Providing Appropriate End-of-Life Care to Religious and Ethnic Minorities

Daniel K. Partain, MD; Cory Ingram, MD; and Jacob J. Strand, MD

From the Department of Internal Medicine (D.K.P.) and Division of Palliative Medicine (C.I., J.J.S.), Mayo Clinic, Rochester, MN.

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Learning Objectives: On completion of this article, you should be able to (1) review the unmet needs of religious and ethnic minorities in end-of-life care and challenges to providing goal-concordant care; (2) describe the pitfalls of the categorical or "cookbook" approach to the care of religious and ethnic minorities; and (3) be able to participate in an interdisciplinary approach to eliciting patient goals by developing a basic framework with which to approach end-of-life discussions with religious and ethnic minorities.

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Abstract

There is overwhelming evidence that racial and ethnic minorities face multiple health care disparities. Recognizing and addressing cultural and religious/spiritual (RS) values is a critical aspect of providing goal-concordant care for patients facing a serious illness, especially at the end of life. Failure to address a patient's cultural and RS needs can lead to diminished quality of care and worse health outcomes. Given the multitude of cultural and RS values, we believe that a framework of cultural and RS curiosity along with a willingness to engage patients in discussions about these elements of their care within an interdisciplinary team should be the goal of all providers who are discussing goals, preferences, and values with patients facing advanced terminal illness.

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PATIENT CASE

MC is a 30-year-old woman hospitalized for progressive abdominal pain. She is originally from Bahrain, where she received a diagnosis of metastatic adenocarcinoma of unknown primary origin. She traveled to the United States specifically for a second opinion of further cancer-directed treatments. On arrival at the hospital, a brief diagnostic workup reveals widely metastatic disease with a pelvic mass, peritoneal carcinomatosis, multiple liver lesions, and pleural masses. Preliminary results suggest a potential gastrointestinal tumor origin. The

medical oncology team plans to initiate chemotherapy.

MC's hospital stay is complicated by difficulties with symptom management, including pain, nausea, and constipation. She is treated with standard medical therapies. The medical oncology consult note mentions that the patient places her faith in God and wants to do "everything possible." She begins chemotherapy. Two weeks into the patient's stay, MC's family arrives from Bahrain and wants to discuss the overall plan of care. How do you discuss goals of care with this patient and family from a religious and cultural minority group?

DEFINING THE PROBLEM

Racial and ethnic minorities have worse health outcomes across multiple domains,[1] and end-of-life care is no exception.[2,3] Cultural and religious/spiritual (RS) beliefs have a profound effect on a patient's goals, preferences, and values, and cultural conflicts often arise when patients have different values than their health care team. Failure to address a patient's cultural and RS values can lead to goal-discordant care and miscommunication, which has been shown to negatively affect health outcomes,[4] especially at the end of life.[5] Patients with RS beliefs generally have better outcomes across multiple health domains[6] and improved quality-of-life scores at the end of life when their RS needs are addressed.[5]

Religious/spiritual care is one of the most critical aspects of providing goal-concordant end-of-life care to racial and ethnic minority patients because RS beliefs are often magnified in patients with serious illness or at the end of life.[7] Although 87% of patients report RS care from their physician to be important in end-of-life care, 94% of patients with advanced terminal illness report receiving no spiritual care from their physicians.[8] This problem disproportionately affects racial and ethnic minorities, who tend to have higher RS needs.[9] Patients with unmet RS needs report less satisfaction with their care and more depressive symptoms.[10] More than half of physicians (51%) believe that they have no role in providing RS care to patients,[11] and the strongest predictor of whether physicians will provide RS care is whether they personally value religion or spirituality.[12]

CHALLENGES TO PROVIDING CROSS-CULTURAL AND RS CARE

Addressing RS needs is viewed as an advanced communication skill,[13] and physicians often do not feel comfortable addressing complex cultural or RS needs. This becomes even more challenging for patients with substantial cultural differences or language barriers.[14] The cultural competency paradigm focuses on integrating cultural values into patient care to provide high-quality care for racial and ethnic minority patients. However, the early days of cultural competency research focused on a categorical or "cookbook" approach,[14] in which the attention was on providing care to specific patient groups. For example, one might find a list of tips for caring for the "Somali female" or the "Indian male" or even "the patient who believes in miracles." However, this approach is fraught with difficulty when physicians are faced with a seemingly endless diversity of religions, languages, and cultures. Although each patient may identify as a part of a cultural group (eg, Hindu), they are still individuals with unique goals, values, beliefs, and interpretations of their unique cultural and religious background. An additional shortcoming of the categorical approach is its inability to account for individuals who integrate values and beliefs from multiple cultures into their personal worldview and, thus, may not reflect or share the beliefs of just one culture. In light of this, we suggest that physicians might maintain a sense of cultural curiosity and use a framework to inquire about cultural and RS beliefs, support patients where they are able, and engage in an interdisciplinary team approach that includes chaplain services and community RS leaders to provide necessary cross-cultural care.

A FRAMEWORK FOR PROVIDING GOAL-CONCORDANT CARE TO RELIGIOUS AND ETHNIC MINORITIES

Asking what matters the most to a patient in the experience of their illness and treatment is something that any physician can do to foster a cross-cultural relationship.[15] Although this simple question can begin the process of providing goal-concordant care to religious

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and ethnic minority patients, we recommend a 5-part framework to approach a discussion with a racial and ethnic minority patient facing advanced terminal illness: (1) elicit the patient's explanatory model of illness, (2) address the patient's RS values, (3) determine the patient's desired approach to truth telling, (4) understand how the patient's family is involved in the care, and (5) negotiate cultural conflicts when they arise (Table).

Elicit the Patient's Explanatory Model of Illness

Patients relate uniquely to their illnesses.[16] Some patients have a detailed knowledge of the pathogenesis, diagnosis, and prognosis of their illness; others may feel that they are being punished by God; and some patients may have a nuanced combination of many different explanatory models. A discussion with a patient who feels that God is punishing them for their sins would be dramatically different than that with someone with intimate familiarity with their illness. Often, racial and ethnic minority patients feel isolated from the health care system because their fundamental conception of illness is vastly different from that of their health care providers, and a lack of mutual understanding in this area can lead to substantial cultural conflicts.

Address the Patient's RS Values

Religion/spirituality is important to most patients, and this is magnified at the end of life. There are several validated scales to assess spiritual well-being, such as the FICA (Faith or belief, Importance of spirituality, the individual's spiritual Community, and interventions to Address spiritual needs) tool.[19] This tool includes key elements, such as determining what gives meaning to a patient's life, how RS beliefs influence how they take care of themselves, and how the patient would like to have their RS needs addressed. Not every physician will have the time or desire to fully evaluate a patient's RS needs, so Steinhauser et al[17] validated a simple 1-question screen ("Are you at peace?") for opening discussions regarding RS values. Once these values are elicited, the health care team can connect patients to appropriate chaplain services or other RS community leaders.

Determine the Patient's Desired Approach to Truth Telling

A dominant value in Western culture is explicit truth telling as part of patient autonomy (eg, explicit information about prognosis). However, in collectivistic and family-centered cultures, explicit truth telling is often perceived as harmful to the extent that some believe it can hasten death through psychological harm.[20] For example, traditional Muslim patients may respond better to euphemisms, and Bushnaq[21] suggests saying something like "he or she is really in a critical condition and it is the right time to meet with family members and discuss preparations for the hereafter in case he or she deteriorates." Physicians can still respect patient autonomy without giving explicit prognostic information by simply allowing the patient to dictate the flow and content of information. By allowing the patient to choose

TABLE. The 5-Part Communication Framework and Example Questions

Key concept	Example questions
Elicit the patient's explanatory model of illness[16]	What do you understand about your illness? What do you think caused your illness? What kind of treatment are you hoping for?
Address the patient's religious or spiritual values	Are you at peace?[17] Do you find comfort in religious or spiritual beliefs?[18]
Determine the patient's desired approach to truth telling	What kind of information about your health would help you make difficult decisions?
Understand how the patient's family is involved in the care	Do you make decisions collectively with your family?
Negotiate cultural conflicts when they arise	What matters the most to you as we think about your illness? Can you tell me more about your values?

which information they want to hear, autonomy is maintained and cultural values regarding the nature of truth can be integrated into the care of racial and ethnic minority patients. Determining how a patient wants to hear sensitive information can have a profound effect on the physical and emotional health of patients, especially those who do not want to receive explicit health information provided directly from physician to patient.

Understand How the Patient's Family Is Involved in the Care

Understanding a family's role in patient care can be particularly challenging in Western medicine, where we tend to prioritize the ethical value of patient autonomy and the individual relationship between the patient and the clinician. However, many cultures tend to place a high value on family involvement in care. Many families believe that they know the patient the best and should be the ones to disseminate sensitive information rather than the physician.[22] Negotiating patient care in the context of family is a common challenge, but learning how a patient relates to their family with respect to health care decision making can help physicians provide goal-concordant care to religious and ethnic minority patients.

Negotiate Cultural Conflicts

Conflicts will arise when patients have significantly different cultural values from the health care system in which they are receiving care. Religious and ethnic minority patients may think very differently about concepts such as patient autonomy, physician authority, family roles, truth telling, and RS beliefs such as death and the afterlife. A genuinely open sense of cultural curiosity regarding religious and ethnic minority patient values is a key element of negotiating cultural conflicts. Schim and Doorenbos[23] suggested that negotiating conflicts requires appreciation of cultural differences, accommodation of requests to the best of the ability of the physician, and explanation when conflicts cannot be overcome. One example they provide is of a Hindu woman receiving hospice care who believes that her pain is penance for past transgressions as part of her cultural belief in Karma. However, her pain compromises her mental status and quality of life. The hospice team incorporates the patient's values into their care by negotiating a small amount of pain medication to improve her mental status while still allowing her to make autonomous decisions in accordance with her cultural beliefs.[23]

APPLYING THE FRAMEWORK

We discussed the need for addressing a patient's cultural and RS values and how failure to address these elements can lead to cultural conflicts. In addition, we reviewed the inherent shortcomings of the categorical approach to care of religious and ethnic minority patients. Our experience with MC, the 30-year-old woman from Bahrain with metastatic adenocarcinoma of unknown primary origin, is particularly illustrative. MC's faith background and cultural practices were very important to her and had a profound effect on her experience with serious illness. Initial discussions with MC about her care goals elicited that she was hoping for a miracle and wanted "everything" to be done in the course of her care, but the rest was up to God. Caring for a patient who hopes for a miracle is a common challenge,[24] and the 5-step framework is in line with other recommended clinical approaches to help clinicians understand what a miracle is or what "everything" means to each individual patient. The method suggested by Delisser[25] focuses on the physician's role in exploring the meaning of such requests and negotiating a patient-centered plan of care. When interpreted in a categorical framework, the team initially assumed that the patient simply meant that all aggressive, disease-focused care be pursued, even at the cost of comfort and quality of life. However, further exploration of the intent of MC's statements revealed a much more nuanced desire for comfort and time with family. Here is an example of a line of inquiry about her care goals using the suggested framework:

Physician: MC, can you tell me what you have been told so far about your illness?

MC: I have been told that I have cancer that has spread to my liver and belly. They are giving me chemotherapy to shrink the cancer and I pray that I will be able to go home when the chemotherapy is completed.

Physician: And what matters most to you when we think about your care?

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MC: I want you to do everything possible to treat my cancer so that I can get home to my family. I also want to avoid being in pain so that I can spend time with my daughter.

Physician: What kind of treatments were you expecting or hoping for?

MC: Well, I know that this cancer cannot be cured by the chemotherapy but I place my faith in God knowing that he will guide my care.

Physician: What type of information is important to you to allow you to make decisions about the care you receive?

MC: I want to know whether the treatments are working and what this could mean for my outcome and chance to be able to travel home to be with my family.

Physician: Are you at peace?

MC: I feel at peace knowing that God is the one in charge of my life and that when it is my time, it is my time. I just want my doctors to do everything in their power to help me. The rest is up to God.

Through an exploration of the personal beliefs, values, and goals, we eventually understood that the patient wanted to "do everything possible to return home to my family" rather than to "do everything to treat my cancer with more chemotherapy no matter what the cost." We discussed that it was no longer within our power to provide effective treatments and incorporated a respect for the patient's religious beliefs that the rest of her life was up to God. The medical oncology team conveyed to the patient that further chemotherapy would not be effective in treating the cancer and recommended best supportive care to allow the patient to return to Bahrain. MC was discharged with an aggressive comfort-based treatment regimen and eventually returned home to be with her family.

Abbreviations and Acronyms: **RS** = religious/spiritual

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Correspondence: Address to Jacob J. Strand, MD, Division of Palliative Care, Mayo Clinic, 200 First St SW, Rochester, MN 55905 (strand.jacob@mayo.edu).

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