



Research Points to Spirituality's Role

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Illness is a spiritual event. It grasps persons by the soul as well as by the body and disturbs both. Illness ineluctably raises troubling questions of a transcendent nature — questions about meaning, value, and relationship. These questions are spiritual.

— Daniel P. Sulmasy, MD, PhD

I first read this quote from Sulmasy in his book *The Rebirth of the Clinic: An Introduction to Spirituality in Health Care*¹ in 2006, the same year I was completing my training in radiation oncology and embarking on a career of caring for patients with incurable cancers. I understood his words as true at the time, but the depth and breadth of their truth has only expanded over the ensuing years that I've cared for, and learned from the experiences of, terminally ill patients.

At that particular time in 2006, Sulmasy's words contrasted starkly with my experience as a trainee in scientific medicine. Medicine was largely blind to the reality that illness is a "spiritual event," and not only for patients but also for their caregivers. In the clash between my training and the truth expressed so poignantly by Sulmasy, I discerned a calling to translate this reality into words that medicine could hear and understand — the language of empirical research.

And so, I embarked upon an academic career dedicated to translating the spiritual realities of patients into the language of numbers and the format of scientific manuscripts. I also had my own questions to pose and answer. Do patients want their physicians and other members of the medical team to recognize and attend to the spiritual aspects of their illness experience? If we do embrace the spiritual aspects of illness, how does this influence patients' well-being and medical care decisions?

These and other questions acted as guideposts on this path, always illuminated by my personal experiences in caring for patients and their families. Now, more than a decade later, I'll reflect on the journey and share what I've learned from the myriad voices of persons grasped by illness both in body and in soul, whether I heard them through research or through my own clinical experience.

A MULTISITE STUDY

I embarked on research within the Coping with Cancer study under the mentorship of Holly Prigerson, PhD, the study's principal investigator, whose vision and creativity have been transformative to the understanding of psychosocial and spiritual factors in end-of-life care. The multisite study, funded by the National Cancer Institute and National Institute of Mental Health, involved interviews and observations of more than 300 patients with advanced, incurable cancers and their family caregivers.²





I was curious about the role of patients' religion and spirituality as they dealt with incurable illness, such as how these played a role in coping with the stresses of illness and in overall well-being. I also wanted to know if patients felt that their religious and spiritual needs were supported by their medical teams and what effect such support might have on their well-being and medical care decisions.

SOME SURPRISING RESULTS

The results were illuminating. Patients commonly reported positive religious coping, or reliance upon their religious and spiritual beliefs to cope with their terminal illness. Notably, patients who relied heavily upon religious coping mechanisms at the time of the initial study interview were more likely to proceed with aggressive medical interventions in their last week of life, including more admissions to, and dying within, an intensive care setting.³ These relationships persisted even after taking into account other patient characteristics such as education and insurance status.

These were surprising results, causing our research team to consider the reasons why the more religious patients were more likely to receive aggressive medical interventions at life's end, despite a pre-existing terminal illness. One possibility is that religious values such as belief in miracles may influence end-of-life medical decision-making. This research now has given rise to other prospective studies of advanced cancer patients, but thus far the data show that such beliefs are common and may influence how patients understand their illness and medical decisions.⁴

Within the Coping with Cancer study, we also examined patients' perceptions of how their medical teams, including doctors, nurses and chaplains, were supporting their religious/spiritual needs. Only about one quarter of patients reported that their spiritual needs were well supported by their medical teams, and, notably, those patients who felt highly spiritually supported had better quality of life, both at the time of the initial interview and ultimately near the end of life.⁵

The study also found that patients who reported their spiritual needs were well sup-

ported by their medical teams transitioned to hospice care more frequently, and they were less likely to die in an intensive care unit. In particular, when patients who heavily relied upon their religious beliefs to cope with illness had a medical team that provided good spiritual support, those patients were no longer at high risk of receiving aggressive medical interventions at the end of life and were more likely to receive hospice care.⁶

Hospice is a form of care for patients with incurable illness who have less than six months to live. Focusing on comfort to the patient, hospice care also aims to keep patients out of the hospital and at home or in settings close to family and friends.

Though of course appropriate in certain settings, aggressive medical interventions for terminally ill patients at the end of life can cause pain and suffering for patients and their families.

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In fact, other work from the Coping with Cancer study focusing on the family caregiver experience found that caregivers of patients who received aggressive medical interventions at the end of life were more likely to have a difficult grieving process following their loved one's death, such as more post-traumatic stress disorder symptoms.⁷

STEVE'S STORY

The realities captured in these research findings regularly hit home for me as I have cared for patients. I remember Steve (names and some clinical details have been changed to preserve privacy), a 50-year-old gentleman with a history of advanced metastatic cancer. Despite becoming too weak to receive cancer therapies, Steve insisted on receiving all available medical treatments in order to live as long as possible, even as the treatments became increasingly risky and often resulted in hospitalizations that kept him away from his family.

A spiritual history uncovered that he and his wife Deb were deeply religious Roman Catholics. Throughout Steve's several-year illness, their faith had grown stronger and was critical to his strategies for coping with his illness. In discussing his faith, his hopes and goals, he indicated that he felt a spiritual calling to be a father and strongly believed that to fulfill this calling, he had to do everything to stay alive until his teenage children were grown and out of the house. Stopping medical treatments would be tantamount to forgoing his calling, he felt.

This conversation opened further discussions about his faith and hopes with his medical team, his wife and other key spiritual supporters. Though it was a long process, as death drew nearer, Steve ultimately was able to come to an acceptance of his illness and became able to consider other callings within its context, including making medical decisions that upheld his priority to be at home with Deb and his children and to prepare as a family for his death.

What if Steve's medical team had never acknowledged this critical aspect of his life and illness experience? One can easily see how he might continue down a path of intensive and unnecessary medical interventions that caused burdens to himself and his family. Such procedures would likely detract from other important goals as his life came to an end, such as having time with family, saying his goodbyes and preparing for death.

PERSPECTIVES ON SPIRITUAL CARE

The complexities inherent to integrating spiritual care into the care of patients with rich and diverse spiritual backgrounds also led me to do research about the perspectives of patients and clinicians on spiritual care. The Religion and Spirituality in Cancer Care study involved interviews of terminally ill patients as well as doctors and nurses who care for those patients at several Boston-area hospitals. We found that most patients (87 percent) believed spiritual care is important within the care of the seriously ill. Furthermore, most patients (78 percent) indicated that religion or spirituality was important to their illness experience.⁸

However, most patients (87-94 percent) had not received spiritual care from their doctors or nurses. Similarly, doctors and nurses indicated

that spiritual care was important within the care of the seriously ill, but that they often experienced barriers to providing such care. The most important barrier was spiritual care training — most clinicians (87 percent) had received no training — yet training was the strongest predictor of providing spiritual care within medical care.⁹

In open-ended responses from patients and clinicians,¹⁰ critical approaches to spiritual care also were named. Spiritual care was frequently viewed as critical to holistic care and patient well-being, and it was identified as an important aspect of a good patient-clinician relationship. However, the responses also emphasized that medical caregivers have a limited role in spiritual care and should

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regularly call upon spiritual care providers, such as chaplains or other spiritual supporters. Also, spiritual care always must be patient-centered, honoring of the patient's beliefs, and not imposing or forcing religious perspectives on patients.

In light of these and other research findings, spiritual care is named by the National Consensus Project for Quality Palliative Care, the quality-of-care setting body for palliative care in North America, as a key domain of palliative care.¹¹ Much research work continues to be required to define how best to provide spiritual care to patients in serious illness. Clearly a team approach is required, and palliative care teams are increasingly integrating chaplains into their care teams to help achieve a whole-person approach that addresses the physical, emotional, social and spiritual aspects of illness for patients and families.

Research has demonstrated consistently that spirituality is critical to upholding quality of life during the experience of illness, both for patients and their family caregivers.¹² Given those findings, it is perhaps not surprising that when spiritual care is provided by the medical team, patients have better outcomes at the end of life.¹³

The importance of such care also is applicable



to patients facing challenging choices. For example, researcher Alexandra Nichipor studies religious and spiritual coping in the context of BRCA genetic mutations. The mutations are linked to dramatically high risk of breast and ovarian cancer and often are identified years before a patient develops cancer, raising difficult questions about how to cope with risk and ambiguity. Nichipor has identified religion and spirituality as important in how patients can make sense of these new technologies.

TEMPERED BY GRACE

The complexity and richness of spirituality within illness was summed up beautifully by Steve, who also participated in one of our studies. In describing the role of his faith in illness, Steve said, “If it weren’t for my faith, I don’t know how I would have kept my equilibrium through this process. It is definitely through grace. My natural state of anxiety and manic nature would have spiraled out of control by now if I wasn’t being tempered by grace. It is profound. Some people say to me that I’m doing so well, but I can’t take any credit for it. Whenever I’m at the hardest places in life, God just sends his Holy Spirit, and it just takes over, just like he said it would.”

As Sulmasy described and Steve has shown, illness is a spiritual event, and as such, so is the practice of caring for the ill. Steve’s story reveals that spiritual wellness has the potential to soar and bring well-being, even as one’s physical health declines. Likewise, one’s spiritual health, if neglected within illness, can bring distress rivaling that of any physical ailment. And so as scientific medicine continues to advance, we likewise need efforts, including research, that promote an understanding and acknowledgement of spirituality’s role within illness. As I reflect on more than a decade of care and research among the ill and dying, and on the experiences of persons such as Steve, I’m fortified in a vocation to help the practice of medicine to care for and understand illness as a spiritual event.

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NOTES

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