and depression levels of spouses may change as cancer progresses and the outlook or prognosis of the disease changes. This study described the complexity between spiritual levels and coping; that they are not directly and linearly related but have more underlying issues that need to be explored. The researchers concluded that spouses with either extremely high levels or extremely low levels of spirituality may experience higher levels of depression than those who use moderate levels of religious coping (Abernathy et al., 2002). The researchers acknowledged that those with very high religious coping may put the reality and seriousness of their disease aside while focusing singly on one style of coping; people with already high levels of depression and helplessness may be the ones to turn to religious coping, causing the relationship between spirituality and depression to be high (Abernathy et al., 2002).
Role of the Nurse in Spiritual Assessment

The review of literature supports the assumption that caregivers have spiritual needs that must be met. However, some studies find that caregivers may have mixed feelings about nursing intervention or assessment to determine their spiritual needs. Taylor (2003) conducted semi-structured interviews with caregivers of 28 cancer patients. The interviews focused on whether caregivers thought that nurses should address and intervene in issues concerning patients' or caregivers' spiritual needs. Responses varied ranging from caregivers' acceptance of nurses participating in spiritual assessment to descriptions of confusion and resistance about this nursing intervention. In contrast, 47% of 267 oncology nurses surveyed in a previous study believed themselves to be the first in line of professionals to identify spiritual distress (Kristeller, Zumbrun, & Schilling 1999). In this study 58% of nurses reported that they would address any spouse or family distress with the patient, and 36% would make a formal referral. However, spiritual distress was ranked very low compared to other issues the nurses would assess. Because nurses deliver direct patient care, they are capable of monitoring changes in the patients' emotional state and spirituality. Yet, because spiritual distress had such a low ranking, spiritual issues may go overlooked when providing patient care.

In a study of 156 cancer patients and 68 family caregivers, Taylor & Mamier, (2005) found that the participants were not interested in having a nurse identify spiritual needs and provide spiritual care. In addition, more than half of the caregivers who completed a written response strongly indicated either they did not want spiritual care from a nurse or they indicated that while nurses were important, they were not needed "to be preachers" (p. 264). In this study the role of a nurse seemed to be confused with that
of evangelist, and the terms spirituality and religiosity were considered as similar concepts rather than different phenomena.

Murray, Kendall, Boyd, Worth, and Benton (2004) found that spiritual care is about helping people whose sense of meaning, purpose, and worth is challenged by illness. Accordingly, every patient who feels discomfort or threatened by their diagnosis and illness should be allowed access to spiritual care. Similarly, Pulchalski, Lunsford, Harris, and Miller (2006) emphasize that spiritual care should be integrated into every patient contact. The researchers stress that spiritual care, "...begins the moment the healthcare professional enter the room...One becomes fully present when one approaches the patient with deep respect, respect stemming from a commitment to honoring of the whole person" (p. 402). In contrast, Murray et al. (2004) found that while spirituality is important it often is not addressed in healthcare because of insecurities, lack of time, or inadequate training. This statement supports the assumption that spirituality may be difficult to comprehend and even harder to understand in others. Nurses may need further training to be able to assess and intervene in times of spiritual distress as part of holistic care.

In conclusion, this literature review found that spirituality is a broad term that can have multiple dimensions and a variety of meanings. Never the less, it is necessary to understand how caregivers personally define the concept in order to understand it's implication in their lives. Because spirituality has been identified as an important coping resource and a source of strength for families facing cancer, more information is essential to clarify its meaning in order to develop supportive programs that emphasize its value.
PURPOSE

The purpose of the study was to better understand the multidimensional concept of spirituality as defined by caregivers of cancer patients, and how it may be used as a coping resource. While spirituality and quality of life has been addressed in studies of cancer patients, researchers have not adequately defined and or agreed upon the definition of spirituality and how it may play an active role in the patient and family caregiver’s wellbeing throughout the course of the disease process. Spirituality appears to be dynamic, and it may shift in multiple directions directly related to the individual's and/or family's beliefs and coping mechanisms. Because spirituality is an important resource, nurses should assess the patient’s and family’s spiritual needs, their ability to cope successfully, and their knowledge about spiritual changes that may occur throughout the disease process.

DATA COLLECTION AND ANALYSIS

The study is a qualitative study based upon the research tradition of phenomenology. A phenomenological study allows the participant to describe their lived experience and is appropriate to address caregivers’ possible spiritual changes in relation to their cancer diagnosis from the individual’s point of view. Participants were recruited from a local hospice agency. Eligibility requirements included participants must be 21 years of age or older, caregiver of a cancer patient, and English speaking. After study approval by the university research review board, all participants were asked to sign an informed consent form prior to the study. The informed consents were either given to the participants during a home visit made by hospice staff and directly returned to the researcher, or they were mailed to the participants to sign and return to the researcher.
with a self addressed and stamped return envelope. Semi-structured interviews using an interview guide were conducted for 7 participants during the fall semester of 2007 and spring semester of 2008. Questions guiding the study focused on understanding the impact of cancer on the participant’s life, his or her meaning of spirituality, and the resources the caregivers’ spirituality provided. The questions were designed to be open-ended and to promote in depth responses to better understand the spiritual phenomenon in caregivers of cancer patients. All interviews were conducted via telephone to provide for convenience and comfort. All information was tape recorded and transcribed verbatim. Data from the semi-structured interviews was carefully analyzed in the spring semester of 2008 using content analysis and organized into dominant themes.

Each participant also received the scientifically valid, self administered 20 item Spiritual Well Being Scale to complete and return to the researcher. It is a Likert type scale with 20 items used for measuring spirituality. The scale has high reliability, and good validity. Most importantly, the scale measures both Existential Well Being and Religious Well Being. This design is useful for any participant, including those who may not seek religion or God as a spiritual source of satisfaction. Copies of the Spiritual Well Being Scale were purchased from its authors along with a research packet describing scoring and interpretation. Because of such a small sample size, the Spiritual Well Being Scales were not able to produce sufficient and valid data for analysis at the current time.

RESULTS

Spirituality Definition

Because spirituality is subjective and intangible, as anticipated, it is difficult to find a definition that was reflective of the population as a whole. When asked to define
the term spirituality, the participants gave varied responses that reflected their personal interpretation. Most defined spirituality as an active state of being within themselves that brought positive returns in their lives. Words used to describe the term included “feeling”, “essence”, and “well-being”. Yet, while many stated that in their opinion spirituality was a personal, inner aspect, others described their source of spirituality to be “greater” and “higher” that anything contained in themselves. In addition, while all participants mentioned God at least one time during the interview, only two participants directly linked their spirituality to God. One participant described her spirituality as follows: “It offers a whole lot that the world just can’t give. Money can’t buy, it isn’t something that you go and search for and find it in someone else. It’s just something you get from God.”

Two of the seven participants believed that spirituality was the same as religion, with one stating that “Well, if you’ve got the Lord in your hear, you’re spiritual.” In contrast, other participants viewed spirituality as set apart from religion. Religion was described as a “duty” and another participant stated, “In many cases, religion is a church doctrine you have to follow, and spirituality is a comfort level that you find on your own, regardless of what religion it is.” The interpretations of spirituality and its relevance to religion are consistent with Dossey’s (1989) definition of spirituality which state that it is “a broad concept that encompasses values, meaning, and purpose…existence of a quality of a higher authority…and may or may not involve organized religion” (p. 24).
IDENTIFIED THEMES

Each semi-structured interview was transcribed verbatim. Data was clustered and grouped according to content. Five dominant themes were recognized using comparative analysis.

A Time to Talk

The need for communication was a dominate theme identified during the research analysis. Communication methods varied for participants. Many identified prayer as a strong spiritual support in their lives. It is during this time of communication with God that the participant transcends the boundaries of earth and reaches for a higher Power that extends beyond physical parameters. Some used prayer as a powerful tool that provides them with a greater sense of belief and a greater feeling of security. One participant described the effect of prayer in her life: “...it allows me to believe when something is so saturated in prayer, I can let go of being worried about it, because you know, what works out is in keeping with God’s plan.” In addition, prayer provided a time of fellowship for the caregiver, the care receiver, family, friends, and ministers. The time could be used for extending thankfulness, reflecting on times past, petitioning for relief for their loved one, and sharing a common love and trust. One participant vividly recalled prayer as an expression of love for her father when she completed his prayers for him when was too weak to finish his petitions before the Lord. Four of the seven caregivers interviewed responded that the use of prayer would be a priority in advising others in similar situations.

Not only was communication with God important, but identifying an earthly confidant who listened as they expressed moments of frustration and worry and
celebrated daily joys and blessings was beneficial for individuals in the caregiving role. One participant discovered the ability to find comfort in talking with other caregivers, and another stated that solace could be found with anyone, not just those who have experienced similar situations. For example, one caregiver expressed: “And you feel like you’re not being fair to the patient you’re taking care of, but you know, sometimes you get frustrated and you need to VENT, and you don’t want to vent to them.” The statement indicates that caregivers encounter emotions related to the caregiving experience that they feel is inappropriate to express openly, but may be expressed in prayer or to another trustworthy source as a positive spiritual or emotional coping resource.

Strengthening Relationships

Because of the relationship to the cancer patient, caregivers often experience the same emotional burdens, pain, and confusion and the contrasting joys and victories they perceive. In the later stages of the disease as cancer progresses, caregivers may also be exposed to the uncertainty and mysticism surrounding uncertain prognosis and pending death. A sense of love was strongly expressed by the participants that appeared to fuel their dedication and service to the care receiver. One participant simply stated, “You just love one another more. And there wouldn’t be a thing in the world I wouldn’t do for my husband.” Other participants also demonstrated devotion mixed with love. One participant recalled a special moment she had with her father.

He used to sit down and talk to us before he got real sick. He said, If it wasn’t for y’all I wouldn’t know what to do. And like I told him, I said, Daddy, we told you we’d be there till the end.
It was through the love and devotion that the participants were able to focus on the task at hand and offer themselves to the one in need of their affection and assurance.

Not only were physical relationships strengthened, but a greater spiritual strength was attained through the caregiving experience according to five of the participants. One participant found that her spirituality provided her with direction. "...the spiritual side is stronger and stronger, because I got a good view of how things are gonna be." Another gained inspiration from looking at her mother's spiritual level. She states, "You know her faith in God... strengthened ME." The other two participants stated there was no change in their spiritual level. Reasons given for a non-changing spiritual condition included previous care giving experiences that allowed insight to the situation and considering one's self to be a strong person presently existing in a stable spiritual state of being. None of the participants reported a decrease in spiritual levels or faith in God.

Three caregivers viewed the caregiver position in terms of a sacrificial relationship. One caregiver paralleled her position to the role of Jesus Christ. Another considered the caregiving role relevant to a parent/child relationship, viewing herself as returning the gift of care she received as a child. A third caregiver viewed the relationship as a combination of the two relationships previously listed. One participant describes that one of the reasons for caregiving is not simply tied to emotions, but it reflects a duty. She states the following:

...I'm not just doing it to be nice, that I'm not just doing it because I love my husband, which both of those things are true, but I'm also doing it because I believe that we are here to take care of each other, to be the hands and feet of God and Jesus Christ...
The caregivers' role is transformed as an overseer and protector to one who may be in a vulnerable situation and may not be capable of providing self directed care. It is in this light that a caregiver's role can be compared to that of Jesus Christ or of a parent.

Blessed Assurance: Coping with the Uncontrollable

All of the participants positively commented on the resources their spirituality provided for them. Three concepts mentioned repeatedly include peace, comfort, and guidance. Several of the caregivers actually used “peace” and “comfort” in their personal definitions of the term spirituality. One participant stated, “It gives you peace in your heart and mind...” Activities that provided assurance to the caregivers included prayer, privately and with groups, and reading the Bible. Three participants mentioned having peace and acceptance concerning the fact that their lives are not controllable beyond the moment that is being given to them. This concept is explained further by the following statement:

...I can not talk about any physical disease without looking to Jesus Christ and spirituality, because, you know, something’s gonna get us all...it’s not like we’re somehow going to escape, and I think it’s important to know that once you receive what you need to be prepared to stand before God, then everything else you can manage.

Guidance was also a positive resource spirituality provided in addition to peace and comfort according to one participant. “I tell you what, peace and comfort, and then too it always gives me like a sense of direction, when I just don’t seem to know, it’s like guidance.” The concept of guidance may be particularly important for caregivers of hospice patients. The caregivers are often surrounded in situations where neither they nor
the care receiver have a sense of control. This situation intensifies as the final life processes draw to an end as in the case of hospice patients.

Concept of a Sacred Caregiver

An important concept largely expressed by the caregivers revolved around understanding that a higher Power, namely God, was providing protection, guidance, and care to their spirit while they fulfilled their roles of caregiving. Ultimately, many caregivers resigned worries and decision making to their Lord. Placing trust in Him, did not indefinitely mean finding answers but finding peace. One participant stated, “...what I’m sad about is I can’t do nothin’ about it. I can’t snap my fingers and make her well. If I could, she wouldn’t even be sick. But then, that’s when I rely on God for more.” Total reliance and an understanding of love is evident in another comment made by one caregiver. “...you love the Lord and the Lord loves you and He’s gonna take care of you and help you through all your trials.” Trusting in God for protection and guidance as a child would a parent allows the caregiver to relax and redirect worries and concerns to another source rather than being personally weighted down with uncertain situations that can cause fear and worry.

Spiritual Nourishment vs. Starvation of the Soul

During the interviews all of the participants openly spoke of the support they have received from hospice services. When asked about nursing spiritual care, one participant stated she was unsure if nurses provided spiritual care to her loved one because she was unable to be present when nurses made visits. Other participants stated that the nurses they encountered through hospice were “real nice” or had “comforting” words to say
concerning spiritual topics. Another caregiver participant described the nurse as "just always a-smilin' and real helpful" and considered that to be practicing spiritual care.

When asked if one caregiver felt like her father had been provided with spiritual care before hospice services, she stated "...I can't say anybody did." In addition one participant described that finding caregivers who address spirituality in a "sterile medical setting" was a "godsend and gift" and often medical professionals "treat the physical body and the poor little soul lies suffering."

Two participants questioned legal issues related to nurses providing spiritual care such as praying with patients. One acknowledged nurses had to be "careful" when speaking of spiritual issues and the other stated "Of course, I know like school teachers and things can't do stuff, and I'm thinking maybe they can't either."

As the disease process intensifies, some participants stated their faith and spiritual beliefs allowed them to view circumstances differently from the medical professionals. A caregiver stated, "...I realized the word of man is not truth, but God will reveal what is true..." and advised "Do not put your trust in what the doctors or medical professionals say." Another statement made by a caregiver describes her family's response to medical opinion, "But the doctors are not giving him any kind of hope. They keep saying he's dying, and he keeps saying No, I'm not." Spirituality may prove to be a great source of comfort and encouragement, especially during times when medical advice seems to permeate with hopelessness and negativity. It is in these delicate moments that medical professionals, particularly nurses, have the opportunity to nourish the soul that may be in more pain than the physical body.
INTERPRETATIONS AND IMPLICATIONS

Because of the varied and personal interpretations and concepts of spirituality, it is important for the nurse to individually assess spiritual needs in their clients and caregivers. Based upon the participants’ responses, confusion of spiritual care and religious practices continue for families coping with cancer. This may cause some families to refuse spiritual care or may impede nurses from fully assessing for spiritual distress or pain. Further, some caregivers may not completely understand the nurse’s role as a provider of spiritual care and may think it is legally prohibited for nurses to speak of spiritual elements and or initiate spiritual activities that may provide comfort to the client and the caregiver. In contrast, some caregivers consider spiritual care to be implemented by simple acts of kindness, having a cheerful disposition, and displaying a helpful attitude.

The identification of communication as a key element in coping with the stresses of caregiving was an important component of spirituality. Communication included the use of prayer and finding individuals to confide in with faith and assurance. Because of this, Christian or spiritual support groups for cancer caregivers may be beneficial in providing spiritual encouragement and helping families to cope with the stresses associated with caregiving.

Each participant spoke of the intangible gifts and resources that their spirituality gave them and/or their loved one. Dimensions of spirituality including peace, comfort, and guidance allowed the participants to have strength, reassurance, and inward tranquility regardless of the uncertainty surrounding them.
STRENGTHS AND LIMITATIONS

The study incorporated the use of semi-structured interviews, which allowed the participants to openly express complicated views and concepts related to spirituality and caregiving. This format also allowed for in depth and detailed responses that is difficult to measure with scales and numbers. The caregivers were also eager to participate and displayed enthusiasm during the interviews about sharing their personal views of spirituality and their caregiving experiences.

Limitations to this pilot study included a small sample which may not have equally represented the views of all caregivers of cancer patients. In addition, the use of a designated chaplain as a recruiter may have excluded certain categories of people. Caregivers and their families who seek a chaplain’s services may be more aware of spiritual needs and inclined to seek spiritual or religious sources rather than caregivers and receivers who do not seek religious sources for spiritual well fare. Lastly, because all information gathered was subjective data, the risk of transferability was increased during the analysis process.

CONCLUSION

From the description of the role of spirituality in their caregiving experience, for many participants, spirituality seemed to provide beneficial resources as they provided care for family members with cancer. As the literature review revealed, issues of spirituality and holistic care may not always be provided within the medical setting. This pilot study supports the need for additional research to more fully assess the issues surrounding the definition of the complex concept of spirituality, methods of evaluating spirituality, and the most effective support or spiritual care given by nurses and other
medical professionals. One participant described her hospice experience as “a caring and sharing time filled with spirituality”, a description that could be implemented across all treatment settings in healthcare to maximize support during a health crisis regardless of the family and patient’s religion or type of illness.

ACKNOWLEDGEMENTS

Without the faithful and patient assistance of Dr. Linda Riley, faculty member, mentor and Honors Program sponsor at UAH College of Nursing, the creation of this research project would still be entrapped inside my thoughts. Many thanks to Dr. Pamela O’Neal, Associate Dean at the UAH College of Nursing, for her approval and steady encouragement during the research process. Lastly, thank you to the administration and staff at the hospice agency used in this project, with a special thanks to Mr. Anthony Ford, who acted as the wheels of my “research wagon” and allowed it to begin moving through his recruitment efforts.
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