Review Article | Psychiatric, Psychological, Social, and Spiritual Issues in Palliative Medicine and Palliative Care

Spirituality in advanced cancer: implications for care in oncologic emergencies

Tracy A. Balboni[1,2]^

[1]Department of Radiation Oncology, Dana-Farber/Brigham and Women's Cancer Center, Boston, MA, USA; [2]Harvard Medical School, Boston, MA, USA
Correspondence to: Tracy A. Balboni, MD, MPH. Department of Radiation Oncology, Dana-Farber/Brigham and Women's Cancer Center, 75 Francis Street, Amory L2, Boston, MA 02115, USA. Email: TBALBONI@bwh.harvard.edu.

Abstract: Spirituality—defined as "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 to the significant or sacred"—plays important roles in the setting of serious illnesses such as cancer. The nature of oncologic emergencies, with their attendant imminent threat to life and urgent medical decision-making, renders more salient the frequent role of spirituality in the context of coping, spiritual needs, and medical decisions. Furthermore, these roles highlight the importance of spiritual care: recognition of and attention to patients' and their family's spirituality within medical care. Extant palliative care quality guidelines include spiritual care as a core domain of palliative care provision. Generalist spiritual care requires spiritual history-taking by clinicians and respect and integration of spirituality and spiritual values into medical care. Specialty spiritual care involves the integration of professionally trained spiritual care providers into the care of patients facing oncologic emergencies. Spiritual care is associated with better patient quality of life and greater transitions to more comfort-focused care; among family caregivers, it is associated with greater care satisfaction. Spiritual care is always patient-centered, and hence can be provided by clinicians regardless of their spiritual backgrounds. The integration of spiritual care into the care of patients and their families holds promise to advance holistic care and improve well-being in this setting of oncologic emergencies.

Keywords: Spirituality; spiritual care; palliative care; oncologic emergencies

Submitted Jan 09, 2023. Accepted for publication Dec 29, 2023. Published online May 22, 2024.
doi: 10.21037/apm-23-40
View this article at: https://dx.doi.org/10.21037/apm-23-40

Introduction

Spirituality, defined by an international consensus group as "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 to the significant or sacred" (1,2), plays an important role in the setting of serious illnesses such as cancer. Spirituality is a broad construct that, though it encompasses communal forms found in religious traditions, extends far beyond to include a diversity of sources of meaning, connection and transcendence (1,2). Across culturally- and geographically-diverse, seriously-ill patient populations, majorities report that spirituality is important to them; furthermore, majorities experience spiritual needs (3). Notably, spirituality is one of the most important factors to patient quality of life in serious illness (3,4), and shapes beliefs that influence end-of-life decision-making (5) and medical care (6). Despite the prominent roles of spirituality within illness, spiritual care, attention to patient spirituality and spiritual needs within illness, is infrequent in the medical setting (3,7). The paucity of spiritual care within medical care of the seriously-ill contrasts sharply with its presence as

^ ORCID: 0000-0001-6564-6951.

a core domain of palliative care within National Consensus Guidelines, the quality standard setting body for palliative care in North America (8). Additionally, most seriously-ill patients believe spiritual care should be integrated into medical care (3), and when it is present, it is associated with better end-of-life outcomes, including better quality of life and greater transitions to hospice care (9).

Oncologic emergencies have been defined as "any acute potentially morbid or life-threatening event directly or indirectly related to a patient's tumor or its treatment" (10). They can occur at any time during a cancer diagnosis, from initial diagnosis to end-stage disease, and are often classified as metabolic, hematologic, neurologic, structural, or treatment related. They require prompt recognition and medical care, and frequently require urgent medical decision-making on the part of clinicians, patients, and their families.

Given the frequent salient role of spirituality in serious illness, including medical decision-making, patient spirituality should be recognized within the care of patients and their families facing oncologic malignancies. This brief review will employ a patient case to illustrate the role of spirituality within oncologic emergencies. Using the backdrop of this case, an evidence-based framework for spiritual care will be characterized, including: (I) spiritual history-taking by clinicians; (II) respect and integration of spirituality and spiritual values into medical care, and (III) the integration of specialty spiritual care providers into the care of patients and families facing oncologic emergencies.

Case presentation

Ms. C is a 59-year-old woman—a non-smoker—who 2.5 years prior to presentation was diagnosed with widely-metastatic, EGFR mutant non-small cell lung cancer. She has had an excellent response to her systemic therapies as well as multiple courses of stereotactic radiosurgery for brain metastases. Within the past few months, however, she has had progression of her disease despite a recent switch in her systemic therapy. She is currently planned to proceed to a phase I trial, for which she has signed consent and is awaiting therapy initiation. During this time, she rapidly developed debilitating fatigue and anorexia—she spends most of her time in bed or in a chair. She then developed worsening shortness of breath, fever and cough, prompting Mr. C to bring her to the emergency department (ED). On evaluation, she has cancer-related cachexia and medical work-up demonstrates masses encasing the trachea and bilateral mainstem-bronchi with severe narrowing, right greater than left. She also has post-obstructive pneumonia on the right, with associated partial lung collapse. Imaging also shows diffuse progression in her liver metastases with associated liver dysfunction evidenced in her elevated liver enzymes. Her oxygen requirement increases over the course of her ED stay, and ultimately she decomponsates requiring intubation and admission to the intensive care unit (ICU). She requires ventilator and presser support in addition to broad spectrum antibiotics. The thoracic surgery team performs a bronchoscopy noting narrowing of the airways at the carina and bilateral mainstem bronchi—a stent could not be deployed. The ICU team discusses with Mr. C having radiation oncology see his spouse for urgent initiation of radiation therapy (RT) to her chest disease. The radiation oncology team is called to see the patient in emergent consultation.

Upon arrival at her bedside, Ms. C is sedated and intubated. Mr. C is attentively using a damp towel to gently wipe her face. After you introduce yourself, Mr. C, looking relieved, says, "I'm so glad you are here. When can we get radiation started? Her cancer disappeared from her brain with her last radiation... We've been praying for a miracle, and I just know that a miracle can happen."

Spiritual history-taking

The central and circumscribed role of clinicians in providing generalist spiritual care is taking a spiritual history. A spiritual history is conspicuously absent thus far from the aforementioned case presentation. The lack of understanding of patient spirituality can leave unstated many motivating values and factors influencing patient and family medical decisions, and result in conversations about care that neglect this core, value-shaping aspect of the patient. Furthermore, in the rare occasion when patients or their family members do independently raise issues of spirituality, such as this anxious spouse's declaration of a belief in a miracle, the clinician frequently does not have the training or the prior understanding of the patient's spirituality (e.g., from a spiritual history) requisite to responding in an empathic and patient/family-centered way. Hence, it is not surprising that silence is a common response to surrogate decision-makers raising spirituality in the context of serious illness care (11). Finally, though there is a paucity of data regarding the impact of spiritual history-taking on patient outcomes, available studies suggest that they are received positively by patients and may improve patient well-being outcomes. For example,

one interventional study prospectively examined spiritual history-taking in the oncology setting in comparison to usual care among 118 cancer patients. Patients receiving the intervention were subsequently found to have better quality of life and better ratings of interpersonal care from their physician in comparison to control patients (12).

In oncologic emergencies, three important barriers to understanding a patient's (and their family's) spirituality and attendant values are worth addressing. First, when patients are seen urgently, clinicians seeing patients are often meeting the patient (and/or the family) for the first time, and don't have the *a priori* knowledge of patient's spirituality and spiritual values. It is worth noting that even among oncology clinicians who know patients well, patient spirituality and other sources of key values are infrequently, if ever, discussed (13). Second, in emergent situations, such questions about spirituality might seem at a minimum unnecessary or even out of place given the severity and urgency of the situation. This case, however, argues against such a sentiment. Before this radiation oncologist and the patient's surrogate decision-maker is a critical medical decision—whether or not to proceed to emergent, palliative radiation therapy. The surrogate decision-maker has already revealed that spirituality is framing how this decision is being made. Notably, evidence suggests that spiritual values inform decision-making for many cancer patients (14). In one multi-site study of 275 advanced cancer patients from across multiple regions of the US, 87% held one or more spiritual beliefs about end-of-life care (5). Furthermore, studies suggest that engagement of spirituality by medical teams can influence transitions to more quality-of-life focused care, and away from aggressive, end-of-life interventions (9). Third, spiritual care barriers are common in any medical setting (15), whether in the ICU or the outpatient clinic. These include the frequent lack of spiritual care training and time (16), as well as historical and cultural biases against the integration of spirituality into medicine (17). Greater spiritual care training for clinicians caring for seriously ill patients is needed, with initial evidence suggesting such training improves clinician spiritual care competency (18). In summary, spiritual care, including spiritual history-taking, is needed throughout the care of patient with serious illness, including in oncologic emergencies. It can be effectively taught and can be quickly performed as part of clinical care and can positively impact patient and family medical decisions and well-being.

To turn to the practical question of how spirituality might be addressed in oncologic emergences, we return to Ms. C's case.

Case continued

In response to Mr. C's statement about his belief in a miracle for his spouse, you say to him, "I see that you and Ms. C have a faith or spirituality that's important to you. Would you tell me more about that?" Mr. C proceeds to explain that he and his wife were nominal Catholics prior to her diagnosis, but her cancer prompted a spiritual "revival" for them both, including regular attendance of mass and even a trip for healing to Lourdes, France last year. He describes how they have never been closer in their marriage as they've gotten closer to God together. He also notes that they firmly believe in medical science, but ultimately it is, "God who has removed the cancer from her body." He then again reiterates how he believes God can do this again because he believes in "a God of miracles".

The spiritual history in this case reveals a prior spiritual transformation for both the patient and her spouse. Spiritual transformation in serious illness, a change in one's beliefs due to illness, is not infrequent in the setting of serious illnesses such as cancer (19). In this case, Ms. C's illness caused a spiritual renewal for her and her husband—something they view positively as a source of meaning and purpose despite the realities of advanced cancer. Though spirituality often functions in positive ways, such as associations with better quality of life among seriously ill patients and their families, spiritual needs, such as feeling abandoned by God, are also common in the setting of illness (20). Performing a spiritual history allows an opportunity for spiritual sources of strength and distress to be uncovered in the setting of illness.

There are several methods of eliciting a spiritual history among seriously ill patients, such as Puchalski's FICA questionnaire (*Table 1*) (21). These questions can be adapted to the setting and to the practitioner/patient. In this case scenario, for example, the practitioner refers to Mr. C's previous reference to miracles, rendering the question fitting to the context. Another way to fit the spiritual history into the context is to include it as part of the social history during an initial intake visit. Spirituality and core values are a natural fit with social history questions such as work history, living circumstances, and social supports.

Respect and integration of spirituality into medical care

As illustrated in the case of Ms. C, the spiritual history itself signals respect for, and initiates the integration of

Table 1 The FICA spiritual history questionnaire (21) and example questions

FICA domain	Example questions
F—Faith (including spirituality, religion, values)	Do you have a spirituality or faith that is important to you? What are key sources of meaning and value for you, especially as you face this cancer?
I—Importance (role of faith/spirituality in illness)	Has your faith/spirituality played an important role in your experience of your illness?
	Do your key sources of meaning and values influence how you think about your illness?
C—Community (role of community in spirituality)	Do you have a spiritual/faith community?
	Are there people in your life who provide support to your spirituality (or your meaning and values) as you face this cancer?
A—Address (how care can integrate patient spirituality)	Spiritual care professionals, sometimes called chaplains, are specially trained to support a patient spirituality in their medical care; would you like to be seen by a spiritual care professional?
	Are there ways that I can be honoring your spirituality as part of my care of you?

spirituality into medical care. The information gleaned from a spiritual history provides key information to guide the patient-centered pathway forward for the integration of spiritualty into care. In this case, Mr. C has signaled that spirituality has been a core source of meaning and value in the setting of the stresses of illness. Care for both Ms. C and for Mr. C hence should continue to uphold and honor that critical source of meaning and value. Of course, clinicians are not trained to provide in depth spiritual care and should not violate professional boundaries in providing spiritual care. Examples of this include proselytizing which can take two forms. The more readily recognized form is that of pressuring a patient and/or their family to adopt the clinician's own beliefs and values. Such an action violates core bioethical principles such as autonomy, particularly given the power differential between clinicians and patients. Spiritual care must always be patient-centered and honoring of the unique spiritualities of each patient. Less recognized, though just as potentially violating of the power hierarchy between patients and clinicians, is the discounting or belittling of patient/family spiritual beliefs. Secular clinicians can be susceptible to this violation as they often do not readily recognize the faith commitments grounding their secular belief system (22). As an example, at an academic center where cultural competency and patient-centeredness are high priorities, a team of secular clinicians denigrated the belief system of a Pentecostal seriously-ill person and their family in the discussion of the patient during rounds and in the direct care of the patient and family. Both forms of proselytizing involve the abuse of a patient and family's spiritual values and are a violation of professionalism. Hence, a core aspect of training in spiritual care is the reflection on our own spiritualities and the recognition of our own value systems, a process that aids in ensuring we don't unknowingly impose our own viewpoints. As part of professionalism and cultural humility, clinicians must recognize their own spiritualities, understand that patients will often have different value systems from their own, and honor the diversity of viewpoints in a patient-centered fashion (23).

Integration of patient spirituality can be as simple as allowing the patient and/or family to frame their understanding of the illness with their spiritual beliefs. For example, in this case where a miracle is framing Mr. C's understanding of his wife's medical situation, the conversation about end-of-life care can proceed with that belief upheld and honored. This approach is advocated in the AMEN protocol, developed by Cooper *et al.* (24). AMEN is an acronym for: "affirm" the patient's/family's belief, "meet" them in their belief; "educate" the patient/family about medical realities; and assure the patient/family you are committed to them "no matter what". *Table 2* provides the AMEN protocol and some example statements within each category.

This AMEN approach is illustrated in the next steps of the case, and also raises the final key element of spiritual care provision—working in an integrated fashion with spiritual care professionals.

Case continued

You respond to Mr. C's sharing of his and Ms. C's faith and

Table 2 The AMEN protocol (24) and example statements

AMEN domain	Definition	Example statements
A—Affirm	Provide affirmation of the patient/family's beliefs/values	I'm so glad you have such a strong faith to help you through this tough time
M—Meet	Meet the patient/family's beliefs and values	I share your hope that (patient name) will come through this tough situation
E—Educate	Provide your medical perspective in clear terms	I also want to share my understanding of (patient name)'s situation based on my medical experience. Is that ok with you?
N—No matter what	Express your firm commitment to care for the patient and family	No matter what happens, I will support (patient name) and you through this tough situation

their belief in miracles by saying, "Thank you for sharing about your and your wife's spirituality. It sounds like it has brought you both much comfort in this difficult time. I also appreciate your sharing your belief in miracles; I also hope for a miracle for Ms. C. As your radiation oncologist, I want to make sure I provide you with all the key information you need to make a decision about her treatment. Can you help me to begin in the right place by helping me understand your and your wife's understanding of her illness?"

Mr. C pauses for a moment, and then shares that his wife, "knows she is going to die." He pauses again and says, "She said to me before they put the tube in that she's ready to go… that I need to let her go. I just can't." He begins to cry. You move closer to him and hand him a tissue, saying, "I'm sorry this is so hard. I can tell you love your wife very much." Mr. C responds, "I don't want to see her suffer like this. I just can't imagine living without her. I thought God would have me die first. Not her. Why does he have to take her?" You allow time for silence and then ask, "I know your faith is very important to you and to Ms. C. Would it be ok if I asked the Catholic chaplain to come?" Mr. C nods, and says, "Yes, I think both of us need that."

The chaplain is called and happens to be in the ICU seeing another patient and family at that time. She comes in and you step away, saying you'll return in an hour. When you return, you learn that Mr. C has decided that his wife would not want to proceed to further anti-cancer therapies, though he wants to continue her ICU care. Ms. C receives "last rights", their two daughters are called and come to the bedside, and she passes away early the next morning.

Integration of specialty spiritual care into medical care

Specialty spiritual caregivers, also known as "chaplains" or "spiritual care professionals", are trained in providing spiritual care to patients and their families facing serious illness. They represent a variety of spiritual traditions, have training in providing in depth spiritual care, and have education and awareness of many different spiritual traditions. Furthermore, they have expertise in addressing spiritual needs, particularly those that arise in the setting of serious illnesses and/or medical emergencies. As illustrated in this case, the urgent and life threatening nature of an oncologic emergency can acutely raise spiritual needs—primarily experienced by the family member. He is struggling with the reality of his spouse's imminent death and with why God is allowing this to happen. One can readily see how easy it might have been for the radiation oncologist to ignore the spirituality of the patient/spouse and simply focus on the technical treatment question at hand. This neglect could likely have resulted in the administration of emergent radiation therapy prior to death without any benefit. Such an emphasis on continued treatment would have done a disservice to the patient, spouse and family by taking away critical hours of preparation and of saying goodbye to a loved one. The provision of spiritual care—a spiritual history by the clinician, respect for spirituality shown in the application of the AMEN protocol, and the integration of a specialty spiritual caregiver—allowed medical care to meet the patent/family key needs and to honor critical sources of meaning and value at a time of tragedy and loss. Envisioning what Ms. C's and her family's medical care would have been like without spiritual care exemplifies the prospective findings of the multi-site Coping with Cancer study (9). In this study of 343 advanced cancer patients, the provision of spiritual care by medical teams was prospectively associated with better quality of life near death and greater transitions to comfort-focused end-of-life care for patients (9). Finally,

though the integration of spiritual care professionals is feasible in some settings, it is not feasible in all settings given that spiritual care professionals are variably present, depending on factors such as the clinical context, hospital resources, and even the country setting. When spiritual care professionals are not available, clinicians can consider reaching out to community spiritual leaders for spiritual support of patients.

Conclusions

Oncologic emergencies are urgent, complex clinical scenarios requiring prompt medical evaluation and treatment decision-making. Integration of spirituality into the care of patients and their families facing oncologic emergencies may seem superfluous to medical care. However, studies support the standard integration of spiritual care into medical care, including data demonstrating: most patients hold spirituality as important, many experience spiritual needs, and spirituality frequently plays a role in medical decision-making. Integration is readily performed and circumscribed in scope, including spiritual history-taking, respect for patient/family spirituality within care, and integration of specialty spiritual caregivers where available. Such care not only upholds patient/family key sources of meaning and values in the setting of serious illness; it also holds promise to further patient and family quality of life and to reduce aggressive medical interventions near the end of life.

Acknowledgments

Funding: This study was supported in part by grants from the National Institutes of Health and the Sir John Templeton Foundation to T.A.B.

Footnote

Provenance and Peer Review: This article was commissioned by the Guest Editors (Isabella Choi, Stephanie Schaub, Simon S. Lo and Charles Simone) for the series for the series "Radiotherapy for Oncologic Emergencies" published in *Annals of Palliative Medicine*. The article has undergone external peer review.

Peer Review File: Available at https://apm.amegroups.com/article/view/10.21037/apm-23-40/prf

Conflicts of Interest: The author has completed the ICMJE uniform disclosure form (available at https://apm.amegroups.com/article/view/10.21037/apm-23-40/coif). The series "Radiotherapy for Oncologic Emergencies" was commissioned by the editorial office without any funding or sponsorship. T.A.B. serves as an unpaid member of Palliative Radiotherapy Subcommittee of *Annals of Palliative Medicine* from February 2022 to January 2024. T.A.B. is supported in part by grants from the National Institutes of Health and by the Sir John Templeton foundation. The author has no other conflicts of interest to declare.

Ethical Statement: The author is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

References

1. Puchalski CM, Vitillo R, Hull SK, et al. Improving the spiritual dimension of whole person care: reaching national and international consensus. J Palliat Med 2014;17:642-56.
2. European Association for Palliative Care. Spiritual Care: What is Spiritual Care? Accessed December 13, 2023. Available online: https://eapcnet.eu/eapc-%20groups/reference/spiritual-care/
3. Balboni TA, VanderWeele TJ, Doan-Soares SD, et al. Spirituality in Serious Illness and Health. JAMA 2022;328:184-97.
4. Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. Ann Intern Med 2000;132:825-32.
5. Balboni TA, Prigerson HG, Balboni MJ, et al. A scale to assess religious beliefs in end-of-life medical care. Cancer 2019;125:1527-35.
6. Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. JAMA 2009;301:1140-7.
7. Gijsberts MHE, Liefbroer AI, Otten R, et al. Spiritual

Care in Palliative Care: A Systematic Review of the Recent European Literature. Med Sci (Basel) 2019;7:25.
8. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th Edition. Published 2018. Accessed January 7, 2023. Available online: https://www.nationalcoalitionhpc.org/ncp/
9. Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. J Clin Oncol 2010;28:445-52.
10. Cancer Network. Oncologic Emergencies. Published 1995. Accessed January 7, 2023. Available online: https://www.cancernetwork.com/view/oncologic-emergencies
11. Ernecoff NC, Curlin FA, Buddadhumaruk P, et al. Health Care Professionals' Responses to Religious or Spiritual Statements by Surrogate Decision Makers During Goals-of-Care Discussions. JAMA Intern Med 2015;175:1662-9.
12. Kristeller JL, Rhodes M, Cripe LD, et al. Oncologist Assisted Spiritual Intervention Study (OASIS): patient acceptability and initial evidence of effects. Int J Psychiatry Med 2005;35:329-47.
13. Phelps AC, Lauderdale KE, Alcorn S, et al. Addressing spirituality within the care of patients at the end of life: perspectives of patients with advanced cancer, oncologists, and oncology nurses. J Clin Oncol 2012;30:2538-44.
14. Silvestri GA, Knittig S, Zoller JS, et al. Importance of faith on medical decisions regarding cancer care. J Clin Oncol 2003;21:1379-82.
15. Balboni MJ, Sullivan A, Enzinger AC, et al. Nurse and physician barriers to spiritual care provision at the end of life. J Pain Symptom Manage 2014;48:400-10.
16. Balboni MJ, Sullivan A, Amobi A, et al. Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training. J Clin Oncol 2013;31:461-7.
17. Best M, Butow P, Olver I. Why do We Find It so Hard to Discuss Spirituality? A Qualitative Exploration of Attitudinal Barriers. J Clin Med 2016;5:77.
18. Jones KF, Paal P, Symons X, et al. The Content, Teaching Methods and Effectiveness of Spiritual Care Training for Healthcare Professionals: A Mixed-Methods Systematic Review. J Pain Symptom Manage 2021;62:e261-78.
19. Alcorn SR, Balboni MJ, Prigerson HG, et al. "If God wanted me yesterday, I wouldn't be here today": religious and spiritual themes in patients' experiences of advanced cancer. J Palliat Med 2010;13:581-8.
20. Astrow AB, Kwok G, Sharma RK, et al. Spiritual Needs and Perception of Quality of Care and Satisfaction With Care in Hematology/Medical Oncology Patients: A Multicultural Assessment. J Pain Symptom Manage 2018;55:56-64.e1.
21. Puchalski CM. The FICA Spiritual History Tool #274. J Palliat Med 2014;17:105-6.
22. Balboni MJ, Balboni TA. Hostility to Hospitality: Spirituality and Professional Socialization within Medicine. Oxford: Oxford University Press; 2019:198-214.
23. Puchalski C, Ferrell B. Making Health Care Whole: Integrating Spirituality into Patient Care. West Conshohocken, PA: Templeton Press; 2010.
24. Cooper RS, Ferguson A, Bodurtha JN, et al. AMEN in challenging conversations: bridging the gaps between faith, hope, and medicine. J Oncol Pract 2014;10:e191-5.

Cite this article as: Balboni TA. Spirituality in advanced cancer: implications for care in oncologic emergencies. Ann Palliat Med 2024;13(3):568-574. doi: 10.21037/apm-23-40

