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Culture and Moral Distress: What's the Connection and Why Does It Matter? Nancy Berlinger, PhD, and Annalise Berlinger, BSN, RN

Abstract

Culture is learned behavior shared among members of a group and from generation to generation within that group. In health care work, references to "culture" may also function as code for ethical uncertainty or moral distress concerning patients, families, or populations. This paper analyzes how culture can be a factor in patient-care situations that produce moral distress. It discusses three common, problematic situations in which assumptions about culture may mask more complex problems concerning family dynamics, structural barriers to health care access, or implicit bias. We offer sets of practical recommendations to encourage learning, critical thinking, and professional reflection among students, clinicians, and clinical educators.

Perceiving Difference and Communicating Uncertainty and Distress in Health Care Work

Culture is learned behavior, including ways of perceiving and thinking, shared among members of a group and from generation to generation within that group. This basic definition is reflected broadly in medicine, nursing, and other clinical professions [1]. Research from cognitive neuroscience suggests that humans are wired to produce culture, in that our brains developed to support social agreement and group collaboration [2]. Culture connects humans to one another in ways that include shared values, beliefs, and practices concerning illness and health. It is a fact of human experience, one that must be examined critically due to the potential consequences for patients of misunderstandings within a culture or concerning culture more broadly.

In health care work, "culture" can function as shorthand for a clinician's uncertainty or distress based on perceptions about difference or distinctiveness attributed to a group to which a patient, family, or patient population is perceived to belong. For example, when a clinician characterizes a patient's or surrogate's decision about a medical treatment as "cultural," without further detail this tends to mean that there is something about the decision that is unsettling to the professional, that the professional perceives this "cultural" something to be representative of a group, and that the professional perceives the decision maker to belong to this group. This article, by a health care ethicist and a practicing clinician, takes an interdisciplinary look at one common problem in health care

work: how "culture" may be used as an explanation for situations that produce moral distress.

"Culture" as Distress Code

Certainly, there are situations in which the specific content of a patient's health-related values, beliefs, preferences, or behaviors can and should be described with reference to culture. For example, religious commitments are one example of culture, which, for some people, include specific values or prohibitions concerning medical interventions, such as Jehovah's Witnesses' refusal of blood products. In all such cases, it is crucial for clinicians to understand the patient's values as they may inform her treatment and care; these values may or may not correspond to her religious commitments or to those of her family members [3]. A clinician may or may not personally agree with these commitments or be able to accommodate them in a health care setting, but he or she should recognize that they are important to the patient.

However, relying on the words "culture" or "cultural" as code to convey a clinician's *own* feelings concerning difference, uncertainty, and distress can be problematic in patient care. Perceptions can be misperceptions. Individuals are more than representatives of groups. Behaviors can be misattributed to groups.

Medical and nursing students and professionals who have read Anne Fadiman's 1997 book, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, a now-classic account of a medical team and a refugee family, are familiar with the consequences of using perceptions about cultural difference, including stereotypes about culturally different patients as noncompliant, as a placeholder for lack of understanding about the content of culturally specific, health-related behavior [4]. Fadiman's book is set in the 1980s in Merced, California, where Hmong refugees from Laos were resettled after years-long displacement following the Vietnam War. Most clinicians at the local hospital had little understanding of Hmong medical anthropology: their health-related beliefs, values, and behaviors. Fadiman describes a medical catastrophe—an anoxic brain injury sustained by a young Hmong child with epilepsy following a massive seizure—that may have resulted in part from professional culture. Clinicians' shared habit of thinking of the Hmong as noncompliant made it difficult for them to consider other possible explanations, such as medical error, for had outcomes.

More than a generation after the publication of Fadiman's book, medical and nursing educators aim to prepare professionals to work in a culturally diverse society and to recognize their own professions and institutions as cultures whose inevitable blind spots interfere with understanding a patient's or family's perspective. Fadiman's splendid book is often required reading in medical and nursing schools, and training in "cultural competence" has become standard in medical and nursing education at all levels [5–10].

These educational efforts emphasize respect for diversity and understanding of how cultural values may shape how people think and behave concerning health. They also aim to help clinicians recognize their own cultural commitments and to identify blind spots in their own perceptions about culture that may prevent them from seeing the effects of professional medical culture—such as shared but untested perceptions concerning the reasons for patients' behavior—on their interactions with patients, families, and communities. The evidence for the effectiveness of cultural competency interventions, however, is mixed [11].

Beyond education and training, students and clinicians should develop the habit of thinking critically, as a normal part of health care work, about situations in which references to the "culture" of a patient, family, or population may function as shorthand for their own uncertainty or distress. Figuring out whether a reference to "culture" is masking a stereotyped perception of a patient's health-related behavior is important, as is attention to why a clinician may reach for that word to explain his own perceptions of uncertainty or distress. This process of reflection on professional practice can start with these questions:

- 1. When I use the words "culture" or "cultural" in a clinical setting, what do I mean?
- 2. If I can't clearly describe what I mean:
 - (a) Do I lack relevant knowledge concerning health-related aspects of a patient's culture?
 - (b) Or am I using the word "culture" or "cultural" to stand for something else? If so, can I say what is troubling me?

Supervisors, role models, and clinician educators should call attention to unclear or euphemistic uses of the words "culture" or "cultural" in a care setting and encourage students and colleagues to explore what they think or perceive these words to mean in everyday use. For example, house staff, newly hired nurses, or participants in clinical ethics consultations or other case-based discussions may notice that, within a health care institution, a phrase such as "it's cultural" stands in for a shared perception of how some local patient population uses health care or makes treatment decisions. Noticing this is an opportunity for learning.

The following questions, when posed by clinical mentors and others responsible for supporting professional practice, can help clinicians look critically at professional and institutional norms concerning encounters perceived as cross-cultural:

What is the "cultural" something we perceive about this population?
 (a) What is its relevance to health?
 (b) How do we know this?

- 2. How should we respond when we encounter patient care issues that our professional (or institutional, depending on context) culture frames as "cultural"?
 - (a) Which "cultural" issues are we comfortable talking about?
 - (b) Which issues make us uncomfortable? Why?

Questions like these can supplement discussions of actual cases or of narratives encountered via readings, videos, or other media, with the goal of each being to sharpen clinicians' understanding of when a professional's reference to "culture" may convey professional or institutional distress or uncertainty about some aspect of the health-related behavior of a patient population. The cultural reference alone does not explain what the distressing problem is. Relieving moral distress, which is rooted in self-perceptions about right and wrong action and one's power to change a situation, involves articulating feelings so others can understand what "feels wrong" and the person experiencing moral distress can gain the critical distance needed to reflect on powerful intuitions and moral judgments [12].

Talking about culture is interesting, and understanding how a professional or institutional culture ascribes health-related behaviors to different patient populations can be enlightening. Reality-testing perceptions is important, so that patients, families, or populations are not stereotyped and structural factors (such as racism, poverty, and lack of health insurance) affecting behavior are not conflated with cultural norms. Simply blaming "the culture" for producing moral distress in clinicians is unlikely to help clinicians understand how to relieve this feeling or to make the most of their agency.

In addition to clarifying issues arising in individual cases, clinicians, mentors, and educators should resist <u>clichéd thinking</u> about culture. Generic references to "Asian," "African," "African-American," "Hispanic," "urban," or "rural" families; nonspecific references to religious teachings; and simplistic "East" versus "West" or "family" versus "autonomy" comparisons are common examples of clichés, which may contain some truth but rely on generalizations. In an immigrant nation such as the United States, and in other multicultural societies, health care professionals need substantive opportunities to learn about the cultures of the populations they serve and what patients and families can have in common cross-culturally—for example, when receiving bad news, facing difficult decisions, or considering obligations to older adults or to children. Whenever possible, organized teaching and learning opportunities about a specific patient population should include a member of that group who is well informed about health-related behaviors and how they can be informed by cultural norms.

Clarifying "Family Values"

Using "culture" as distress code often arises in decision making on behalf of a seriously ill patient, when a surrogate or other family member expresses a view framed in cultural terms, or when a professional perceives something "cultural" concerning a decision-making process. For example, a family member may tell a team member that withholding a diagnosis or prognosis from a sick person is appropriate within their culture. This type of culturally framed behavior may reflect agreements within a culture that family members should shield a sick person from the burden of this information and bear it themselves or a more specific belief that hearing bad news or talking about the possibility of death is inauspicious and will lead to a worse outcome. How should the professional respond?

Acquiescing to "what the family wants" would not be ethically sufficient if the patient has decision-making capacity or is capable of participating in decision making. In the United States and in other jurisdictions, the patient has legal rights, including the right to receive health information or to delegate this right to someone else. Therefore, clinicians need to find out how much the patient wants to know or prefers not to know. It would be a mistake to assume that the patient has no preferences and simply keep the patient in the dark.

Asking this family member, "Can you tell me more?" about a belief, value, or behavior that has been framed as cultural can help elicit concerns in a respectful way. This approach also begins a discussion about ethical obligations concerning disclosure. Enlisting the help of a chaplain, social worker, or other team member with strong communication skills (including an interpreter if needed) can be helpful. Clinical ethics consultation can also be helpful if uncertainty about how to talk with a patient about her preferences concerning health-related information, and how to explain to family members why it is important to clarify the patient's preferences, persists among bedside clinicians [3]. In such cases, an ethically sound outcome may include a patient expressing a preference for diagnostic or prognostic information to be disclosed to a family member or the patient expressing a preference to receive some or all information directly. Discussion might also reveal that the patient is already aware of her diagnosis and prognosis, even if she does not discuss this directly with her family.

Avoiding Cultural Explanations for Structural Problems

In addition to clichéd thinking, another problem with using "culture" in a general way—to signal distress or a problem—is that it may, as noted, misattribute a <u>structural problem</u> to the culture of a patient, family, or population. Structural problems for low-income workers, for example, may include lack of sick days, transportation, or child care. Ascribing no-shows to the patient's "culture" does not fix the problem. Professionals who observe access problems for some patient populations should ask:

- 1. What does our system look like from the perspectives of members of this population?
- 2. What barriers do members of this population face in connecting with us?
- 3. How can we learn from patients who have limited options?

The literature on the social determinants of health includes studies of structural problems affecting health care access or patients' ability to complete needed treatment [13]. Discussing an article from this literature may help clinicians, including medical social workers often responsible for working with patients to resolve access problems, to identify similar problems in their own setting, and, whenever possible, to identify structural solutions, such as more flexible scheduling or investments in care coordination so patients can receive services closer to where they live or work.

Culture and Bias

A third caution about using "culture" as a distress code is that perceptions framed in terms of "culture" can conceal implicit bias. In a widely reported 2016 study, preschool teachers who were asked to view videos of four well-behaved children and look for signs of behavioral problems tended to focus on boys, specifically, on the black boy [14]. The researchers concluded that heightened scrutiny of one child reflected implicit bias. The teachers' observations, measured via eye-movement tracking as well as their recollections when asked which videos they had focused on, suggested that their expectations of problem behavior were associated with race and gender.

Clinicians' shortcuts for identifying "problem" patients or "difficult" families might also reveal implicit biases concerning groups [15]. Health care professionals should understand the difference between cultural understanding that helps them respond to patients' needs and concerns and implicit bias expressed in "cultural" terms that can perpetuate stereotypes or obscure understanding. A way to identify biased thinking that may reflect institutional culture is to consider these questions about advocacy:

- 1. Which patients or families does our system expect to advocate for themselves?
- 2. Which patients or families would we perceive or characterize as "angry" or "demanding" if they attempted to advocate for themselves?
- 3. Which patients or families do we choose to advocate for, and on what grounds?
- 4. What is our basis for each of these judgments?

Conclusion

We are never done learning about culture in health care work. It is much too important to be relegated to a one-off training session or course. Health care professionals, especially those in teaching, mentoring, and supervisory roles, should make a practice of reflecting

on and discussing their perceptions about the cultural components of patient care. In 2010, approximately 27 percent of physicians and surgeons and 15 percent of registered nurses in the US was foreign-born [16]; these clinicians thus bring additional cultural perspectives to cross-cultural encounters [16]. The diversity of the US health care work force is one of its great strengths. It presents a ready opportunity for mutual learning about culture—including professionals' perceptions and uncertainties concerning patients, families, and populations—and how these uncertainties can trigger moral distress. But diversity can also provide opportunities for self-reflection on how the different cultures with which professionals identify have shaped them.

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