

Shamasundar, M. R. C. (1999). Understanding empathy and related phenomena.

American Journal of Psychotherapy, 53(2), 232-245.

Shneidman, E. S. (1985). *Defining suicide*. Indianapolis: Wiley.

Yalom, I. D. (2002). *The gift of therapy*. New York: HarperCollins.



David H. Wendleton,
Therese A. Johnson,
and Renee S. Katz

Caregiving of the Soul: Spirituality at the End of Life

Introduction

For those of us charged with the care of the spirit (clergy, chaplains, and all those who integrate the spiritual into their practices), impending death often creates a desire to engage, comfort, and create safe space for “the work of dying.” For the dying person, the “work” is often about exploring the meaning of one’s life, preparing for the demise of one’s body, and depending on belief, coming to terms with the transition or annihilation of the spirit. For the dying person and the family, this work is also about legacy: what traces of meaning will be left in the hearts and actions of others?

This is heavy stuff! As spiritual caregivers in this context, our work can feel more urgent, more “important,” even critical. It can feel larger than simply addressing the perceived concerns of those for whom we care. It can feel like a yearning that emanates from deep within our being. In fact, we often hear spiritual counselors declare that this work is not just a job but a “calling.” We warn that when our work becomes simply a

means to pay the bills we should look for something else to do with our lives. Given this great responsibility and the wish to respond to the needs of the dying, spiritual caregivers may find it difficult to resist delivering the answer, the fix, the understanding, or the determined insight into the deeper meaning of our connectedness to this world.

□ Countertransference “Hooks” in Providing Spiritual Care

Subtle pressures, both internal and external, can contribute to our exaggerated expectations of what we can and should be able to do as “caregivers of the soul.” Our responses to these pressures, whether conscious or unconscious, whether emanating from within us or from within our patients (our countertransference), hold the potential for danger and for opportunity. Let us examine some common experiences and reactions that can “hook” us when we provide spiritual care at the end of life.

Recognizing the “Forest from the Trees”

Spiritual care is not synonymous with religious practice. This necessary differentiation is a constant point of tension for those of us in practice as pastoral counselors and chaplains. What is the difference between spirituality and religion? How does the difference manifest itself in providing care to our patients and clients? Dr. Rachel Naomi Remen (1988) made the following observation many years ago:

There is no place to go to be separated from the spiritual, so perhaps one might say that the spiritual is the realm of human experience which religion attempts to connect us to through dogma and practice. Sometimes it succeeds and sometimes it fails. Religion is a bridge to the spiritual—but the spiritual lies beyond religion. Unfortunately, in seeking the spiritual we may become attached to the bridge rather than the crossing over it. (p. 4)

A major concern for pastoral care providers lies in clarifying the differences between religion and spirituality, for themselves and for the patients. If we are not clear about our own beliefs, we may give a false sense of sharing the same religious beliefs and practices as our patients. We may presume to understand a particular religious stance or theological belief

and respond to patients based on our own assumptions. This can cause us to overreact or lose focus. For example:

Ann was a 65-year-old woman who was dying of cancer. Her principal spiritual dilemma was her fear that she would not see her daughter, Emily, who had committed suicide 15 years ago, in an afterlife. As a Catholic, she reasoned that if the Church does not allow burial of those who commit suicide alongside those who die naturally, perhaps Emily would also be excluded from heaven.

This fear was expressed to a volunteer from the Catholic ministries who attended to parishioners in the hospital by giving communion and joining in prayer. As fate would have it, this volunteer had experienced the loss of a family member through suicide, and she immediately moved to both reassure Ann that she would see her daughter in heaven and to debate the Church doctrine of burial. Ann quickly changed the subject by asking if the volunteer could call the nurse for her nighttime medication. The volunteer, having some recognition of her misstep, called the chaplain and explained what had occurred. The following day Ann was able to address her fears with the chaplain and, in response to gentle questions, she was able to express her long-held sadness and guilt surrounding her daughter's death. She began to mourn her daughter and the years spent yearning for one more embrace. When the chaplain left her room, Ann was more at peace despite the lack of answers to her religious dilemma; somehow her spirit had been eased in the mourning of her losses.

As this case illustrates, if we cannot engage a patient around his or her belief system because of our reaction to their beliefs, we have allowed countertransference to adversely affect our care for this person. We must clearly focus on creating opportunities for patients to speak to the deeply held religious beliefs that shape and guide their spirits, and we must stay clear of any pressure to make our patients' beliefs fit certain schemas in our minds. If we can be open to hearing *all* the meanings attributed to our patients' beliefs, then we have a great opportunity to explore the ways in which these meanings can be used to help them address difficult existential questions and challenges as they confront dying and death.

Lofly Expectations Related to One's “Holiness”

As spiritual caregivers, we may find ourselves believing that we ought to bring an experience that is different from that which any other helping

professional can provide our patients. This self-imposed belief can reflect our own insecurities about what others expect of us and about what we expect of ourselves. We wonder: "Shouldn't we have more to offer than other caregivers because we have a relationship with the holy or because we practice the disciplines of the religious?" "Isn't it realistic for patients to expect the spiritual care provider to have more meaningful answers to the questions of essence at the end of life?"

Often patients or family members harbor underlying expectations that clergy can bring them healing—physical, emotional, and spiritual. They may make assumptions about what the chaplain believes or doesn't believe. Many desire to receive "answers" from God's representative. What may seem to be a simple request for prayer often holds multiple levels of meaning. It is very easy to make the mistake of "performing" based on an assumption of the patient or of the patient's family. How easy it is to forget our true roles and succumb to patient, family, and staff notions of what we are "supposed" to do. These role expectations may be voiced directly or communicated implicitly with requests or even a simple look, as Dave illustrates below.

Dave worked with a social worker in a busy county hospital emergency room. The social worker would always introduce him to the family in the waiting room and then declare: "I'm sure the chaplain would love to have a prayer with you!" Despite many direct conversations in which Dave asked her not to set him up and establish his agenda with the family, she continued her declarations. Other staff members seemed to carry a belief that Dave's role was to sit with the patient and family and make sure that important issues were addressed. Dave often wondered *whose* important issues really needed to be addressed.

External expectations about our roles, along with our own fears that we may not do what is "needed," make it easy to take on an assigned role rather than providing care in a way that honors the patient's and family's needs and reflects the provision of effective spiritual care. If we feel compelled to lead with our role and not our person, we are not truly invested in the care of the other, but rather, in the establishment of our sense of superiority and "specialness." If we can move beyond these expectations related to our "holiness," we can invest in the care of the other and be present as fellow sojourners. We can stay *human* and use the many tools we bring from our spiritual work and training to be present first as a person, then as a provider.

You Love Me; You Really Love Me

If we are unaware of our own personal needs around self-esteem and self-worth, we can easily find ourselves interpreting our job description in ways that meet our own needs for adoration and affirmation. On a number of occasions Dave found himself in this position and realized it was connected to his early need to "be a good boy." He began to ask himself, "How does this manifest itself in my spiritual care?"

Early in Dave's work he would find himself coming to the hospital at all hours of the day and night. He would spend many, many hours with family members—unknowingly seeking affirmation from them and from staff members, looking for confirmation that he was "the best" for always being there. Dave would find himself lingering (often hovering) amid the patient and family in order to become known as the "best chaplain we have ever had." These encounters were very seductive and fed his desire to please and to be accepted by the team. Of course, a great deal of his response to these encounters was also driven by fear. Would he do the right thing? Would he be judged as not being good enough? Would he lose respect and integrity?

Fear, whether real or perceived, is a powerful motivator. The question is, motivation for what? And, for *whom*? While it may feel great to receive feedback that we are amazing people providing wonderful care, we must continually evaluate our needs for recognition and admiration so that they do not get in the way of providing authentic pastoral care. Our motivation in doing this work must be to assist our patients to discover their own resources and plot their own courses. The greatest gift we can give our patients is to companion them on their journeys and help them discover new and fulfilling ways of engaging their own spiritual work.

The Quick Fix

The push for a "quick fix" can influence issues of boundary setting, professional competence, and appropriate emotional/spiritual connection. The following vignette illustrates one such interaction:

Mary, lying on a gurney parked outside the Operating Room, was refusing to go forward with her open heart surgery. The nursing staff called Jonathan, the chaplain, and asked that he come down and convince Mary to go through with the surgery. Jonathan arrived at

Mary's bedside ready to do the job. His strategy was to help her see how much she had to live for. Thus began their dialogue:

Jonathan: "But, you have so much to live for!"

Mary: "Like what?"

Jonathan: "Well, what about your husband?"

Mary: "He's having an affair with my son's wife."

Jonathan: "Well, what about your children?"

Mary: "I haven't talked to them in 25 years."

And on and on this went until Jonathan "got it." Finally, he said, "It sounds like you really don't have anything to live for." To which Mary replied: "That's what I've been trying to tell you for the past 45 minutes!"

Jonathan took his leave. He realized that in his attempt to do the "quick fix," he was actually responding to the nursing staff's needs, not to Mary's. This certainly was not his idea of good chaplaincy work!

How is it that we can be so vulnerable to moving into "fix it" mode? Most of us have entered into this work because we want to make a difference. We want to create experiences that bring healing, insight, reconciliation, and even hope, particularly at this critical time of transition, one's dying and death. Often, we have been drawn to this work because we have experienced firsthand the benefits and challenges of our own losses. When we look back on our experiences, we may realize that working with those facing death is our way of "mastering" emotional conflicts about our own losses. We may unconsciously want to make sure that others do not make the same mistakes. We may want to protect our patients from experiencing the hurt, pain, and suffering that we experienced. But, the desire to smooth the way creates an unnecessary burden for the professional and distracts the patient from focusing on his or her own work. Often, that "work" is about the patient's personal struggle with the "dark night of the soul," that is, the struggle with questions about meaning, values, things held dear, or contributors to their current existential emptiness.

If we inadvertently find ourselves avoiding difficult or uncomfortable spiritual crises, or if we notice that we are feeling the urge to "make nice" or deliver a "quick fix," we must ask: "What is making me feel

uncomfortable? Is there something about the current situation that is touching me personally? Am I perhaps being reminded of my personal struggles in my own "dark nights?" At such times, it is useful to engage a trusted colleague or colleagues to help identify the source of our discomfort and to "move us along," so that we can do our work with the best interests of the patient in mind.

Delivering "The Answer"

When an individual receives a life-limiting prognosis, the quintessential spiritual process of exploring meaning and purpose takes on an urgency that only this final stage of life can induce. The spiritual caregiver must consider his or her position in relationship to the questions of essence at the end of life: What is the meaning of health and illness? What is the nature of the human person? What is the meaning of bodily life? What is the meaning of death? How do we respond to those who are separated from hope? How are pain and fear replaced by care and healing?

This does not mean that the caregiver must have answers to these questions, but she must be willing to wrestle with such questions. Richard Groves (2002) identifies four primary spiritual arenas associated with spiritual pain: meaning, relatedness, hope, and forgiveness. To empathize with and to understand the source of spiritual pain, the caregiver must reflect upon tragic, often incomprehensible suffering, and the corresponding dilemmas in finding meaning in suffering. The caregiver must understand the dynamics associated with relatedness—that is, the ways in which the processes of disease and life-changing illness can have an impact on relationships with others, with ourselves, and with God or the transcendent. The caregiver must examine what hope means and how these meanings can change in the course of the dying trajectory. For instance, initially a patient might hope for a positive prognosis. As the disease progresses, the patient may express the hope to see a loved one get married. Later, as the patient is dying, hope may mean the desire for a pain-free death.

Finally, the caregiver must be able to wrestle with forgiveness. What does forgiveness mean? Who determines the legitimacy and the need for forgiveness, the caregiver or the client? What power delivers it? Is it a requisite act for the dying person to "save their soul?" For those of us who have not struggled with these questions in our own lives, we may feel intimidated when we sit with the patient and the family. In our discomfort we may quickly move to provide an "answer." When we do this, we lose the opportunity to understand *their* experience and needs. This can

lead to a superficial “feel good” experience with insignificant depth for the patient.

A classic example is the way in which the tool of prayer can be used to exit a conversation versus engage in it. When Dave is asked to provide a prayer for a patient, he takes the request seriously and sees it as an invitation to help the patient open to the sacred. Rather than delivering “the answer” (that is, a rote formulaic, “feel good” prayer), Dave asks what the patient would like to include in the prayer. This allows patients to talk about what holds value and meaning for them and thus helps them connect to the sacred as they see it.

While we may want to create outcomes full of happy endings, we must be able to stay present and compassionately “hold” the hard reality and seemingly unanswerable questions. If we deliver “the answer” without embracing these questions, spiritual care cannot be effective. In the words of Parker Palmer (1998):

If we want to support each other's inner lives, we must remember a simple truth: the human soul does not want to be fixed, it wants simply to be seen and heard. If we want to see and hear a person's soul, there is another truth we must remember: the soul is like a wild animal—tough, resilient, and yet shy. When we go crashing through the woods shouting for it to come out so we can help it, the soul will stay in hiding. But if we are willing to sit quietly and wait for a while, the soul may show itself. (p. 150)

Thus, we must take heed: when patients find themselves in need of spiritual care, it is the person who is comfortable with the “unknown,” with the angst associated with difficult and challenging life events, and with the struggle for making meaning in suffering, who will be perceived as most helpful. In order to develop the capacity to sit with the discomfort, we must attempt to understand why it is difficult for us to tolerate the unknown. We must *listen* instead of direct. As Rilke (1993) declares: “Live the questions now. Perhaps you will then gradually, without noticing it, live along some distant day into the answer” (p. 35).

Father Knows Best or Whose Agenda Is It?

Training, continuing education classes, and years of experience in the field increase our comfort with and knowledge of what we can realistically do to help our patients and families at the end of life. When we are further along in our careers, we can let go of earlier needs to “hover,” to be “loved,” and to make ourselves “indispensable.” Instead, we can truly

focus on being present with patients, families, and staff members—on their terms, when *they* need it.

However, there are times when we may also find ourselves presuming to know best what the patient *should* do or what the patient *should* need. Lorna, a hospital chaplain, illustrates:

Early one morning, Lorna was paged by the son of an elderly patient. He wanted a prayer of healing for his 90-year-old, dying mother. Lorna knew that this 90-year-old woman had no chance of recovering, so such a request really seemed unrealistic. She did not want to provide a sense of false hope, and she secretly wanted to “help” the son accept the fact that his mother's death was imminent. Lorna used her good chaplaincy skills to try to achieve her goal: rather than directly impose her beliefs and try to persuade the son to accept reality, she asked him about the meaning of “healing.” He stated that he wanted a prayer for physical healing. Lorna suggested that there were many forms of healing and that death might also be embraced as an ultimate healing experience. She was not sure how convinced he was. Yet, she did offer a prayer that voiced the son's wishes and at the same time maintained *her* integrity (i.e., not providing false hope or colluding with his denial about the reality of his mother's approaching death). Feeling confident that they had moved to a place of compromise and understanding, Lorna was surprised when she was paged as she was leaving the nursing unit. The nurse making the page stated that the son with whom Lorna had just spent so much time was wondering if there was another chaplain he might speak to! Here, Lorna thought she was so insightful and aware—but, in fact, in her need to be right, she presumed to know what the son needed. In fact, she didn't “know best”; he did. If Lorna had been able to respect the son's way of facing the difficult reality of his mother's death, perhaps she could truly have been of help. Instead, she helped *herself* to maintain her “I know best” position.

When we find ourselves thinking that we know best, we have lost any potential for supportive care. Spiritual caregivers must acknowledge that there are encounters where we feel afraid, confused, and out of control. To deny these feelings leads only to a false sense of security wherein our personal agendas become the foremost component in the relationship. If we can tolerate fear, we can be open to opportunities to hear clearly the needs and desires of patients or family members. Then we can move deeply into the patients' and families' experiences so that we can respond to *their* agenda, not ours. Accepting a patient's or family member's agenda can move the relationship to a transforming and respectful place that allows

□ Conclusion

At the end of life we strive to provide spiritual care that enables patients and families to voice their fears, questions, and personal spiritual struggles. We work to encourage them to declare what is true for them, and we pursue opportunities to accompany them on the quest for understanding the greater and deeper questions of our existence.

As professionals engaged in end-of-life care, it is particularly necessary that we understand the experiences, values, and beliefs that lay the foundation for our own tentative answers to these questions. If we do not, we may find ourselves caught up in the desire to deliver “the answer,” the fix, the insight, the understanding, or the “feel good” experience. We may even assume that it is our *role* to do so.

Awareness is the key to separating our own needs, beliefs, and projections from those of our patients. We must constantly question our motivations, understandings, and temptations to “do good.” Only by being clear about which needs belong to the patient and which to us, can we provide care that allows patients and families to wrestle with their relationships to the spirit on *their* terms, not ours. Only then can we truly be with our patients as they attempt to make meaning at the end of their lives.

□ References

- Groves, R. (2002). *The sacred art of dying: Diagnosing and addressing spiritual pain*. Bend, OR: Sacred Art of Living Center Press.
- Palmer, P. (1998). *The courage to teach*. San Francisco: Jossey-Bass.
- Ramen, R. N. (1988, Autumn). Spirit: Resource for healing. *Neofic Sciences Review*, 4.
- Rilke, R. M. (1993). *Letters to a young poet*. New York: Norton.



Brian Kelly
and Francis T. N. Varghese

The Seduction of Autonomy: Countertransference and Assisted Suicide

□ Introduction

The request for assisted suicide presents complex social, ethical, cultural, interpersonal, and psychological dilemmas. Current discussions of the issue tend to reduce these complexities to debates about individual rights and legal issues. This narrow view, however, does not take into consideration the interpersonal and social forces that shape the patient's appraisal of his or her illness and that in turn inform his or her personal choice for hastened death. The doctor-patient relationship is only one such force, but is nevertheless critical in influencing how patients perceive their situation, how they attribute meaning to it, and how they make decisions about whether to seek assistance in dying (Varghese & Kelly, 1999).

The most common issues debated *vis-à-vis* assisted suicide generally surround those of “rational” decision-making, ruling out major