Case Report

"If it weren't for my faith": spirituality in advanced cancer

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Abstract: Patient spirituality plays a frequent and salient role in serious illness. Using a patient case, we illustrate the importance of recognizing spirituality and spiritual needs in palliative care provision.

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Introduction

Patient spirituality plays a frequent and salient role in serious illness. Using a patient case, we illustrate the importance of recognizing spirituality and spiritual needs in palliative care provision.

Case presentation

Cancer diagnosis and treatment

Mr. R is a 46-year-old teacher and father of two children with metastatic lung cancer. Four years after undergoing curative management for his cancer, he presented with back pain and was found to have bony metastases. Despite receiving multiple therapies, his condition worsened with increasing burden of disease. When the option of palliative radiation therapy was broached, Mr. R was aggravated by the point of "palliative" therapies. Upon learning that it served to relieve symptoms but not cure the cancer, Mr. R retorted, "*I don't like your attitude, doctor. We're going to kick this thing and I expect you to be on my team.*"

The role of religion and spirituality

That same day, Mr. R consented to participate in an interview study (institutional review board approved) about his experience with advanced cancer (1). During that interview, Mr. R shared that his desire to fight for a cure stemmed from his strong religious faith. He identified as a devout Roman Catholic who had experienced a powerful religious conversion several years prior to his cancer diagnosis. Since his conversion, he had found a spiritual home in a Roman Catholic parish, and its community had both nurtured his faith and supported him and his family through his cancer. His belief in God was the "absolute center" of his life, and his faith formed the foundation of how he coped with his illness. He explained:

"*Since being diagnosed with cancer, the way my wife and I pray together has become a lot clearer, 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.*"

He explained that interwoven with his strong faith was a sense of responsibility for his family. He saw his children as a responsibility given by God for which he had a spiritual vocation to take care of them. His religious beliefs also provided him hope for healing, stating, "*I believe that God does intervene in our affairs and that God will use whatever means at his disposal to effect a cure.*"

End-of-life care

During the last few years of his life, Mr. R formed a close

relationship with a nurse practitioner named Patrick. Mr. R first shared a story with Patrick about a prior near-death hospitalization during which his clinical course suddenly improved, contradicting medical explanation. He attributed his improvement to be a miracle, and heard God's voice telling him that, "*It is not time for you yet.*" Upon relating this story to Patrick, also a Roman Catholic, their spiritual bond deepened, and they shared prayers together.

The relationship between Patrick and Mr. R was especially noteworthy during the last month of Mr. R's life. Given Mr. R's worsening metastatic disease and lack of response to systemic therapies, the medical team recommended hospice care and a family meeting was called with Mr. R, his wife, Patrick, the nurse, and physicians. The family meeting started poorly. Mr. R became increasingly angry and frustrated by his medical caregivers' recommendation to pursue hospice care. His medical team (apart from Patrick) had never inquired about his religion/spirituality or spiritual needs, so his spiritual needs were unknown and not discussed. Patrick asked to speak with Mr. R alone, and after the other medical team members left the room, he spoke with Mr. R, asking: "*What are you doing? These people are trying to help you. The way you are acting and talking is not who you are.*" Although Mr. R was initially taken aback by Patrick's words, he replied after a long pause, "*You are right. My body is not cooperating. Nothing is cooperating. I'm scared. And my family…*" Mr. R bowed his head, starting to shake and cry silently. Patrick put a hand on Mr. R's shoulder and after a long silence, Mr. R and Patrick discussed his spiritual needs, including his need to care for his family by helping them to prepare for his death, as well as his need to trust that his family is "in God's hands." Mr. R saw the medical team was trying to help him prioritize time with his family, and that, although miraculous cure was possible, perhaps his "time had come."

When the family meeting resumed, it took an abrupt turn. Mr. R's anger quickly dissipated, and after asking several questions, he acknowledged there were significant risks to aggressive medical interventions and ultimately agreed to home hospice. Mr. R returned home and 25 days later, he passed away. Two days before his death, Patrick spoke to Mr. R by phone during which they recited a familiar prayer together and Mr. R mumbled the closing, "Amen."

Discussion

What is spirituality and religion?

Spirituality has been defined as "the aspect of humanity that refers to 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 (2)". In contrast, while the definition of spirituality is orientated from an individual and personal perspective, religion encompasses a more communal experience of spirituality. Religion is often understood as the collective practice of a spirituality, characterized by shared texts, practices, beliefs, and/or symbols (3).

Spirituality and religion influence the understanding and experience of illness, which includes the physical, spiritual, and social aspects of medical disease (4,5). According to a 2017 Gallup poll of adults in the United States, 87% of Americans believe in God and 77% of Americans identify as religious (6). Spiritual care is one of the eight core domains of palliative care provision (7) and includes recognition of the role of spirituality/religion in illness and addressing spiritual needs.

What is the role of spirituality and religion in advanced illness?

Spirituality and religion play important roles in patients with advanced illnesses, and their roles increase with the onset of life-threatening illness (5). In the Religion and Spirituality in Cancer Care (RSCC) study, a multisite, survey-based, cross-sectional study of advanced cancer patients from four Boston academic medical centers, 78% of patients indicated that spirituality or religion were important to their cancer experience (5). A common theme in the illness narrative is spiritual coping, defined as how patients respond to and view the impact of spirituality and religion on their cancer experience (8). While positive coping mechanisms such as finding meaning through illness are associated with improved quality of life, negative coping mechanisms such as viewing disease as divine punishment are associated with decreased quality of life (9).

Closely intertwined is the importance of religious beliefs, including those that can influence medical decision-making in the end-of-life. In a multi-site study of 275 advanced cancer patients, 82% of patients endorsed one or more religious beliefs in end-of-life care, including those related to God's sovereignty over medical decisions, belief in possibility of a miraculous cure, concerns that some end-of-life decisions violate beliefs about sanctity of life in, and the possibility of spiritual growth through suffering. Notably, increasing religious beliefs in end-of-life medical care is related to less understanding and acceptance of the terminal nature of illness (10).

Many spiritual needs and concerns are experienced by patients and their caregivers. Most cancer patients (86%) in the RSCC study identified one or more religious or spiritual concerns, and these spiritual needs were common (60%) even among patients who did not identify themselves as religious or spiritual (5). Spirituality and religion also play a role in family caregiver relationships. Studies have shown the importance of faith, spiritual practices, and attendance of religious services in improving depressive symptoms and quality of life in caregivers (9,11).

How do religion, spirituality, and spiritual care interface with end-of-life outcomes?

Patient religion, spirituality, and spiritual care are associated with their end-of-life quality of life and medical care. Religion and spirituality shape treatment preferences and medical decisions. For example, patients relying upon spirituality or religion to cope with illness, termed high religious coping, receive less hospice care and more intensive medical interventions at the end of life (12). Additionally, patients who receive high levels of spiritual care from religious communities are less likely to receive hospice care and more likely to receive aggressive medical interventions at the end-of-life and die in a critical care setting. One hypothesis for these findings is that religious patients and their communities hold certain religious beliefs about end-of-life care that lead to more aggressive care (10). In contrast, terminally-ill patients receiving spiritual care from their medical teams have better quality of life, existential well-being, and social support (13-15). Furthermore, when spiritual care is provided to the patient by the medical team, patients are more likely to transition to hospice care and are less likely to receive aggressive end-of-life care (13). As aggressive medical interventions lead to decrements in patient and family caregiver quality of life (16) and increased medical costs, the neglect of spiritual care by the medical team has important implications.

Is spiritual care incorporated into medical care?

As detailed above, there is robust research demonstrating the need and importance of spiritual care for patients with advanced illnesses such as cancer. Spiritual care is one of eight core domains of quality palliative care practice according to the National Consensus Project for Quality Palliative Care guidelines in 2018 (7). Furthermore, the Joint Commission recognizes spirituality as an important part of end-of-life care requiring assessment and accommodation (17).

Yet, despite evidence-based research and guidelines pointing to its need, spiritual care remains infrequent. In a recent study of advanced cancer patients, 89% of patients considered religion/spirituality as important, but approximately 90% did not receive spiritual care by their medical care team (18). The presence of unmet spiritual needs is associated with lower satisfaction with care and lower quality of care (19). Integration of spiritual care into medical practice has been limited in the setting of advanced illness, in particular due to inadequate training of clinicians (20).

What is the role of clinicians in providing spiritual care?

Clinicians can provide spiritual care by asking open-ended questions as part of a social history. These questions can enhance spiritual and social understanding of the patient that is essential to the biopsychosocial-spiritual experience of illness (4,5). Moreover, as research demonstrates that medical team-guided spiritual support is associated with fewer futile, aggressive intervention at life's end (14), taking spiritual histories is crucial for guiding patients through medical decision-making. Common tools used for spiritual history-taking include the FICA model (21) which asks about the *faith* and beliefs, *importance* of spirituality in the patient's life, spiritual *community* of support, and how the spiritual issues should be *addressed*. Clinicians should also inquire about any spiritual concerns and if their religion or spirituality is a source of comfort or stress.

From a short initial spiritual assessment, clinicians can utilize an understanding of patient spirituality/religion to guide referrals to chaplaincy and further spiritual care (22). While clinicians themselves can be trained on the basics of spiritual care, they are not expected to be the main providers of it. If additional spiritual care is appropriate, clinicians should involve hospital chaplains, the patient's spiritual supporters, and/or community faith-based organizations. Notably, chaplain involvement in the care of patients with serious illness is associated with improved satisfaction with care in the hospital (9).

How did spirituality and spiritual care affect Mr. R's illness experience and medical care?

The interplay of spirituality, religion, and spiritual care in illness is illustrated throughout Mr. R's story. Mr. R exhibited religious coping by relying on God for strength through his illness. His spiritual practices and faith beliefs

grounded his understanding and approach to life, allowing him to maintain a sense of purpose through his illness. Mr. R's role as a father coupled with his belief that God could provide healing motivated his desire to pursue further medical interventions. Of note, there is an important distinction between healing and a miraculous cure. The holistic view of healing, which is associated with themes of wholeness, narrative, and spirituality (23), differs from modern medicine's emphasis on diagnosis and treatment to cure disease. In fact, patients can experience healing without cure. While Mr. R eventually concluded that a miraculous cure would be unlikely, he was still able to experience healing through his spirituality.

In addition to personal spirituality, Mr. R's relationship with Patrick, the nurse practitioner, shaped his ability to experience healing through illness. This relationship was underscored by their concordant life circumstances, beliefs, and values. Patrick was able to elicit that Mr. R's spiritual needs stemmed from his sense of responsibility to his family and his belief in a miraculous cure. Through spiritual support, Mr. R recognized other spiritual values, including his desire to be at home with his family during the last phase of his life.

Apart from Patrick, most other clinicians failed to acknowledge the central role of Mr. R's faith. This neglect of the spiritual dimensions of illness is common despite national and international guidelines (9,24), and likely contributed to Mr. R's mistrust of physicians. The medical team was unable to recognize his spirituality and his spiritual needs, including its role in medical decisions, likely due to the team not inquiring about his spirituality and the disconnect between biomedical care and spiritual care provided by the hospital chaplain.

A critical piece missing in Mr. R's end-of-life care was not only inquiring about patient spirituality but also integrating chaplains onto medical teams. The hospital chaplain visited Mr. R several times, but had limited involvement in medical decision-making and was not invited to the family meeting. Integrating the chaplain could have better informed the medical team's understanding of Mr. R's values and needs. While Patrick was able to fill this gap due to their unique relationship, chaplains could have provided expertise and experience in engaging the intersection of patient spirituality, illness, and medical care (2).

Lastly, Patrick received spiritual support from his immediate family, particularly his spouse, and his religious community. Community spiritual supporters are important to ongoing spiritual care for patients (10,24,25), and chaplains are specifically trained in spiritual care that incorporates them. Moreover, family members of seriously-ill patients also face frequent spiritual and psychosocial needs, and chaplains can provide spiritual support to families as well. While the evidence regarding caregiver and family psychosocial-spiritual needs are currently limited, the available data suggest that these needs are great and often overlooked (9).

Conclusions

Patient spirituality plays a frequent and salient role in serious illnesses such as cancer. Spiritual care—the recognition of patient spirituality and attention to spiritual needs—has important implications for patient end-of-life medical outcomes, including quality of life, treatment preferences, and medical-decision making. The central role of spirituality in Mr. R's advanced cancer experience illustrates the complexities of spirituality and spiritual care in terminal diseases. The integration of spiritual care through a team-based approach involving medical staff, spiritual care professionals, religious communities, and families is essential to holistic, patient-centered care for many patients like Mr. R for whom spirituality is essential to their illness experience.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The authors are 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. Written informed consent was obtained from the patient for publication of this report and any accompanying images.

References

1. Balboni MJ, Balboni TA. Hostility to Hospitality: Spirituality and Professional Socialization Within Medicine. 1st ed. Oxford University Press; 2018:352.
2. 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.
3. Hill PC, Pargament KI, Hood RW, et al. Conceptualizing Religion and Spirituality: Points of Commonality, Points of Departure. J Theory Soc Behav 2000;30:51-77.
4. Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. Gerontologist 2002;42 Spec No 3:24-33.
5. Balboni TA, Balboni MJ. The Spiritual Event of Serious Illness. J Pain Symptom Manage 2018;56:816-22.
6. Gallup Historical Trends: Religion [Internet]. 2017. [cited 2018 Oct 15]. Available online: https://news.gallup.com/poll/1690/religion.aspx
7. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th Edition. 2018; Available online: https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf
8. 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.
9. Steinhauser KE, Fitchett G, Handzo GF, et al. State of the Science of Spirituality and Palliative Care Research Part I: Definitions, Measurement, and Outcomes. J Pain Symptom Manage 2017;54:428-40.
10. 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.
11. Hebert RS, Dang Q, Schulz R. Religious Beliefs and Practices Are Associated With Better Mental Health in Family Caregivers of Patients With Dementia: Findings From the REACH Study. Am J Geriatr Psychiatry 2007;15:292-300.
12. 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.
13. 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.
14. Balboni TA, Balboni M, Enzinger AC, et al. Provision of Spiritual Support to Patients With Advanced Cancer by Religious Communities and Associations With Medical Care at the End of Life. JAMA Intern Med 2013;173:1109-17.
15. 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.
16. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 2008;300:1665-73.
17. The Joint Commission [Internet]. [cited 2018 Oct 14]. Available online: https://www.jointcommission.org/
18. 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.
19. Astrow AB, Wexler A, Texeira K, et al. Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? J Clin Oncol 2007;25:5753-7.
20. 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.
21. Puchalski CM. Spirituality and End-of-Life Care: A Time for Listening and Caring. J Palliat Med 2002;5:289-94.
22. Best M, Butow P, Olver I. Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality. Palliat Support Care 2016;14:519-31.
23. Egnew TR. The meaning of healing: Transcending suffering. Ann Fam Med 2005;3:255-62.
24. Balboni TA, Vanderwerker LC, Block SD, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. J Clin Oncol 2007;25:555-60.
25. Balboni MJ, Sullivan A, Enzinger AC, et al. U.S. Clergy Religious Values and Relationships to End-of-Life Discussions and Care. J Pain Symptom Manage 2017;53:999-1009.

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