Permissibility to Accept Refusal of Potentially Life-Saving Treatment

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Column Editor’s note: This column presents a case that poses an ethical dilemma for patients, families and healthcare professionals. It is based on a real case, though some facts have been changed to preserve confidentiality. The story is presented to a Fellow of the Center for Bioethics and Human Dignity, and his or her analysis is published for our readers. Our goal is to offer careful ethical analyses and recommendations that are consistent with biblical standards. Readers are encouraged to comment on our commentaries.

Column editor: Robert D. Orr, MD, CM, Consultant in Clinical Ethics, CBHD.

Question
Is it ethically permissible to accept this patient’s refusal of potentially life-saving treatment?

Case
A 22 year-old woman has been re-admitted for treatment of active tuberculosis. She emigrated with her family from Somalia approximately 18 months ago.

Three months ago, she came to the hospital because she was coughing up blood. Work-up revealed pulmonary tuberculosis without evidence of spread outside the lungs. The organism was not resistant to standard therapy. She was not critically ill, had not lost weight, and was Human Immunodeficiency Virus negative. Active disease in family members was excluded. Her
prognosis for cure was good. In addition, her inpatient and outpatient treatment was to be provided without charge by a religious hospital that exercised a prominent mission to the indigent community.

Therapy was begun, but she frequently refused medication and occasionally said she wanted to die. Her nurses suspected that she induced vomiting after taking her medication. She refused treatment by injection. Because of concern about compliance and contagion, the Health Department recommended inpatient, monitored anti-tuberculosis therapy for 6 weeks rather than discharge for outpatient treatment.

Multiple management conferences were held with translation services. Her parents and siblings were included, as well as a Muslim cleric, but support could not be engendered for the prescribed treatment goals. The Somalis perceive tuberculosis as a death sentence and could not be convinced otherwise in spite of hearing repeatedly that in contrast to the dire prognosis of tuberculosis in Somalia, the treatment here would have a high likelihood of success. She and her family were consistently resistant to the necessity of inpatient treatment and subsequent outpatient follow up.

She was diagnosed as depressed, but she also refused treatment for depression. Psychiatric, Palliative Care, Health Department, and Ethics committee consults were obtained. All the consultants were consistent in their exhortations for her to comply with therapy. She again refused injections and began to pull out intravenous lines. She completed the 6 week course, such as it was, had improvement in her symptoms and chest x-ray findings. She was sent home, presumably cured. She did not return for scheduled ambulatory visits.

She is re-admitted now, three months later, with fever and intermittent mental confusion. She has been found to have recurrent pulmonary disease plus tuberculosis inside her skull, both meningitis and a cerebellar abscess. It was surmised by the Infectious Disease Consultant that there were substantial medication gaps in her hospital regimen during the last admission. When lucid, she again refuses or expectorates her medications and pulls out her intravenous lines. Her family supports her decision to refuse medication. The attending physician has asked the ethics consultant to address the question: Is it ethically permissible to accept this patient’s refusal of potentially life-saving treatment??

The professionals caring for this patient understand that, like other African immigrants, Somalis have a high incidence of tuberculosis and complications. One-fifth of infected Somalis have drug resistance compared to 2% of Americans. In this 22 year-old, the organism was sensitive to standard therapy (3 months ago), all drugs could be administered orally, with a significant portion of treatment performed at no cost in an ambulatory setting, and with a good prognosis for cure. Treatment at that time did not appear to be burdensome from the professional perspective. Now, three months later, her burden of treatment is considerably higher and her prognosis is much worse. Without aggressive treatment, she will likely die soon.

**Discussion**

Those involved in this patient’s care are experiencing a sense of helplessness and frustration. They are trying to prevent an untimely and avoidable death. Initial discussion should dissect why caregivers are being resisted by the patient, her family, and possibly their culture. What is animating their decision to forego life-saving therapy? With an expanding interface between the
West and increasing diversity, this case may be a portent for the future. Specific questions should be answered by the consultant. What principles may inform the withholding of treatment when cultures clash? Is the burden of treatment reasonable? How can one remain culturally respectful while retaining personal moral agency?

To begin with, respecting others? beliefs is good. So how might this assertion simultaneously inform care and draw moral boundaries? Patients? preferred method of communication should be honored. Cultural assessments, such as the Culture and Health Belief Assessment Tool can assist.2 Translating content like ?what do you fear most about your illness? is critical, adding transparency to healing relationships.3 How to break bad news, prayer, and identifying cultural bias to Western medicine are important. Healthcare is ministry and individuals should be involved in decisions, in a manner respecting their humanity. Respect for a diverse culture seems to be present here. Drawing mutual boundaries may be more difficult.

The consultant has learned that in Somalia, persons with tuberculosis are shunned.4 There, tuberculosis is a death sentence, period. After moving to America, the stigma persists. Her family would be ostracized while she remained with them. As a family, they have no emotional support outside the Somali community, all of whom reside within a few miles. Her death would free the family from culturally-imposed isolation. So, they continue to refuse even after a complete cure has been repeatedly ?guaranteed.? The patient accepts this line of reasoning and is basing her refusal on her understanding of her obligation to her family.

**Recommendations**

1. Based on this patient?s poor prognosis and her firmly entrenched cultural beliefs, it is ethically permissible, though regrettable, to accept her (and her family?s) refusal of potentially life-saving treatment. It may still be appropriate to attempt persuasion while therapy might be effective, but since this avenue has been used exhaustively, it is not likely to be effective. If her disease progresses to the point of irreversibility, further attempts at persuasion should be discontinued.

2. If the patient continues to refuse curative therapy and it is expected that she will not survive, it is appropriate to offer palliative care measures, though the purpose of these (patient comfort) will need to be fully explained to her family.

**Follow-up**

Despite multiple multidisciplinary conferences with her family and community elders, each individual from her cultural background again agreed with her decision to decline treatment. She progressed to ventilator dependence as a result of progressive pulmonary and neurological complications. Her clinical situation worsened, she became comatose, and her family requested that ventilator support be withdrawn. She died immediately.

**Commentary**

Since life is so important, did we do enough? Should she have been forced to take potentially life-saving medications? Forcing this patient to take therapy, in the presence of family?restrained and sedated?would be cruel. It also would have to be forced by ?foreigners.

How far can we proceed in defending life amidst a cacophony of cultures? Can we be more
proactive? Is not cultural diversity a mission field in our communities? Might future Somalis be amenable to similar therapies if education can be provided in advance, before they are critically ill? Do diverse ?others? (for example, those from other locations in Asia, Africa, or Latin America) have access to care as well as necessary relationships to develop mutual trust with caregivers? Or, are diverse groups in general outside the treatment pale because of lack of insurance? Sincere, non-judgmental efforts over time may prevent similar refusals, thereby transforming ?diversity? into healing partnerships.

The efforts of the healthcare team and community in caring for this woman are commendable. Unfortunately, this young Somali? s course will be played out in various scenarios as increasing diversity is imbedded into a ?one size fits all who can pay? system. Either society is going to be politically correct and establish diversity itself as an absolute good?an easy way out?or shared decision-making will change for the better with caregiver compassion and education changing hearts.

Endnotes


3. See www.hhs.gov/ocr for regulations regarding translators.