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#### September/October 2011 Issue

**Spiritually Sensitive Hospice Care** By Ann M. Callahan, PhD Social Work Today Vol. 11 No. 5 P. 24

Spiritually sensitive hospice care occurs through patient relationships with staff who can discern, assess, and help meet patients' spiritual needs at the end of life.

It is common for patients in the United States to rely on religion and spirituality to help them cope with terminal illness. Even if a patient is not religious or a spiritual person, spiritual needs can be just as important as other needs at the end of life. Providing spiritual care can help a patient regain a sense of purpose so spiritual healing can occur before death.

Providing spiritual care is often reserved for a patient's religious leader, volunteer clergy, or hospice chaplain. Nevertheless, there are times when a patient and his or her family need ongoing spiritual support, particularly when a spiritual care provider is not available or a patient refuses referral for spiritual care.

Hospice care and related providers typically rely on the helping relationship to facilitate patient comfort at the end of life. The provision of spiritual support is one aspect of this relationship, so it is important to consider what aspects of the helping relationship can be spiritually supportive. The concept of spiritual sensitivity lends insight into this form of care.

In Spiritual Diversity in Social Work Practice: The Heart of Helping, Canda and Furman describe spiritual sensitivity as "a way of being and acting throughout the entire helping process." This concept has been extended in this article to include spiritually sensitive hospice care, which is relative to a hospice worker's ability to enhance patient life meaning or spiritual well-being.

Excerpts from a recent survey are used in this article to explore what it means to provide spiritually sensitive hospice care. Sixteen nonpastoral hospice workers with at least six months of hospice experience volunteered to participate in a semistructured telephone interview lasting 45 minutes to an hour. Almost all respondents had a Christian religious orientation. The majority were female and worked full time. About one-half of the respondents had an undergraduate degree and one-half had a graduate degree. There were slightly more respondents employed as social workers than those employed as nurses, with two being in another type of position. The median number of years of professional experience was 12 with five years of hospice experience.

Survey results suggested spiritual sensitivity was relative to the worker's ability to prepare for providing spiritual care, assess patient readiness to address spiritual needs, engage patients in spiritual assessment, discern patient spiritual needs, refer patients to a formal spiritual care provider, and communicate spiritual sensitivity through interpersonal support.

# Worker Preparation for Spiritual Care

Spiritual sensitivity began with some staff preparation to provide patients with spiritual care. Some used personal prayer to help with being more open to the spiritual needs of patients. One respondent said, "I ask the Lord to be my voice, give me the words, and help me discern what my patient needs."

# Ability to Assess Patient Readiness

Spiritual sensitivity further involved a respondent's assessment of a patient's readiness to address spiritual needs. One respondent described the reaction of a patient who was not ready to discuss spiritual needs. The patient said angrily, "I don't want to hear anything about that God stuff. Don't bring that God stuff in my residence again." The patient continued to be irate despite the respondent's apology.

Another respondent found some patients would shut down during efforts to discuss spiritual







needs, which led to a more cautious approach partially due to the hospice worker's freedom to take more time to assess patient readiness and conduct a spiritual assessment. The respondent said, "I try not to intrude or overstep those boundaries." The respondent would invite patients to talk about spiritual needs when they felt comfortable and would "go where they take me."

#### Ability to Engage in Spiritual Assessment

Respondents suggested using simple language to begin a spiritual assessment. This style was compared with a "back-porch conversation" where you "ask the right questions to get the patients more comfortable ... until they begin to open up." This can lead to the hospice worker being able to ask more specific questions of the patient.

One respondent explained, "I ask patients what their religious affiliation is when I first admit them. We always write down what church they go to and who their religious leader is. If they say that they don't go to a church but have a particular religious affiliation, then I ask, 'Do you have a relationship with a pastor or priest?'

Then I inform them that we have a grief and bereavement counselor. I explain that he is not here to preach to you; he gives you ways to deal with what you are going through. Sometimes I will ask them, 'Where do you draw your strength from?'"

Spiritual assessment was the most basic form of spiritual care delivered by hospice workers. Respondents indicated that spiritual assessment questions were integrated into admissions and other paperwork maintained in the patient chart for reference. It was not uncommon for respondents to return to spiritual assessment questions when spiritual needs emerged.

#### Ability to Discern Spiritual Needs

Spiritual sensitivity was also indicated by the ability to discern spiritual needs as in the following account:

"When people are told they are going to die, they work toward accepting that so when the dying is prolonged, it gives patients a longer time to think about what they have done in life. A lot of times they begin to think 'I must have done something wrong. God must be punishing me. Why is it taking so long to die? What have I done? There must be something wrong with my faith because now I am scared to die.' When people have died, we close the doors to prevent people from seeing the mortuary workers coming in to remove the body. The patients realize why those doors get shut. One woman told me, 'If I leave and go home, maybe I will not die.'

Others have said, 'I know the lady across the hall died because I don't hear her anymore.' They become aware that the other residents are dying and have to sit with the anticipation of their own death. It is a very trying thing to sit with that."

Another respondent said some patients miss being part of their church congregation, "engaged with the body of believers weekly." When church members stopped visiting, the respondent said these patients felt "completely abandoned."

# Ability to Refer for Spiritual Care

Spiritual sensitivity further required the ability to recognize the need for patient referral to a formal spiritual care provider as indicated here: "If they say, 'I don't have a religious affiliation' or if they say, 'Oh, I believe in God,' I usually back off, especially if they say this upon admission. I just don't get into that seriously. I leave that to our chaplains because that is their specialty. I report back to them, 'This is what the patient said to me' and they know how to approach people with spiritual needs."

The provision of formal spiritual care usually involved referral to the patient's religious leader or hospice chaplain; however, there were times when patients refused referral and requested the respondent to provide spiritual care. This required providing of informal spiritual care, which involved the communication of spiritual sensitivity through interpersonal support.

# Ability to Communicate Spiritual Sensitivity

The communication of sensitivity through interpersonal support consisted of nonclinical and clinical interventions. These interventions were often combined in the process of providing spiritual care. Nonclinical interventions included recognizing patient personhood, being present, therapeutic touch, singing, and listening.

• Recognizing personhood: In recognizing personhood, respondents said it was important to "see beyond" a patient's illness and relate to the patient as a person. One respondent described it like this: "I was at a patient's home a few weeks ago. He did not have much to say. I saw a hiking stick in the corner. He said he and his wife both used to go hiking. His wife said he makes those hiking sticks. I started telling him I have a grandson who is starting to whittle. The patient just came alive."

Another respondent said, "If you can just show a person that you care, that you are not afraid of the disease they have ... I go in there and give them all the love I can. It doesn't matter what their religious denomination is or how their life may have been in the past."

• Therapeutic touch/being present/listening: Respondents said compassion was also communicated "without ever saying a word" by "the gentleness of the way you turn a patient" and when you "sit in silence with the patient." This was especially important when the patient was not

alert or was unresponsive. One respondent said, "A lot of these conversations are one or two words since people may be going in and out of consciousness with the disease process. They ask you not to leave. They fall asleep in the middle of telling you something and you move a little bit and they wake up and continue what they were saying."

- Being present/therapeutic touch/singing: Spiritual care even included singing, as demonstrated by this account: "The more accepting, loving, and attentive I am, the more comfortable and open they become with me. One of my patients loves hymns so I started singing to her. The next thing I know she is trying to sing with me. She is holding my hand and wants me to keep singing. I think touch is so important so I started to rub her head. She said to me when I was finished singing, 'Just sing one more song; just let's sing one more song."
- Recognizing personhood/being present/therapeutic touch: Over time, some respondents cultivated deep care for their patients as they began to relate to one another on a more personal level. According to one respondent, "Patients need a hospice worker who is willing to let down their guard and show that they really care about them. If there is ever a time when people need someone to care, it is when they are dying. I tell them that I will be looking forward to seeing them next time. I try to extend physical contact in some way that is not uncomfortable, such as a casual patting of the arm and squeezing of the hand."

#### **Additional Interventions**

The second set of interventions associated with interpersonal support seemed clinical in nature because they required more expertise to communicate spiritual sensitivity. Clinical interventions were reframing, affirmation, self-disclosure, normalization, and advocacy.

#### Reframing

One respondent used reframing to help a patient gain new life meaning by challenging the patient to consider the impact of being a father. The respondent said, "I worked with a man who was not religious. He said, 'I have nothing.' I said, 'But you do have a daughter finishing high school about to go to college. She wants to be a pediatrician. Maybe you were not there to help your daughter when she was young, but you still had an impact on her. The world is a different place because of you."

#### Affirming/Self-Disclosure

Respondents tried to be universal in their approach but also drew from specific knowledge of a patient's faith to meet the patient's spiritual needs. In one account, the respondent affirmed patient beliefs and engaged in self-disclosure to help the patient find comfort in their shared beliefs about an afterlife: "I will use whatever the patient brings up. I will affirm it. If they are people of Christian faith and they express their faith, I will affirm my own Christian faith. I will join them as a believer by affirming them. I try to reaffirm whatever their faith has taught them. I can reflect it back to them by using the words of their own church."

# Normalization/Advocacy

In this example, normalization was used to educate family members about phenomena associated with the dying process and as a form of advocacy to ensure family members respected the patient's experience: "Many times patients will talk with family members who have already gone on. I will tell those who are concerned about the patient's behavior that it is very common. We don't know, maybe the patients are talking to their loved ones. If they see things that we do not see, that does not make it less real to them."

# Advocacy

Patient advocacy further involved the solicitation of interpersonal support for and on behalf of patients. This required awareness of the risk of neglecting patient spiritual needs and the potential for spiritual pain as seen in this example: "It was right about the end of this patient's life. ... At that time, the daughter was called in. She said, 'Daddy, don't go.' I just bluntly told her, 'Don't say that to him. Don't hold him back here like that.' She then expressed affirmation of his departure. He calmed right back down and passed. A patient will hold on for a long time until they get permission to go; that spiritual support brings them peace."

Respondents consistently reflected a profound desire to reduce patient spiritual pain. In the process, interpersonal support emerged as an integral component of informal spiritual care. As one respondent said, "We only die once. ... I do believe it makes a difference."

# The Last Connection

This study began to clarify the meaning of spiritual sensitivity in hospice care. Spiritual sensitivity required a willingness to address patient spiritual needs and ability to assess patient readiness to address their needs. Prayer seemed to help some respondents prepare to provide spiritual care. Taking time to determine patient readiness helped minimize violation of patient boundaries.

Spiritual sensitivity was further communicated through the respondents' ability to engage patients in a spiritual assessment, determine patient spiritual needs, and make an appropriate referral for additional spiritual care. Some patients refused a formal spiritual care referral, which fostered alternative spiritual care interventions that communicated spiritual sensitivity.

Nonclinical interventions included recognizing personhood, being present, therapeutic touch, singing, and listening. Clinical interventions included reframing, patient affirmation, self-disclosure, normalization, and advocacy. Clinical interventions seemed to require more expertise

to communicate spiritual sensitivity.

Study results further suggested that patients solicited spiritual care from nonpastoral hospice staff likely based on the strength of their relationship, which led to a meaningful experience for both the worker and the patient. This finding emphasizes the importance of spiritual sensitivity from any hospice staff member, as he or she could be the last one the patient talks to before passing away.

— Ann M. Callahan, PhD, is an assistant professor of social work at Lincoln Memorial University in Harrogate, TN.



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