Spiritual Distress Is Not Confined by Walls

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A few years after her husband, David, died, Carol found a lump in her breast. When she found the lump, questions ran through her mind: "What do I do now?" "Is it cancer?" And the one that echoed the loudest, "Why bother?"

Carol and David had been married 40 years. Carol was a critical care nurse but, as David's health deteriorated, she left nursing to be her husband's caregiver for 15 years until his death.

After David died, Carol moved to St. Louis to be near his family. She left her own friends and social network behind, hoping to feel closer to David by being closer to his family. Instead, the support she thought would be comforting never materialized. There were difficult family dynamics. She felt lonely, her life lacking in meaning and purpose, and she was stuck in her grief.

On the recommendation of her sister-in-law, Carol made an appointment with a Mercy chaplain who works with patients who are not admitted to the hospital. After their first few encounters, Carol felt like she was beginning to make some headway in her grieving progress. And then she found the lump. That's when, Carol said, she lost her faith in God.

In terms of a diagnosis, Carol was experiencing spiritual distress, recognized in the health care field as "the impaired ability to experience and integrate meaning and purpose in life through connectedness with self, others, art, music, literature, nature, and/or a power greater than oneself."[1] To find her way back to herself and to her health, Carol needed spiritual care, a clinical intervention with clinical outcomes that would follow her just like the rest of her medical care.

Carol needed help making sense of a situation that felt overwhelming. Together, she and her chaplain explored Carol's journey to that point in her life. The chaplain completed a spiritual assessment and developed a spiritual care plan. They identified places of gratitude, regret, anger and places that called for forgiveness. Carol's goal was to find her faith again.

SPIRITUAL CARE OUTSIDE HOSPITAL WALLS

For many in the Catholic health care ministry, providing holistic spiritual care means moving beyond the confines of hospitals and out into patients' homes and communities. Health care professionals are recognizing that patients' spiritual health needs do not end when they are dis-

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charged from the hospital, but extend through their whole lives. They carry their spiritual distress to the primary care physicians' offices, to outpatient clinics, to grocery stores, workplaces and back to their homes.

To meet patients where they are and address their health issues from a spiritual perspective, the ministry is working to add spiritual services to the continuum of care that wraps around patients and cares for them when they go home. Using new and old technologies, such as virtual technology, telephones, email and more, Catholic systems are developing ways of integrating chaplains into care teams and adding spiritual care assessment and care plans for patients inside and outside the hospital. Adequate, appropriate spiritual care can have a lasting impact on a patient's physical, mental and spiritual health.

Almost 10 years ago, Mercy, based in St. Louis, recognized that the future of health care is primarily outside the walls of the hospital. For example, the vast majority of perinatal care is managed in ambulatory clinics — including diagnostic testing for any problems during the pregnancy. Chronic and complex diseases are managed in clinics, as well, and often a cancer patient's long-term cancer journey includes only one or two forays into the hospital. Their entire diagnosis and oncology treatment regimen tend to occur in the outpatient arena.

As more patients were receiving medical treatment outside of the hospital, Mercy recognized that spiritual care needed to follow them to the ambulatory settings too — so Mercy began reaching out to these patients by phone, with surprising success. Mercy chaplains also can meet with patients at their doctor's appointment if that is what the patients prefers.

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Patients can use their online MyMercy patient portal to request a phone call from a chaplain, an appointment at the pastoral services office, or to have a chaplain meet them at an upcoming doctor's appointment. Mercy physicians, nurses or physician's office staff also can refer patients to the chaplain using the integrated referral features available in Mercy's electronic medical record.

JOINING CONTINUUM OF CARE

At Ascension, headquartered in St. Louis, providing spiritual care outside of the hospital is critically important to serving patients, and it is a growth area. Just as patients carry their health and psychosocial issues home with them when they are discharged from the hospital, Ascension recognizes that they carry their spiritual needs home too.

Spiritual care departments across the Ascension Health system are piloting ways of reaching patients by calling them on the telephone, meeting them at doctor's appointments or emailing them. Patients have expressed surprise and pleasure that their health system cares about them enough to remember to call and support them at home.

Research supports spiritual care as a positive clinical intervention. Christina Puchalski, MD, professor of medicine and health science at George Washington University School of Medicine and Health Science in Washington, D.C., and director of the George Washington University Institute for Spirituality and Health, notes that for oncology patients, "From initial diagnosis, through treatment, survivorship, recurrence, and dying, cancer patients' understanding of their illness and their lives with their illness range from the physical, social, emotional, and spiritual."[2]

This opinion echoes Mercy and Ascension chaplains' experiences in ambulatory spiritual care. Patients who are experiencing life issues, including health issues, need support in all dimensions of their being, including their spirit. Chaplain interactions allow patients to talk about heartache and soul-ache in a way that can positively affect their health outcomes.

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die every day, but it's different when the possibility of death is suddenly personal — "I will die, and this might be what causes it."

Some patients struggle with existential meaning when they are experiencing a health crisis. They ask, "Why me?" "What did I do to deserve this?" "Why is God doing this to me?" "What difference does my life make?"

Other patients experience spiritual distress as a result of loneliness, isolation and a future that no longer looks like what they imagined. Spiritual care can alleviate spiritual distress and improve patients' well-being.

Puchalski advocates for the inclusion of spiritual care at all stages in a patient's experience of cancer. Summarizing earlier research, she writes, "Integrating spirituality as an essential domain of care will result in better health outcomes, particularly quality of life for patients across the trajectory of cancer care."[3]

Finding peace and resilience may be the reason so many oncology patients who have received adequate spiritual care report fewer symptoms of depression.

CARE IN ONCOLOGY CLINICS

Tina Zimmerman in Indiana and Keith Travis in Wisconsin are two Ascension chaplains pioneering on-demand and ambulatory spiritual care for patients in their oncology clinics. They follow up with their patients by phone, email and sometimes in person. They provide a continuum of care that encompasses patients wherever they are in their care, resulting in concrete, positive changes in their patients' lives.

They both tell stories of women who came in needing spiritual care for breast cancer diagnoses. The women talked about the fear and devastation they felt when they were first diagnosed with breast cancer and their worries about dying and leaving their spouses and children. One described her fear of leaving her son without a mother. Another expressed worry that her larger-than-life and expressive personality was overwhelming the very loved ones she needed to support her through such an emotional journey.

All of them talked about feeling guilty about how much they were depending on spouses, family and friends for emotional support. They knew they were placing enormous burdens on loved ones already weighed down with fear and worry.

The patients talked about how some friends stopped calling — likely because they didn't know what to say. Other friends would say too much, trying to "fix" the cancer by offering a litany of suggestions of things the women should do. The patients said they felt isolated and alone in their struggles.

These patients needed someone outside their family and friends who would be a support to them, someone whom they didn't have to worry about hurting or burdening. They wanted and needed someone who would be there just for them, who didn't require support in return. In other words, they needed a chaplain: someone from the clinical care team whose whole job was to be there for the patient. Having a chaplain meant that the women had someone with whom they could speak freely about all their worries, concerns and pain about their illness in a way they could not to their loved ones. Their chaplain provided a supportive presence who would love them, care for them and listen to them without any pressure.

Ascension's ambulatory chaplains are board certified and, as skilled spiritual-care providers, were able to help the women discover their own coping skills and strengths. Many of the women said they felt they could not recognize their bodies. But through their work with the chaplain, they said they were able to see themselves again as beautiful and beloved. In essence, the spiritual care brought them peace. The spiritual care interventions the patients received via phone, email and in the ambulatory settings helped them cope with their life-threatening illness.

Finding peace and resilience may be the reason so many oncology patients who have received adequate spiritual care report fewer symptoms of depression. In a study of 150 patients with advanced cancer, 42 of the 150 patients received less spiritual care than they desired. Those 42 patients reported more symptoms of depression

and fewer feelings of meaning or peace. Furthermore, the study showed that attention to spiritual care could improve patient satisfaction while hospitalized by 35 percent.[4]

Other research has shown that when patients are in advanced stages of cancer, having a chaplain provide spiritual care as part of the clinical team results in higher hospice usage among patients, and increased quality of life scores at the end of life. Those patients who felt completely supported spiritually also received fewer aggressive treatments, such as resuscitation, at the end of life.[5] The patients lived better at the end of their lives because of the spiritual care they received.

SPIRITUAL CARE AS CLINICAL INTERVENTION

Spiritual care as a clinical intervention positively affects patients' health outcomes. What's more, it is care that patients can benefit from whether they are inpatient, outpatient or in the home.

Similar data on the impact of spirituality on health exists for many issues beyond oncology. A study of congestive heart failure patients showed that spiritual peace was a better predictor of mortality risk over a five-year period than physical health indicators such as functional status or comorbidity. Spirituality was, in fact, significantly associated with a reduced mortality risk, by 20 percent, even after controlling for the patients' health status, behaviors and demographics.[6]

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In addition, research has shown that loneliness and social isolation can significantly and negatively affect a person's health. A recent study in 2017 showed that loneliness in adults over age 50 was correlated with decline in cognitive function over a 12-year period.[7] Another research study showed that in participants over age 60, loneliness and feelings of isolation or lack of social companionship was a predictor of death. It also was associated with decline in a patient's ability to do his or her activities of daily living, such as feeding him- or herself or bathing.[8]

Health care organizations work diligently to manage the care of complex and chronically ill patients outside of the hospital. Patients prefer it that way, and changing health care reimbursement rewards reducing readmissions. As a result, the patients who were hospitalized frequently two decades ago now rarely would be admitted. However, as a result of the same disease processes, contemporary patients continue to experience spiritual distress and loneliness. For patients who are admitted, the spiritual distress they feel continues after discharge, affecting their health negatively.

One young woman patient was admitted to the hospital for an impending perinatal loss. The staff referred the patient for spiritual support to Jennifer Jarvis, an Ascension labor and delivery chaplain. The patient, her family and the chaplain developed a relationship that the patient said helped her and her family say goodbye to her baby.

After the patient was discharged, she and her family continued to receive spiritual care from Jarvis by phone. During their visits together in the hospital, the chaplain had learned that the young woman's family had suffered another death of a close family member within the previous year. Because of those two deep spiritual wounds, Jarvis knew that the young woman and her family would need ongoing spiritual care. So she called them at home and helped them make meaning of their double loss. She also helped arrange referrals for the patient and her family members for counselors to support them in their complicated grief.

The patient said she had lost her belief in God when her baby died, but that the spiritual care she received helped her find her belief again. She said that the chaplain's care and love showed her that God loved her still, and the ongoing spiritual care inside and outside the hospital helped her and her family recover. The telephone calls from their health care chaplain helped the family learn that they had the resilience and strength to live and move forward.

Harold Koenig, MD, professor of psychiatry

and behavioral sciences at Duke University Medical School in Durham, North Carolina, and founding co-director of Duke's Center for Spirituality, Theology and Health, notes that "Not only are the vast majority of patients religious and often use it for health, but many have spiritual needs that they would like addressed as part of their health care." His 2004 study of 838 hospitalized patients over the age of 50 revealed that 97 percent identified themselves as either religious, spiritual or both.[9]

Koenig defines religious coping as "the use of religious beliefs or practices to reduce the emotional distress caused by loss or change."[10] It is a key to resiliency in the health care journey. Essentially, religious or spiritual coping is how the patient makes meaning out of the uncertainty of his or her medical path.

Many times, patients across the continuum of care report being isolated from their local religious community. Some have moved to be closer to family and they haven't been able to get established in a new religious community. Others aren't able to attend physically any longer, or their clergyperson has changed, making them feel as though they've lost their trusted religious adviser. Still others have been estranged from the religious community for longer than they have been ill, though they still identify as religious or spiritual.

Patients in spiritual distress, whether inside or outside a hospital, need their religious and spiritual needs addressed by their health care team. Professional chaplains, as part of the care team, are the experts at assessing patient spiritual needs, identifying and providing appropriate spiritual care interventions and creating spiritual care plans for the ongoing healing journey of the patient.

In Carol's case, for example, working with a chaplain helped her identify what mattered in her life. Through the chaplain's spiritual care plan, Carol began to rediscover her calling to care for others. She had lived her calling first as a nurse, and then as her husband's caregiver. Now she was able to entrust her husband to the hope of heaven, she was able to reconnect to her faith in God and she found purpose and meaning in life again. Carol, like so many patients, received spiritual care that helped her soul and her body.

The provision of spiritual care, the act of providing love, support and spiritual healing, is a clinical intervention with actual health outcomes. That healing spiritual intervention is one that we in Catholic health care are called to provide to the patients in our care, wherever they are.

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