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Deriving Meaning and Faith in Caregiving

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Abstract

Objectives—To review assessment of spiritual needs of family caregivers and four core interventions by nurses in addressing spirituality: presence, deep listening, bearing witness and compassion in action.

Data Sources—Literature review.

Conclusion—Spirituality is increasingly recognized as a key domain of quality of life and essential to quality cancer care. In addition to the needs of patients, family caregivers also experience enormous spiritual needs throughout cancer diagnosis and treatment. Nurses can provide valuable spiritual assessment of family caregivers and support them as they seek support services to address spiritual needs.

Implications for Nursing Practice—Family caregiving can be a time of growth and meaning when support is provided by nurses and their colleagues.

Keywords

Spiritual care; spirituality; family caregiver

Family members and others providing care and support to the person with cancer have been recognized as vital throughout the trajectory of disease. Over the past three decades, oncology nurse-researchers have contributed significantly to the evolving recognition of the experience of the oncology caregiver.[1–8] Many nurse researchers, including contributors to this issue of *Seminars in Oncology Nursing*, have documented the psychological, social, and physical aspects of family caregiving unique to cancer. However, there has been less attention to the spiritual well-being of family caregivers and even less focus on the positive aspects of caregiving such as by deriving meaning and strengthened faith in caring for a loved one with cancer.

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Research and Evidence Supporting Spiritual Care for Family Caregivers

Numerous studies have described the psychological experiences of family caregiving and common issues of depression, anxiety, living with uncertainty, and the anticipatory grief of family care-givers.[4–7] This body of literature has provided the evidence for development of care for family care-givers, including support groups, Web sites, written materials, peer support, and counseling services. Beyond these emotional needs, there are also profound spiritual needs as caregivers wrestle with their faith, their ability to believe in a God or higher being who could allow cancer in a loved one, the experience of witnessing pain and suffering, and the struggle to maintain hope and faith when life now includes one of the most dreaded threats to life, a cancer diagnosis.

Regardless of the ultimate outcome of the cancer, whether in early stage disease with excellent prognosis, a cancer with chronic treatment but long-term survivorship, or in terminal disease, one's faith is tested and spiritual needs are an important part of the whole-person support of family caregivers. The National Consensus Project for Quality Palliative Care developed clinical practice guidelines for the emerging field of palliative care,[9] a field with significant application to oncology. The eight domains of care (Table 1) include the spiritual domain, as well as a domain devoted to family members. Thus, quality palliative care is possible only when attention is provided to spiritual and existential concerns, including the concerns of family caregivers.

In 2010, researchers at the City of Hope National Medical Center (Duarte, CA) collaborated with colleagues from George Washington University Institute for Spirituality in Health (Washington, DC) to create recommendations through a consensus process to improve the quality of spiritual care in palliative care.[10,11] One contribution of this consensus conference was development of a definition of spirituality[10]:

> "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred."

This definition can be applied to oncology patients, but also to family caregivers. The definition is important in recognizing that spirituality extends beyond religion and encompasses a broad range of existential concerns. The definition also suggests that illness experiences, for patients or family care-givers, offer opportunities for meaning and growth.

Assessment of Spiritual Needs of Family Caregivers

Chaplains are the spiritual care experts and an invaluable support to oncology nurses. Chaplains offer skilled spiritual assessment and screening, spiritual care intervention, bereavement support, rituals, and many other forms of care for patients and families. However, in most cancer settings, there may be only one chaplain position or even less than a full-time chaplain devoted to an entire oncology service. This is also often limited to the inpatient area and for a limited number of hours per day. Oncology nurses are often in the position of responding to spiritual needs and in identifying which patients and families are in greatest need of chaplaincy support. Table 2 includes examples of screening questions that may be useful to oncology nurses in communication with family caregivers.

Clinical Application of Spiritual Care

Given that in most medical settings chaplains are few in number, it is all the more important that oncology nurses have, at the very least, a strong, basic understanding of spiritual care. Nurses are often called upon and expected to provide such care in the absence of trained chaplains. It is easy to understand how oncology nurses might feel uncomfortable or even

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inadequate in providing spiritual care, especially if it is defined only in religious terms. While religious care is most definitely an important part of spirituality, it is only one of the many ways spirituality is expressed. The family caregiver's religious concerns and questions are clearly in the chaplain's domain and should be left to the expertise of the chaplain.

Applying the consensus conference definition of spirituality, spiritual care supports family care-givers in their process of seeking and expressing meaning and purpose, and also in their relationships and in their connectedness.[12] Spiritual care addresses the thoughts, feelings, and experiences of being human. It is about being in touch with one's own humanity and about touching the humanity of others.[13] Addressing spiritual care from this perspective can take some of the mystery out of this domain and make it more understandable, accessible, and perhaps ultimately easier to provide.

Foundation of Spiritual Care

As previously stated, many spiritual issues must certainly be addressed by trained chaplains who have experience and expertise in the area. There are four core interventions that form the foundation of spiritual care: presence, deep listening, bearing witness and compassion in action.[14] These essential interventions can be provided by anyone with willingness, practice, and self–awareness.

Presence

Being present is more than just walking into a room. It means being fully and completely in the room – body, mind, and spirit. True presence includes awareness of one's preconceived ideas, personal biases, and judgments. Presence does not require those ideas, biases, and judgments to disappear or go away; but rather realize and acknowledge that they exist.

To be fully present means leaving all other patients, caregivers, job responsibilities, and personal issues at the door.[15] It means unconditional, undivided attention, appropriate body language, and earnest eye contact. Spiritual care cannot take away a caregiver's pain and suffering, but it can provide an authentic connection to another human being that may ease the sense of distress and isolation so that the caregiver might feel more supported and can, perhaps, in the midst of that compassionate support, find meaning and purpose in the experience.[16] Genuine presence provides the kind of care that the spirituality definition alludes to: "Spirituality is the aspect of humanity that refers to the way individuals… experience their connectedness…to others…".[17] To be fully present sends the message that the nurse truly, compassionately cares. Being fully present is a spiritual intervention that can be provided by any member of the health care team at any time.

An example of presence with family caregivers would be the following. Mrs. James is a 65-year-old very beloved mother and grandmother. She was admitted to the hospital for a breast biopsy for suspected recurrent breast cancer. Mrs. James and her four adult children have been very optimistic that the biopsy would be benign as she has been disease-free for 10 years and has been in excellent health. An hour ago, Mrs. Jones learned that her biopsy was positive for recurrence and she is now in Radiology undergoing further scans. It is late evening and Mrs. James' three sons have gone home to their families; but her youngest child, a single daughter, remains in her room waiting for Mrs. James to return. The nurse enters the room and sees her daughter Dora quietly sobbing. The nurse, Joe, quietly closes the door, sits next to Dora and gently holds her hand, silently offering his presence and support.

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Deep Listening

An elderly woman lived at home with her husband of 45 years. She was dying and on hospice care. Her husband, a deeply religious man, was unable to discuss his fear and sadness at the prospect of his wife dying, unwittingly used his faith as a weapon against his wife. Whenever she would get close to expressing any genuine feelings about her situation or condition, his response was always the same; to interrupt her, admonish her to pray, tell her God would take care of it and she would be fine. The wife would quietly cry and walk away.

Discussing the patient one afternoon, both the hospice nurse and chaplain felt there was something the patient was trying to tell them even though she would always report she was "fine." It was obvious she could not be honest about her feelings with her husband in the room. The nurse and chaplain made a joint visit to the couple's home. The nurse took the husband into the kitchen so the chaplain was finally able to talk with the wife alone. The woman was able to say what her husband could not bear to hear, that she was dying soon and needed to see their daughters who lived 500 miles away. The woman and the chaplain were able, together, to tell the husband what was really happening and he was finally able to listen and hear the news his wife had been struggling to express. Their daughters were able to spend time with their mother and father before her death.[18]

The second core spiritual intervention is deep listening. This husband could not, for a time, even bear to hear the words. Likely, he suspected what he might hear and chose not to listen. On the occasions she did try to tell him her fears, he redirected the conversation to something he could deal with – his faith. While the woman continually reported to the hospice staff she was fine, deep listening and a compassionate presence allowed them to understand there was something she was not saying and implored them to explore further to find out what was behind the inordinate sadness of this wife and mother.

Deep listening is more than just hearing the words and being able to recite them back. It is about hearing what is said and what is not; the intention behind the words. These spiritual interventions of being fully present and listening deeply can help to create a space of support and trust so that the family caregiver might be encouraged to express honest feelings and perhaps explore ways to find meaning and renewed faith.

Bearing Witness

Life includes both crisis and joy - airplanes crashing into buildings, a tsunami, a cancer diagnosis, a grandchild just born, a long-overdue promotion, or graduation from college. When profound and even mundane events occur in life, we often rush to the phone, get on the computer, or run next door to share the news; the good and the bad. The third spiritual intervention is bearing witness.

Bearing witness requires active participation on the part of the witness, and at the same time, caution. Watching the pain and struggle of another can be a difficult task. In an effort to alleviate the suffering of patients and caregivers, as well as our own, a frequent response is to offer suggestions to "help" or "fix" the distress. "In the Service of Life," an article written by Rachel Naomi Remen, MD, tells of the differences between "helping"/"fixing" and "serving." "Helping is based on inequality; it is not a relationship between equals. When you help, you use your own strength to help those of lesser strength." "When I fix a person I perceive them as broken, and their brokenness requires me to act." Serving, however, is about seeing the "wholeness" in the other. "When I serve I see and trust that wholeness." "Service is a relationship between equals."[19]

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Bearing witness is a spiritual intervention and an act of service. It is not about changing the situation or fixing the other person. To bear witness is to "be with" another person and what she is experiencing. To bear witness is to "compassionately accompany another" on his journey (J. Halifax; personal communication, 2008).

It can be quite difficult to bear witness to another's suffering. It can seem an impossible task if that witness goes into the encounter unprepared. Every person has experienced pain, loss, and grief. If a nurse has experienced such great pain and loss, perhaps multiple times, and has cast those feelings aside without acknowledgement or introspection, it is unlikely that she would be able to be in the company of anyone else's pain and grief without it tapping into her own. It is not uncommon to hear an exchange between a patient and caregiver that sounds something like: "It feels like the cancer is winning. I don't think I have much longer to live." To which the response from the caregiver, either professional or family, is: "Now stop talking like that. You're going to be just fine. Just do what your doctor tells you and you'll be back on your feet in no time. No more negative talk!"

It can be very distressing to listen to someone talk about raw emotions and real fear. Although quite unconsciously, the caregiver often derails the patient's desired conversation because the topic touches the caregiver in ways that are painful. Even years of nursing education and experience are not enough to keep the oncology nurse from wanting to avoid difficult conversations with patients and families. Nurses are human beings who have their own lifetimes of emotional hurts and needs. Until professional caregivers attend to their own grief and loss, it is very difficult to sit with others in the midst of their pain and suffering without wanting to run from the room, change the subject, or emotionally "check out" of the conversation. Such responses are not a part of bearing witness.

Compassion in Action

Presence, deep listening, and bearing witness are powerful interventions that can often be all a family caregiver needs to feel spiritually well-supported. At times, however, during the process of providing these interventions, it can become evident that there are other interventions, perhaps more tangible and concrete, that might be equally beneficial.

Certainly, the nurse can make a referral to the chaplain who can then assess the spiritual needs of the family caregiver. The chaplain can then provide spiritual care and/or make a referral to community clergy if the caregiver might benefit from such support.[20] However, in addition to the chaplain, or in the absence of, the nurse is in a prime position to attend to some basic spiritual needs.[21] These fundamental spiritual interventions are simply about being human.

A patient's wife who was adamant about staying at her husband's bedside and had not eaten all day was very pleasantly surprised and grateful that a compassionate and attentive nurse arranged for dinner to be delivered to her in her husband's hospital room. A night nurse makes it her mission to serve tea to family members who sit wakeful vigils. It is her gentle way to say, "I see you. I see what you are going through. I care." For days, a worried husband was unable to make contact with his wife's doctor. His voicemail requests went unanswered and the husband and the doctor were never in the hospital at the same hour. With so many questions and concerns, it was his wife's nurse who was finally able to make a face-to-face meeting happen. During a conversation with the daughter of a patient, a nurse discovered the daughter's husband had recently died. The nurse called in the social worker and the chaplain to provide psychosocial, spiritual, and grief support. There are endless ways for nurses to provide spiritual care for caregivers. Table 3 includes several resources for nurses related to spiritual care.

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Conclusion

The impact of cancer affects more than just the person whose body it inhabits; it affects the whole family. From the time of diagnosis and the beginning of treatment there is a great deal of focus on the patient's physical, mental, emotional, and spiritual needs. The needs and adjustments of the caregiver, whose life has also been radically altered with the diagnosis, are greatly increased as well.[22–25] Spiritual intervention can make a positive difference in a caregiver's life and cancer experience. Presence, deep listening, bearing witness, and compassion in action are four simple, though not always easy, spiritual interventions that can be readily provided by the oncology nurse who has a desire to be a compassionate presence for patients and their family caregivers.

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TABLE 1

Clinical Practice Guidelines for Palliative Care

Domain
Domain 1: Structure and Processes of Care
Domain 2: Physical Aspects of Care
Domain 3: Psychological and Psychiatric Aspects of Care
Domain 4: Social Aspects of Care
Domain 5: Spiritual, Religious, and Existential Aspects of Care
Domain 6: Cultural Aspects of Care
Domain 7: Care of the Imminently Dying Patient
Domain 8: Ethical and Legal Aspects of Care

Data from www.nationalconsensusproject.org.

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TABLE 2

Potential Screening Questions to Assess Spiritual Needs of Family Caregivers

1	Is religion or spirituality important to you as you provide support for your loved one with cancer? How has your spirituality changed since your loved one's diagnosis of cancer?
2	Are you or your loved one a part of a faith community or do you have a minister or other clergy available to you?
3	How has your faith or spirituality been of support as you have faced other challenges or in facing the cancer in your loved one thus far?
4	We recognize that often family caregivers' spirituality may be similar to or very different from the patient's spirituality. Are there spiritual needs you have as a family caregiver?
5	Many family caregivers tell us that while caring for a loved one with cancer is very difficult, caregiving can also be a very meaningful experience. What has it been like for you?

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TABLE 3

Resources for Oncology Nurses Related to Spiritual Care

Websites:

City of Hope Pain & Palliative Care Resource Center

http://prc.coh.org/Spirituality.asp

The George Washington Research Institute (GWISH) for Spirituality and Health

http://www.gwish.org/

Passport to Comfort: Reducing Barriers to Pain & Fatigue Management #27 – City of Hope, Duarte, CA

- This model addresses patient, professional and system barriers to the relief of pain and fatigue and is based on established guidelines developed by the National Comprehensive Cancer Network (NCCN). An NCI supported program. Most available in English and Spanish.
- Patient Spiritual Care Card http://prc.coh.org/Barriers/Patient%20Spiritual%20Care%20cards.pdf
- Spirituality Card http://prc.coh.org/Barriers/Spirituality.pdf

Association of Professional Chaplains

http://www.professionalchaplains.org

Books:

Making Health Care Whole: Integrating Spirituality into Patient Care

Puchalski, C. M., & Ferrell, B. R. (2010). PA: Templeton Press. ISBN: 9781599473505.

The Nature of Suffering and the Goals of Nursing

Ferrell, B., & Coyle, N. (2008). NY: Oxford University Press. ISBN #: 9780195333121.

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Puchalski CM, Lunsford B, Harris MH, et al. (2006). Interdisciplinary spiritual care for seriously ill and dying patients: A collaborative model. *Cancer Journal, 12*(5), 398–416.

Other Resources:

Fast Facts and Concepts – End of Life/Palliative Education Resource Center (EPERC), Milwaukee, WI

- Taking a Spiritual History
- Music Therapy
- Physicians and Prayer Requests
- Pain, Suffering and Spiritual Assessment

Available at: http://www.eperc.mcw.edu/EPERC