

# Provider Difficulties With Spiritual and Forgiveness Communication at the End of Life

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## Abstract

**Background:** Due to an absence of communication training, provider responses to patient/family spiritual distress are highly variable. Assessing spiritual and forgiveness concerns are important to ensuring quality holistic care. **Methods:** Cross-sectional survey data were collected from providers attending 1 of 2 continuing education courses. The survey measured the frequency and initiation of communication about spirituality and forgiveness with patients/families, the perceived difficulty in communication across topics, and preparation and resources for these discussions. **Results:** Most participants (n = 124) were nurses followed by social workers with over half of providers having 10 years or more of clinical experience. Participants reported the highest level of difficulty in spiritual communication when talking with family after the death of a patient, followed by conducting a spiritual history with a patient. Facilitating forgiveness communication between parent and adult child, followed by facilitating forgiveness between partners was most difficult for all participants. Social workers reported much lower difficulty than nurses on all items of spiritual and forgiveness communication. **Conclusion:** The majority of participants indicated they were involved in spiritual and forgiveness communication. The most difficult communication included talking with family after death and facilitating forgiveness between patients and families. These findings support the importance of spiritual communication in clinical practice, and the need for clinician training in communicating about spirituality and forgiveness with patients and families.

## Keywords

spirituality, forgiveness, communication, palliative care, hospice, end-of-life

## Introduction

Reviewing life priorities is common when a serious, chronic, or terminal illness diagnosis is received. Reflecting on life can involve evaluating critical life events, relationships, missed opportunities, and trigger feelings of regret or the need for forgiveness of self, from others, or from God or a higher power. These topics emerge during routine patient visits and can be raised by patients and families, representing opportunities for health care providers to address spiritual or religious concerns.<sup>1</sup> Unresolved issues can cause depressive symptoms for family caregivers,<sup>2</sup> including denial, behavioral disengagement, dysfunctional coping strategies, and lower quality of life.<sup>3</sup> Among family members with lower levels of religiosity, anger or disappointment with God is prevalent and results in depressive symptoms and the belief that the patient is experiencing greater pain.<sup>4</sup> Similarly, patients who do not feel forgiven at the end of life can experience a delayed death and appear to linger.<sup>5</sup> Research has found that there are similar attitudes toward guilt and forgiveness between patients with cancer having no evidence of disease and those with advanced cancer.<sup>6</sup>

Communication about spirituality and forgiveness can aid the patient or family members in coping with illness, and conversations with health care providers are seen as a helpful coping mechanism. However, spiritual communication is commonly initiated only when the patient is terminal or the patient requests spiritual care,<sup>7</sup> whereas spiritual communication may not be initiated with patients at other points in the disease trajectory who might also benefit from psychosocial intervention. Additionally, nurses report that spiritual care providers are involved but have a limited role specific to religious rituals.<sup>5</sup> The likeliness of discussing concerns related to spirituality and

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DOMAIN 5: SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE		
5.1: The interdisciplinary team assess and addresses spiritual, religious, and existential dimensions of care.	5.2: A spiritual assessment process, including a spiritual screening, history questions, and a full spiritual assessment as indicated, is performed. This assessment identified religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family; as well as symptoms, such as spiritual distress and/or pain, guilt, resentment, despair, and hopelessness.	5.3: The palliative care service facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.

**Figure 1.** Clinical Practice Guidelines for Spiritual Care in Palliative Care.<sup>9</sup>

forgiveness with patients and families is based on the providers' communication skills and comfort with sensitive topics.<sup>8</sup>

Spiritual care is included as 1 of the 8 domains in the National Consensus Project for Quality Palliative Care (NCP) guidelines for palliative care.<sup>9</sup> The NCP defines spirituality as "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/or to the significant or sacred." The NCP Clinical Practice Guidelines for Quality Palliative Care specifies that all palliative care team members are accountable for the assessment of spiritual, religious, and existential concerns of patients and families (see Figure 1). Communication about spirituality is essential to the provision of palliative care.

Spiritual support involves presence, communication, and emotional connection.<sup>1</sup> Spiritual needs can include discussions about forgiveness and support, God and eternal life, meaning and purpose, religious literature and prayer, and a search for inner peace.<sup>1</sup> Assessing spiritual topics and forgiveness concerns are important to ensuring quality holistic care.<sup>2</sup> In the absence of a chaplain or other spiritual care counselor,<sup>10</sup> providers should be able to discuss these topics, identify appropriate internal or external spiritual support, and provide referrals.

One of the primary challenges to spiritual communication is the ability to discern and explain the difference between spirituality and religion.<sup>11</sup> It is not uncommon for new patients and families to misunderstand spirituality and thus decline a visit from a spiritual counselor.<sup>12</sup> Spiritual discussions can also be difficult for health care providers who are uncertain about when and how to approach discussions about spirituality.<sup>7</sup> Barriers to spiritual care include differences in spiritual belief systems between provider and patient, different perspectives on the importance of spiritual care, providers feeling incompetent to discuss spiritual topics, limited spiritual care training,

professionals who do not consider spiritual care as part of their role, perceived lack of time or setting for spiritual care discussions, and feeling there is little emphasis on spiritual care in the organization.<sup>7</sup>

Communication about spiritual care and forgiveness requires providers to personalize their communication approach based on the individual's beliefs and culture.<sup>13</sup> Although interprofessional education has been identified as one way to improve communication and collaboration, especially for end-of-life care discussions that involve spirituality and forgiveness, little is known about the difficulty providers have with these communication tasks.<sup>14</sup> Research has shown that physicians are often not comfortable talking about end-of-life care,<sup>15</sup> and nurses do not feel prepared for the communication tasks and needs of palliative patients.<sup>11</sup> For example, nurses report inadequate training as a primary barrier to engaging in spiritual communication and providing assistance to patients and families in seeking forgiveness.<sup>5</sup> As a result of a lack of communication training, responses to spiritual distress are highly variable, with no differences found between registered nurses and student nurses.<sup>16</sup> Nurse responses to spiritual communication include sidetracking with tangential questions, denying the patient's suffering, focusing on staff priorities rather than patient needs, providing advice, imposing a positive spin, evangelizing, and focusing on physical needs.<sup>16</sup> Still, a nurse's own sense of spirituality makes him or her more likely to provide spiritual care.<sup>17</sup> Nurses with religious beliefs that teach openness and acceptability of other creeds are more willing to engage in end-of-life conversations.<sup>18</sup> However, nurses remain concerned about whether or not they should show emotion during discussions about forgiveness.<sup>5</sup>

Overall, health care providers need additional training in spiritual communication and discussions of forgiveness,<sup>5</sup> yet little is known about what makes these conversations difficult for them. A better understanding of the range of difficulties

providers have with communicating about spirituality and forgiveness would inform future communication training, improving the likelihood of these conversations and impacting the quality of palliative care for patients and families. Using a cross-sectional survey design, we explored the frequency of provider discussions of spirituality and forgiveness with patients and families, the perceived difficulty of communication on the scope of these topics, and preparation and resources for these discussions.

## Methods

Surveys regarding communication related to spirituality and forgiveness were administered at 2 educational courses. Health care providers completed surveys prior to receiving course content. This educational activity was determined to be exempt under the institutional review board at the supporting institution.

### Instrument

The research team developed a 30-item survey to measure provider communication about spirituality and forgiveness with patients and families. First, participants were asked to report the frequency and initiation of spiritual communication with patients and family. Providers were then asked to rate the difficulty in communication across a variety of spiritual communication tasks. Ratings were provided on a scale of 0 = not difficult to 10 = very difficult. Participants were also asked to identify the greatest challenges in spiritual communication. Next, two open-ended questions afforded participants an opportunity to share what advice they were given about spiritual communication and to provide an example of spiritual communication.

To assess communication about forgiveness, participants were asked to indicate the frequency of discussing this topic with patients and family as well as rate the degree of difficulty with topics of forgiveness. Ratings were provided on a scale of 0 = not difficult to 10 = very difficult. An open-ended question was included to capture provider-recommended resources. In order to address face validity, the survey was reviewed by experts in nursing, palliative care research, and survey development.

### Statistical Analysis

Demographics and survey items were summarized using the SPSS (IBM SPSS Software Version 13.0) to produce descriptive statistics (frequency and mean scores). Qualitative comments from open-ended questions were content analyzed.

## Results

A total of 124 health care providers completed the survey, primarily nurses (76%) in the state of California (89.5%). Table 1 summarizes participant demographics. Overall, 43.5% providers reported having a managerial role. The majority of

**Table 1.** Overview of Participant Demographics.

Demographic	n (%)
Discipline	
Nurse	95 (76%)
Social worker	17 (14%)
Other	12 (10%)
Managerial role	
Yes	54 (44%)
No	66 (53%)
Not reported	4 (3%)
Geographical regions	
Northeast (Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Vermont)	3 (2%)
Midwest (Illinois, Indiana, Iowa, Kansas, Michigan, Missouri, Nebraska, Ohio, South Dakota, Wisconsin)	9 (7%)
West (Alaska, Arizona, California, Colorado, Montana, Nevada, Oregon, Utah)	111 (90%)
International (Korea)	1 (1%)
Years of experience	
1-5 years	37 (30%)
6-10 years	23 (19%)
11-15 years	17 (14%)
16+ years	45 (36%)
Not reported	2 (1%)
Type of institution <sup>a</sup>	
Home care	2 (1.6%)
Hospice	11 (8.9%)
Outpatient/Ambulatory care	11 (8.9%)
University/School of Nursing	4 (3.2%)
Hospital	99 (79.8%)
Other	7 (5.6%)

<sup>a</sup>Categories not mutually exclusive.

participants reported that they address spirituality with patients (66.4%) and family members (68.3%) up to 50% of the time and that spirituality is initiated by patient (75.6%) and family (78.9%) up to 50% of the time.

Table 2 provides a summary of the perceived degree of difficulty for communication about spirituality. Talking with the family members after the death of the patient (mean = 4.43) and conducting a spiritual history (mean = 4.23) were considered the most difficult spiritual communication tasks. Participants reported the least difficulty in talking about their own spirituality with a patient/family (mean = 2.21) and talking with team members about a patient's spiritual distress (overall mean = 2.87). Nurses reported having the most difficulty overall with spiritual communication (mean = 3.75), while social workers reported having the least difficulty overall (overall mean = 1.85). Providers representing other disciplines reported greatest difficulty defining their role in providing spiritual care (mean = 6.0) and talking about a patient's cultural background and spiritual beliefs as least difficult (mean = 2.15).

Participants were asked to report what advice they would give colleagues about spiritual communication. Advice predominantly focused on how the topic of spirituality should be part of patient/family discussions, and responses revealed

**Table 2.** Perceived Degree of Difficulty in Spiritual Communication.<sup>a</sup>

Spiritual Communication	Disciplines			
	Nurse (n = 95)	Social Worker (n = 17)	Other (n = 12)	Total (N = 124)
Talking with family after the death of the patient	4.59	3.35	3.97	4.43
Talking with patients/family members about religion	3.64	1.53	3.40	3.32
Talking with patient/family about spiritual distress (inner conflict, questioning, and anguish)	4.37	2.24	4.17	4.01
Talking with other team members/colleagues about a patient's spiritual distress	3.04	1.71	4.27	2.87
Talking about your own spirituality	2.34	1.00	2.97	2.21
Defining your role in providing spiritual care (what you are responsible for, how you do it, how it is different from other team members/colleagues)	4.32	1.53	6.00	4.05
Conducting a spiritual history or life review with a patient	4.53	1.67	5.55	4.23
Talking with patient/family about their cultural background and spiritual beliefs	3.13	1.73	2.15	2.95

<sup>a</sup>Based on a scale of 0 (not difficult) to 10 (very difficult).

contrasting perspectives. Participants noted that spirituality should be included in assessment and advised others “not to be afraid to ask” whether the patient had “religious beliefs” or “customs.” Recommended approaches ranged from asking the patient/family to describe their life views or perspectives/role of spirituality in their everyday life to specific questions such as “Do you have a religion? Do you believe in God?”

However, several responses indicated that participants advise colleagues to let patient/family initiate the topic of spirituality (“let it come up on its own”). One participant noted: “because of restrictions, let the patient/family bring it up.” Referral to a chaplain/spiritual care provider was also encouraged: “if it is beyond me, I call the chaplain.” One nurse explained that because of the enormous amount of nursing responsibilities, she felt that “this division of care should be passed on to the spiritual care and social services.”

Advice about spiritual communication also emphasized nonjudgmental listening skills and refraining from discussions about personal spiritual beliefs. Learning about the patient's story, cultural background, and life experience were offered as strategies for learning about spirituality. “Listening without judging” was emphasized to allow the clinician to be “present” and “attuned” during spiritual communication conversations that required “deep listening” that is “genuine and focused.” Silence and use of touch was recommended to accomplish “a place of commonality” and support the patient/family member's feelings. Understanding personal spiritual beliefs and being comfortable with them were highlighted as a tool for being more comfortable in discussions about spirituality with patient/family.

When asked to provide an example of spiritual communication (either that they provided or observed), only half of the participants responded with examples. These examples provided specific questions to initiate spiritual communication, including:

- How are you feeling inside?
- What gives you strength?
- What helps you to be brave? (to oncology patients)

- How did you prepare for the procedure? (to surgical patient)
- How is your spirit today? (from chaplain/spiritual counselor)
- How have you found your belief system to help you as you go through this time in your life?
- Do you have any spiritual practices? How can I support those practices?

Other strategies included presenting spirituality as a service or opportunity with education (eg, showing the wheel of health to a patient which includes spirituality), observing the bedside for any religious articles or books and recognizing that spirituality includes any practice that creates peace and comfort. Participants shared stories recounting misunderstandings between religion and spirituality that impeded spiritual communication, successful spiritual care interventions related to end-of-life care, and explicit fear in discussing spirituality with patient/family.

During patient visits and interactions with family members, the majority of participants (83%) reported addressing forgiveness up to 50% of the time. The perceived degree of difficulty with communication about forgiveness is summarized in Table 3. Among all participants, facilitating discussions about forgiveness was most difficult, especially between parent and adult child (mean = 4.86) and spouses/partners (mean = 4.73). Least difficult conversations about forgiveness involved talking with a patient after forgiveness was granted (mean = 3.45) and discussions about seeking forgiveness from God (mean = 3.86) and the patient's relationship with God (mean = 3.85). Similar to spiritual communication, participants representing other disciplines reported greater difficulty overall with forgiveness yet had greatest ease talking with the patient/family about cultural background and spiritual beliefs (mean = 3.42). Compared to social workers (overall mean = 2.47), nurses reported more difficulty (overall mean = 4.48). Of the 124 participants, only 8 responded with a self-help resource for the patient/family to help with issues of forgiveness, with the Bible suggested by 3 participants.

**Table 3.** Perceived Degree of Difficulty Communicating about Forgiveness.<sup>a</sup>

Communication About Forgiveness	Disciplines			Total (N = 124)
	Nurse (n = 95)	Social Worker (n = 17)	Other (n = 12)	
Talking with a patient/family member who is seeking forgiveness (of self)	4.43	2.19	5.00	4.18
Talking with a patient/family member seeking forgiveness from others	4.37	2.44	5.06	4.18
Talking with a patient/family member seeking forgiveness from God or a higher power	4.19	1.82	4.75	3.86
Talking with a patient/family member deciding about granting forgiveness	4.20	2.53	4.50	3.98
Talking with a patient/family member after forgiveness is granted	3.63	2.06	4.42	3.45
Talking with a patient/family member about their transgressions	4.60	2.82	5.00	4.37
Talking with a patient/family member about regret (need for forgiveness)	4.19	3.00	3.83	4.03
Assisting patient/family with spiritual searching related to forgiveness	4.61	2.30	4.17	4.19
Talking with a patient about the meaning of relationship with God or a higher power	4.26	1.82	4.46	3.85
Facilitating forgiveness between spouses, significant others, and partners	5.09	3.06	4.46	4.73
Facilitating forgiveness between parent and adult child	5.21	3.30	4.79	4.86
Talking about cultural background and spiritual beliefs related to forgiveness	4.82	2.24	3.42	4.30

<sup>a</sup>Based on a scale of 0 (not difficult) to 10 (very difficult).

## Discussion

This study provides unique findings about health care provider frequency and difficulty engaging in spiritual and forgiveness communication with patients and families. Of special importance in these findings are the identification of the most challenging tasks and topics, and the variability of difficulty between nurses and social workers. Notably, up to 50% of the time, the majority of participants experience communication about spirituality and forgiveness, with patients and families initiating spiritual matters of concern more frequently than providers. As over half of this sample of professionals had 10 years or more of clinical experience, their descriptions of difficulty represent experiential credibility fortifying our findings.

All providers identified highest difficulty communicating with family after the death of a patient. Nurses and other providers reported high degrees of difficulty conducting a spiritual history with a patient, talking about distress with patients/families, and defining the role of the nurse in spiritual care. Social workers' high communication difficulty included talking with patients/families about spiritual distress as well as their cultural beliefs. Calling upon another professional trained in spiritual care, and letting the patient or family initiate spiritual topics, dominated participant "advice to a colleague" about spiritual communication. When asked to provide an example of spiritual communication used or observed, only half of the sample responded, and those responses predominantly used a question form directed at the patient/family.

For participants, forgiveness communication was most difficult when facilitating communication between parent/adult child and spouses (partners/significant others). Just as with spiritual communication, social workers' mean difficulty scores were consistently lower across every topic area compared to nurses and other providers. Overall, the findings of this survey suggest that significant improvement in facilitating communication about spiritual distress, loss of life, forgiveness, faith/cultural beliefs, and provider role are exigent in meeting the NCP Clinical Practice Guidelines, mandating

accountable assessment of spiritual, religious, and existential concerns of patients and families.

Limitations in this study can be noted in terms of the sample's presence at an educational training for palliative, oncology, and end-of-life care practice. The providers attending likely have a predisposition to privilege spiritual care in their day-to-day practice and team work and are not representative of a range of practice settings with a less common need for spiritual care.

The spiritual care challenges identified in this study support the development of transdisciplinary training for providers including spiritual needs assessment, education, and patient/family satisfaction data collection.<sup>19</sup> Findings on spirituality support its incorporation at the health system level, with integrated oversight from nursing management to implement, improve, and evaluate the delivery of spiritual care.<sup>20</sup> Participant difficulty in communicating spirituality and forgiveness with family underscores the importance of the system to the nurse as well as social worker in caring for family. Recent work on spirituality and oncology calls for the integration of spirituality for patients and family not only at the end of life but also for those in early stages of the illness and survivorship.<sup>21</sup>

Training in spiritual care, specifically for nurses, should be more intentionally and systematically integrated into undergraduate curriculum. When integrated, it proves to benefit nurse competency and performance in spiritual care practice<sup>22</sup> and reduce uncertainty and fear surrounding the border between personal spirituality and professional practice.<sup>23</sup> Participants described education as an essential key to providing practice tools to navigate culture, religion comfort skills, and deep listening in spirituality care.

Educational interventions such as role-play, clinical simulation, communication skills laboratories, and other strategies for enhancing professional practice should be studied and integrated into undergraduate and graduate provider training. Inter-professional opportunities for chaplains and spiritual care providers to train and share expertise with other team members

has been shown to develop overall team competence in spiritual care. Training interventions should also evaluate ways to introduce spiritual care communication early in professional education and for clinicians beginning practice.

Meeting the patient's spiritual needs can increase patient satisfaction.<sup>17</sup> Forgiveness intervention research has illustrated the benefits of talking about these complex issues: improvement in quality of life, decision making, and communication.<sup>5</sup> The majority of literature and focus in palliative care have been on topics such as breaking bad news, discussing prognosis, advance directives, or treatment decisions. Yet these data and other recent literature emphasizes that spiritual care is also a critical area of communication for patients and families across illnesses and populations.<sup>24-26</sup> Spirituality is of essential importance to patients and families facing illness and loss. Quality spiritual care is contingent upon professionals who are prepared to assess and respond to spiritual needs.

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