

Humanities: Art, Language, and Spirituality in Health Care

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The Spiritual Event of Serious Illness



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Abstract

Thought leaders in palliative care have long recognized the spiritual implications of illness, including Dame Cicely Saunders' groundbreaking concept of suffering as comprising physical, emotional, social, and spiritual sources of pain. However, despite such recognition, spirituality remains an oft-neglected component of the biopsychosocial spiritual model of caregiving in serious illness. We aim in this article to highlight, through an in-depth account of patients' experiences and attitudes, the concept of illness as a spiritual event. J Pain Symptom Manage 2018;56:816–822. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Spirituality, palliative care, religion, spiritual care

Introduction

“Illness is a spiritual event,” suggests internist and philosopher, Daniel Sulmasy.¹ This statement echoes the work of other thought leaders in palliative care. Dame Cicely Saunders in the early 1960s set forth the holistic concept of total pain, comprising physical, emotional, social, and spiritual sources.² Twenty years later, Eric Cassel's landmark article in *The New England Journal of Medicine*—“The Nature of Suffering and the Goals of Medicine”³—named transcendence as one of the components of personhood threatened in illness and also as, “probably the most powerful way in which one is restored to wholeness after an injury to personhood. When experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares those meanings.”

But the claim that illness is a spiritual event remains frequently unrecognized within medicine and hence deserving of ongoing substantiation and illustration. The Religion and Spirituality in Cancer Care (RSCC) study is an institutional review board-approved, survey-based, multisite, cross-sectional study of advanced

cancer patients that aimed to describe how spirituality functions in the terminal cancer experience, and findings were published in three separate peer-reviewed journals.^{4–6} Herein, by summarizing RSCC patient findings, adding illustrative patient quotes and stories from its 68 participants, and placing these findings in context of the larger literature, we aim to provide an in-depth account of patients' experiences of spirituality within advanced illness.

Religion and Spirituality: RSCC Study and U.S. Population Characteristics

The RSCC study, which drew its sample from four Boston academic medical centers, provides a snapshot of denominational characteristics in the Boston area, which, with some variation, reflect that of the U.S. In the sample, 78% of patients identified with various Christian traditions, 7% were Jewish, 4% were Buddhist, and 1% was Muslim. The RSCC patient sample had a higher number of Roman Catholics (46%) and lower number of Protestants (32%) compared with the U.S. population (24% Catholic and 51% Protestant), but rates are similar to regional expectations in the state

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of Massachusetts (43% Catholic and 28% Protestant). National surveys have indicated that 3%–7% of the U.S. population identify with non-Christian religious traditions.⁷ Our findings also track with the U.S. Religious Landscape Survey.^{8,9} Although more than 70% of people in the U.S. identify with various Christian traditions, religious demographics are in flux¹⁰ and religious diversity is growing in the U.S.¹¹ Notably, there is a growing minority of Americans who are unaffiliated with a religious tradition, coined the Nones.¹² It is unclear if the Nones will remain unaffiliated throughout their lives, or if, as psychological theories of aging and the life cycle predict,^{13–15} there will be a gravitation toward religion and spirituality in the aging process¹⁶ and intensified within the experience of illness.¹⁷

Most RSCC patients reported being moderately to very religious (56%) and moderately to very spiritual (73%). After combining religious and spiritual characteristics, 53% of patients described themselves simultaneously as moderately to very religious and spiritual, 19% were spiritual but not religious, and 25% were neither spiritual nor religious. Most Boston patients indicated that they attended religious services less than once per month (63%).

Three observations place these RSCC findings into context. First, data suggest that religiousness and spirituality increase with the onset of life-threatening illness.¹⁶ Hence, religious surveys of the general population may underestimate the role of spirituality and religion in the context of serious illness. A multisite U.S. study of 230 advanced cancer patients demonstrated that daily spiritual activities (e.g., prayer) increase after diagnosis (47% before vs. 61% after, $P < 0.001$).¹⁷ In a study of 108 women with gynecologic malignancies, 49% reported becoming more religious after diagnosis, with none becoming less religious.¹⁸ This has been termed the foxhole effect¹⁹—a reference to the adage that there are no atheists in war foxholes. Freud²⁰ believed this shift emerges out of a direct confrontation or heightened awareness of one's fear of death or hope for immortality. This effect does not necessarily explain the origin of religion, as Freud believed,²¹ but it is a dynamic that sheds light on why religion and spirituality become increasingly operational when physical health wanes.

Second, although religious service attendance is a powerful predictor for a number of health outcomes in healthy populations,²² it is an imprecise proxy for spiritual commitment within serious illness. Several studies have found that religious service attendance decreases with the onset of illness and aging.^{17,23,24} But although attendance wanes, there is a corresponding increase in private spiritual activities.¹⁷ This may reflect patients' decreasing physical mobility but continuing or even deepening spiritual consciousness.

Third, although religiousness and spirituality are affected by regional variation, U.S. patients as a whole are fairly religious and spiritual. A survey of 542 hospital patients in North Carolina found an extremely high endorsement of religious attitudes and practices, with 65% attending religious services at least a few times per month.²⁴ In another study of 100 terminally ill patients living in Houston, 80% of patients were Protestant, and they had remarkably high levels of self-reported spirituality and religiousness.²⁵ In a survey of 230 patients surveyed from multiple sites around the U.S., religion was considered important by 68% of terminally ill patients,¹⁷ with the highest rates among blacks (89%) and Latinos (79%). Finally, in a survey of cancer patients in New York City, 22% of patients attended religious services weekly, and 66% described themselves as spiritual but not religious.²⁶

What we may conclude from these studies is that although there is notable variation in religious/spiritual characteristics between settings, in general majorities of patients are spiritual, and many are also religious in their self-description. The RSCC survey reflects this national reality, where 73% were spiritual and more than half considered themselves both spiritual and religious.

Patient Religion, Spirituality, and Spiritual Concerns Within Illness

In the RSCC study, patients were asked to respond yes or no to the question: "Has religion or spirituality been important to your experience with your illness?" Most patients (78%) indicated that religion or spirituality had been important to their cancer experience. Patients who indicated religion/spirituality (R/S) to be important within illness were then asked: "How has religion or spirituality been important to your experience with your illness?" Using qualitative analytic methods, five primary themes were extracted from patients' open-ended descriptions of the importance of spirituality to their cancer experience: spiritual coping, spiritual practices, faith beliefs, spiritual transformation, and faith communities.⁴

Spiritual Coping

Spiritual coping was defined as patients' expressions of how spirituality impacted their endurance of the cancer experience. This was the most widely expressed theme within the open-ended interviews (39 respondents). The most frequent way that spirituality facilitated coping was by extending longevity (10 of 39), exemplified by this statement by a participant: "You've got to have faith and a positive outlook because it is going to help you last longer." Other spiritual coping concepts mentioned by patients included a promise of

a potential cure (9 of 39), source of strength (8 of 39), source of meaning (8 of 39), foundation of comfort (7 of 39), acceptance (6 of 39), and emotional stability (5 of 39). A 49-year-old African American woman with metastatic cancer, who died five months after the interview, expressed the many dynamics of coping through faith:

You can't always believe in man because man will deceive you in a minute. But with God, he's true. He's gone and bled for us, he going to bless us. You just have to put more faith in him, and he will make sure everything is all right. He has lifted all my burdens from me. Where the devil kept a door closed, God or Jesus Christ opened two doors for me. And I give him all the praise because at times I didn't think I was worthy. But he still loves me no matter how unworthy I am or feel that I am I've never been sick. Eighteen years working hard and never been sick. When it happened to me, he said, "Time for you to take a little nap." Everybody thought that I had one foot in the grave, but Jesus said, "I have plans for you." And look at me now, I tell them all that I am one of Jesus Christ's blessed.

In a similar fashion, a 46-year-old Roman Catholic man and father of two young children, explained, in tears, the complexity of his own coping experience:

Since being diagnosed with cancer, the way my wife and I pray together has become a lot more clear, and we have made our faith the absolute center of our lives with our children. 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. That's been my experience [patient sobbing].

Although these two patients are demographically quite different (gender, race, and socioeconomic background), faith framed their cancer experience in similar ways. Both experienced an enormous power through their faith that provided a context of meaning to endure their trial. In the measures of religious coping by RSCC,^{27,28} we found that most patients (84%) indicated that they relied on their religious beliefs to cope with their illness. These findings depict that religious coping is pervasive among patients and can offer a powerful means for peace and strength within illness.

Spiritual Practices

The spiritual practices theme was defined as patients' descriptions of practices important to their cancer experience. The most frequently noted practice was prayer (27 of 31). Patients reported praying for themselves (21 of 27), praying more frequently (5 of 27), receiving prayer from others (4 of 27), praying with others (3 of 27), and praying for others (4 of 31). The most cited reason for prayer was to ask for strength (4 of 27), illustrated by a patient who shared, "I just say to God, 'Okay. You're going to give me something to deal with, just give me the strength to deal with it.'" A few patients indicated that they were praying for healing (3 of 27). This was often conceptualized in religious language; for instance: "Jesus said that if you had belief the size of a mustard seed you could move mountains;" and I find myself asking, "Why not me? Why can't I be like the masses that were healed?" Patients also conceptualized healing in terms of nonreligious spiritual practices: "I have a personal faith to heal that goes alongside Western treatments. This consists of believing in myself and my inner capacities to heal. I go and do my alternative therapies in order to finish healing, which the radiation was not able to complete."

Faith Beliefs

The faith beliefs theme was defined as patients' references to spiritual beliefs important to their cancer experience. Most patients mentioned one or more beliefs as playing an important role. Several patients indicated that spirituality had played a significant role in their life independent of and preceding cancer (13 of 28), making comments such as "religion has always played an important part of my life." Another frequently mentioned belief was trusting God's will (12 of 28). The centrality of this belief was expressed by a 35-year-old man with metastatic cancer who described himself as a very religious and spiritual Protestant who attended church services weekly:

I think that God doesn't randomly put people on a path to do strange things, or bless or curse them with one thing or another. So I think that I was given a certain number of days on this earth from day one, and I don't think that changes any with my diagnosis. So, that to me is very important because it tells me that if God wanted me yesterday, I wouldn't be here today. And if he wants me to survive this twenty years without a cure, then that's His will also ... I thank God every day when I wake up because I still feel fine. I'm not symptomatic of anything, and I go to bed and I feel fine. And I thank God for my daughter, my wife and my little one that's on the way. We're four-and-a-half-months pregnant. And, um, so I just don't think it's a

random occurrence. I think that, you know, for me religion and faith in God means that you have to follow the path that He puts you on. And, you know, that could be a long path or a short path, but I have to do with it what it is.

Additional faith belief subthemes included belief in an afterlife (7 of 28). For example, one patient indicated that, although she did not want to focus on dying, she knew that physical death was not the end: "I don't want to say that it is a future event, but I don't think that I'm just going to die and then just be nothing."

Some patients explained that their faith beliefs were spiritual in nature but not religious (5 of 28). One 54-year-old female patient explained:

My spirituality is an energy form. A lot of people have offered to put me on their church prayer list or chapel or whatever. And I think if a friend or person believes in that, it is giving a gift to you as a cancer patient, which is something that they believe in. I do not necessarily believe in their form, but I think that it probably does do a heck of a lot of good to help me because when a person believes in what they are doing, even if it doesn't do me any good, certainly it will not do me any harm. It is a win-win for me; and if they believe in it, then it is a win for them also because it is a gift they are giving. I personally believe that spirituality is an energy that is beyond what we can understand.

What this theme illustrates is that spirituality takes particular forms, not only in actions like prayer but also around faith beliefs concerning the nature of reality, afterlife, and meaning of illness. Such beliefs play a critical role in being able to respond to the existential questions that arise for many facing mortality.

Spiritual Transformation

The religious/spiritual transformation theme, defined as patients' expressions of transformation in R/S beliefs or participation resulting from the cancer experience, was raised by 38% of patients. Several patients mentioned that their cancer engendered a new or deeper reflection on faith and mortality (10 of 20), reflected in statements such as "it's a transformative experience to have an illness such as this, and when you have that you have to reevaluate all you've done in life, who you are, and who you're going to be." Patients also expressed spiritual transformation through an enhanced personal faith (8 of 20), an increase in faith-based activities (8 of 20), a heightened sense of companionship with God or a higher power (7 of 20), and a greater appreciation for life and health (3 of 20). Two months before she passed away, a 54-year-old African American woman spoke

of her spiritual transformation within her Christian faith:

Well, you find out that you have fourth stage cancer and boom, everything is over. And then I turned to Christ again. The body might be gone, but I'm still alive and I know that there is a place for me afterward. I know that I have my family and I have faith, and it's going to be better for me when I go there. There's still a place for me to go, you know, I will be with my father and my mother, and all my siblings, and just meet up with everybody.

A 62-year-old Roman Catholic white male also reflected on his spiritual quest after diagnosis:

It is funny that people wait till they have a threatening disease because then they seem to turn to God for help. Any belief in God or an inkling in a higher power is something you start researching because the unknown is very scary to everybody, and there are so many thoughts and philosophies on reincarnation and your soul and energy and going to a better place. You try to research this out in case your prognosis doesn't turn out the way that you want it to and you end up crossing over and dying. However, when you look for God, I found that in my own personal experience, the things that I feared the most, after I got diagnosed with cancer, I learned to accept, because for some reason asking God - who I think is my God - to stand by me, I have felt his presence on more than one occasion. It really has put a big grin on my face saying "Uh-huh." This has been my own personal experience, and not something that I just made up. It is something that happened through the intervention of whoever that greater power is outside of myself.

As cross-sectional data, the RSCC study cannot measure spiritual change over time. But in the available data, many patients indicate spiritual changes, with the illness event itself catalyzing that change.

Faith Communities

The faith community theme, defined by patients referring to a religious or spiritual community (e.g., clergy or other spiritual supporters) as important to their cancer experience, was also raised by patients (11 of 39). For example, a 48-year-old white Pentecostal woman with metastatic cancer described how her cancer reoccurrence had shifted her priorities toward serving in her church:

God has always been number one. Church, church, church! But I had other things like family, work, and my job—a job I hated for 21 years at the phone company. After being diagnosed with cancer the first

time, I went back to work. After being diagnosed again, I will not be going back but hope to go on disability ... I feel that I've gotten closer to God this time around ... I feel like God is saying, "OK, you've got cancer again and we've got to do something about it, and I want you to slow down and work for the church."

Similarly, an African American patient rediscovered the importance of her church after her diagnosis:

God has been preparing me for a while. And church, it was just in my bones. "I've got to go to church; I've got to go to church." June 4th was Pastor Sunday, and I got blessed with the Holy Spirit. Six days after that, that's when everything came out. That is how good God is. And I still have him in my bones. "Got to go to church Sunday; got to go to church Sunday." I go to hear the Word, and it feels good. I might not be a member of my church, but I go to hear the Word. I was brought up on church as a little girl, and it feels good; it is in my bones and deep down in my soul now.

Religious communities can hold a powerful social role in the life of patients facing life-threatening illness as it offers supportive relationships, pastoral support, and relational connection within a time of change and potential disintegration.²⁹ Yet studies also suggest that serious illness decreases patients' religious community participation and religious service attendance, likely because of less mobility and the difficulty in being in social situations when feeling unwell.¹⁷ This may explain why fewer patients endorsed this theme in comparison to the other four.

In summary, most patients in the study indicated that spirituality was important to their experience of life-threatening illness, with spirituality manifesting in five primary ways: coping, practices, beliefs, transformation, and community. Many of these themes were interrelated and mutually sustained one another. For example, one patient shared, "I'm praying a lot more. I'm receiving cards, which are mass cards, from family, friends—it's just incredible ... So, that has helped me to be more faithful and have more faith." This quote demonstrates connections between spiritual practice (prayer), faith community (spiritual family and friends), and spiritual transformation (increased faith) in this patient's cancer experience. Three of four patient interviews contained at least two themes, further illustrating theme interrelationships.

Patients' Spiritual Concerns

In the RSCC study,⁵ religious and spiritual concerns encountered in the advanced cancer experience were

assessed quantitatively and qualitatively using a 15-item checklist based on previous studies.^{30–32}

Most participants (86%) identified one or more religious or spiritual concerns. The RSCC study assessed conceptual subcategories, which we termed seeking and struggle. Spiritual seeking refers to the recognition of a spiritual deficit that engendered a search for existential and/or spiritual resources to fill a void. Most patients (83%) indicated that they were spiritually seeking within their illness. The most common spiritual seeking items, endorsed by approximately half of patients, included "seeking a closer connection with God or one's faith," "finding meaning in the experience of your cancer," "what gives meaning to life," and "thinking about forgiveness."

Spiritual struggle refers to the presence of a spiritual tension or conflict over sacred issues and questions.³³ The most commonly endorsed struggle (named by 30% of patients) was "wondering why God has allowed this to happen." Notably, 43% of patients described experiencing one or more of the six spiritual struggles defined by Pargament's negative religious coping items. The frequency of several of these struggles is notable, including the experience of divine abandonment (29%), questioning God's power and love (25%), and feelings related to divine punishment (22%).

The only significant predictor of spiritual concerns was younger age. Younger persons facing life-threatening illness may be more at risk for existential crisis because most are not prepared to consider their mortality,³⁴ and many lack spiritual resources given the tendency to delay spiritual questions until older age.^{16,35} Furthermore, younger patients are more likely to have dependent children and other life responsibilities and expectations that are profoundly impacted by illness.

In considering both importance of religion and spirituality and spiritual concerns together, four categories emerged. The largest group (71%) comprising those who said that religion or spirituality is important and also reported one or more spiritual concerns. A minority (15%) indicated that religion or spirituality is not important and yet reported at least one spiritual concern. Notably, among these patients, more than half (6 of 10) reported four or more spiritual concerns. A small minority (7%) said that religion or spirituality is important to them but reported no spiritual concerns. Finally, a similar minority of patients (7%) reported that religion or spirituality is not important to them and had no spiritual concerns.

This information highlights several practical considerations as they pertain to religion and spirituality in the experience of terminal illness. First, only 7% of patients expressed no spiritual concerns and did not value spirituality or religion as important to their

illness experience. By contrast, the vast majority of patients (93%) either considered R/S important to illness and/or were experiencing spiritual concerns. As demonstrated by the methods of the RSCC study, importance of R/S and the presence of spiritual concerns can readily be identified through a variety of interview approaches including one-item screening questions,³⁶ a screening checklist,³⁷ short open-ended questions,³⁸ or active listening attuned to the potential importance of spirituality.³⁹

It is important to note that two-thirds of patients who said that spirituality or religion was unimportant acknowledged spiritual concerns. This highlights how spiritual histories should be inclusive of inquiries about spiritual concerns, even for those not religious or spiritual. This dynamic is illustrated by one young woman interviewed in the RSCC study, a 39-year old woman suffering from metastatic cancer. During the initial part of the interview, she consistently indicated that spiritual care did not apply to her and that she was not at all spiritual or religious. As the interview continued, we learned that she grew up Roman Catholic but did not attend religious services and no longer knew what she believed. But she admitted that she felt punished by God and was questioning God's power. She had also been asking for forgiveness for her sins and trying to see how God might give her strength. She agreed that she was angry with God and doubting her belief in God. Without additional probing or employment of more sophisticated spiritual checklists, about 15% of patients will likely be classified as uninterested in spirituality or religion when in fact there are multiple spiritual issues under the surface.

Ms. G's state of spiritual ambivalence suggests that her unresolved religious and spiritual issues are what psychologist Kenneth Pargament described as a spiritual "fork in the road."⁴⁰ Spiritual concerns can lead toward either resolution or spiritual disintegration and decline. One well-designed prospective study that evaluated the relationship of spiritual concerns and several mental health indicators found that unresolved spiritual concerns were associated with worse quality of life and worse mental health outcomes.⁴¹ The same study reported that struggling with the divine was associated with higher rates of mortality. In the RSCC study, we found that a greater increase in spiritual concerns was associated with worse psychological well-being.⁵ Thus, spiritual concerns mark an area of tension and confusion that can erode personal well-being.

Although we cannot state with certainty the frequency with which patients experience spiritual transformation, this would appear to be a key pathway that leads to spiritual resolution and peace. This highlights the importance of spiritual care, the role of chaplains, and the importance of spiritual communities in

assisting and supporting the large majority of patients who face spiritual concerns in terminal illness.⁴¹ Patients such as Ms. G. are potentially at risk because of their spiritual struggles and disconnection from spiritual supporters. When we asked Ms. G. if it would be appropriate for medical staff to offer spiritual care, she indicated that it was appropriate to do so. She said, "To be asked means that it is not being pushed. Asking doesn't impose." She also indicated that an offer of spiritual care would be personally supportive. Although Ms. G. initially appeared to be categorically nonreligious or spiritual, additional probing unearthed spiritual concerns and a willingness to engage over these issues if offered sensitively.

Conclusion

We began with the goal of descriptively substantiating the claim that "Illness is a spiritual event."¹ Although this overview of findings from this Boston-based sample are limited because of being derived from a modest sample from a single U.S. region, they do provide a thick account of patient experience. The summarized findings of patients' experiences of spirituality within illness echo and complement the statements of Sanders, Cassel, and Sulmasy, each shining light on the complexities of illness as a spiritual event.

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