

## Does Doctor Know Best? Cultural competence is patient-centered care

KIRA NEEL, BA; LAURA A. DEAN, BA; NICOLE A. NEGBENEBO, BS; BONNIE B. O'CONNOR, PhD; NICHOLAS WARD, MD

### THE CASE

Ms. M is a 77-year-old American Indian woman with a history of multiple myeloma who presents with severe back pain. Imaging reveals five new, in addition to four known, spinal compression fractures. She is otherwise healthy. Her physical exam is notable for tenderness to palpation along the lumbar and thoracic vertebrae.

She is being treated in the hospital only for her pain. She has declined orthopedic consultation and chemotherapy. Ms. M is appropriately alert and conversant. The primary care team deems her capable of medical decision-making. Nevertheless, she repeatedly voices concerns that the government and the hospital are conspiring against her and her people, intentionally poisoning them and trying to kill them. She insists that no one in any hospital ever has her interests at heart and see her as a vehicle for scientific experimentation, her current care team included. She is not even convinced that she either has multiple myeloma, or that if she does, that it will prove fatal. She states, "Doctors would never tell white people it's fatal for them."

At the time of her diagnosis months ago, she declined any intervention, and she continues to deny the severity of her disease. Presented again with evidence supporting treatment for symptomatic improvement as well as disease modification, she remains strongly opposed to any such treatment.

### THE ETHICS DILEMMA

Ms. M carries a deadly diagnosis. However, she distrusts the findings and suggestions offered by those caring for her. Ms. M's situation puts in tension her well-established right to autonomous decision-making about her health and the obligation of beneficence on the part of the team. Her physicians must determine what is "best" for this patient – or if such a decision is even theirs to make.

### STUDENT ANALYSIS (KN, NAN)

The central issue of Ms. M's dilemma is a pervasive current of institutional and historical racism, discrimination and maleficence towards Native Americans and communities of color. At first mention, this woman's claims could be written off as the ideas of a conspiracy theorist. However, Ms. M's resistance to allopathic treatment is justified based

on historical context.<sup>1</sup> A review of medical history reveals a sordid past of forced sterilization, coerced experimentation, and intentional infection with incurable diseases.<sup>2</sup> Beginning in the 15th century, smallpox was spread throughout American Indian tribes as a form of ethnic genocide.<sup>3</sup> Later, physicians with the Indian Health Service (IHS) performed non-consensual total hysterectomies and tubal ligations on women without their consent.<sup>4</sup> The IHS also tested new drugs on American Indians in the name of research.<sup>5</sup> The hepatitis trial vaccine program in South Dakota involved giving experimental hepatitis A vaccines to American Indian children. As incentives to participate in the program, they offered free diapers to families and candy to children.<sup>5</sup>

This history seeded a distrust that contributes to worse health outcomes. American Indians/Alaskan Natives are more likely than non-Hispanic whites to experience a delay between cancer diagnosis and cancer treatment.<sup>6</sup> American Indians who perceive discrimination in the clinic are less likely to complete treatment for chronic disease.<sup>7</sup> This cultural dissonance can undermine even the best intentions.<sup>8</sup> In order to alleviate this distrust – and subsequent substandard care<sup>9</sup> – we must acknowledge and educate ourselves about the systemic and historical racism that continues to alienate many patients.

Critics will suggest this places an undue burden on physicians but ignoring Ms. M's concerns is disrespectful and has not worked. Recent literature suggests that medical curricula can and *should* confront the systemic inequities perpetuated by generations of oppression.<sup>10</sup> With such training, doctors will develop a more nuanced understanding of patients' values and concerns, enabling equitable decision-making that honors both autonomy and beneficence allowing future generations of physicians to feel confident in the practice of anti-racist cultural competence, delivering improved outcomes for all patients.

### ETHICS COMMITTEE COMMENTARY #1 (NW)

This case describes a patient who is making decisions that the medical team feels are wrong and not in her best interest. Worse still, these decisions will prevent her from getting life-saving care and the reasoning seems unsound (and perhaps insane). The question is what to do next. The principle of autonomy dictates that we respect her decisions and the

principle of beneficence dictates that we not allow her to harm herself because of a possible mental illness affecting her ability to make these decisions.

Determining when a patient has capacity to make decisions can be complex and unrecognized “incapacity” may be common in adult medical patients.<sup>11,12</sup> In general, patients tend to fall roughly into three categories. The first category (no capacity), is patients who have a definable, clear-cut, major mental illness and we deem them unable to make medical decisions. The second group is comprised of patients who are clearly of sound mind, fully grasp the consequences of their decisions and choose an approach that goes against conventional medical wisdom or societal norms (i.e. Jehovah’s Witnesses). The third group is more difficult (capacity unclear). There are occasionally patients who seem to pass the test for mental health using our usual, often cursory bedside tests (do you hallucinate? What day is it? Do you understand what will happen if you don’t do this? etc.) but seem to lack insight into the consequences of their actions or present such an unusual set of reasons that suggest to the team that they may have some low-grade (or masked) psychiatric condition or cognitive deficit. What happens next in this case depends on the category to which our patient belongs.

Because of this, a lot hinges on the student’s sentence, “The primary care team deems her capable of medical decision-making.” Given the import of these decisions, the radical nature of the patient’s stance, and almost paranoid beliefs (suggestive of schizophrenia) it is important that this be delved into in much detail, perhaps with more psychiatric consultation. For the purposes of this discussion however, we will take as given that the patient does not have a major psychiatric illness. If this is the case, there is actually not much that the team can do. The team should make every effort to engage the patient and her family in discussions about her reasons. While there is a chance that short-term emotions, misconceptions, or poor advisors are influencing her and a different decision may be made, this patient’s decision may stand after such engagement.

Ultimately then, there are not many options in a case like this. Were the team to decide that the best decision was to pursue therapy against her will, what would happen next? If she held to her decision, they would have to force therapy on her. This may require physical and or chemical restraint. How successful would weeks of intense therapy be with a patient who does not cooperate? Practically, this would be very difficult. By causing harms *and* violating her autonomy (capacity having been established), such a course would have two ethical “strikes” against it, and would be hard to defend.

## ETHICS COMMITTEE COMMENTARY #2 (BO’C)

*“I have lived a long time with the white people and I know what they do. They are people who are very kind to anyone who is ready to do whatever they wish.”* Sarah Winnemucca

(1844–1891), Northern Paiute educator, activist, and author.

This case demonstrates the critical importance of cultural and historical issues to possible resolution of an ethical dilemma, and to accurate diagnosis of a patient’s state of mind.

Ms. M will know of the several-hundred-year history of abusive practices on the part of Anglo-European “officialdom” with respect to American Indian tribes and Nations.

Health care for Native Americans has since 1955 been the responsibility of the Indian Health Service (IHS), an agency of the federal government. The IHS has been rife with inadequate care and abuses of patients. Our patient or her daughters might well have been at risk or even been victims of this malfeasance.

In light of these facts, declarations of intentions “to help you” may be received with skepticism if not outright disbelief and mistrust. This history puts Ms. M’s mistrust of medical advice in a light of rationality and self-protection

Is Ms. M perseverating, or is she being vigilant in guarding her own safety? Is she engaging in “conspiracy theories” (implying some irrationality), or is she responding reasonably to a well-documented history of threats from “officials” and healthcare professionals to Native American patients, especially women? Is she ignorant of her diagnosis/prognosis, or is she taking precautions against allowing others who may have their own agendas to define her likely outcome and her treatment options? Should we work to redirect this patient’s concerns, or to redirect our own understanding of where she is coming from?

We cannot accurately diagnose Ms. M’s mental status or accurately interpret her rationales without some non-medical, but clinically relevant knowledge. Without this information, we cannot confidently defend as ethical any decisions regarding whether to attempt to override her autonomy (always ethically dicey, for *any* adult patient with decisional capacity) in refusing medical treatment for her diagnosis of multiple myeloma.

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### Disclosure

The views expressed in this article are the opinions of the authors and do not necessarily reflect the views of the Warren Alpert Medical School of Brown University.

### Authors

Kira Neel, BA; Alpert Medical School of Brown University, Providence, RI.

Laura A. Dean, BA; Alpert Medical School of Brown University, Providence, RI.

Nicole A. Negbenebor, BS; Alpert Medical School of Brown University, Providence, RI.

Bonnie B. O'Connor, PhD; Professor emerita of Pediatrics, Alpert Medical School of Brown University, Providence, RI.

Nicholas Ward, MD; Associate Professor of Medicine, Alpert Medical School of Brown University, Providence, RI.

### Correspondence

Kira Neel

Alpert Medical School of Brown University

222 Richmond Street

Providence, RI 02903

[kira\\_neel@brown.edu](mailto:kira_neel@brown.edu)