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CLINICAL ETHICS DILEMMA

A Clash of Medical Cultures

ROBERT D. ORR, MD, CM; FERDINAND D. YATES, JR, MD, MA (BIOETHICS): COLUMN EDITOR

Editor's Note:[1]

This column presents a problematic medical-surgical case that may pose a medical-ethical dilemma for patients, families, and healthcare professionals. As this case is based on a real medical situation, identifying features and facts have been altered in this scenario to preserve anonymity and to conform to professional medical standards. In this case, a family wishes to offer cultural treatment rather than continue traditional American treatments.

Question: Should we go to court to prevent this Samoan man's family from taking him home against medical advice?

Story:

Tuiasosopo is a 39-year-old Samoan agricultural worker who was admitted 7 weeks ago after two weeks of headaches and intermittent nausea and vomiting and blindness for 24 hours. He was found to have cryptococcal meningitis[2] and has been treated with 2 standard antibiotics for this uncommon infection (amphotericin intravenously and flucytosine by mouth). He initially had gradual improvement, demonstrated by repeatedly testing of his spinal fluid and considerable improvement in his mental status. He was nearing the end of his 6-week course of treatment when 1 week ago he suffered a stroke. This precipitated vomiting which precluded retention of his flucytosine for several days. He has subsequently had a worsening of the spinal fluid test, and his mental status is again severely depressed. Immunosuppression[3] is suspected, but no source has been found.

The patient has lived in this country for 2 years, is married, and has one child, a 6-month-old son. He has been employed as a farmer worker, but has no health insurance. He has qualified for emergency Medicaid coverage for this hospitalization only. He has a supportive large extended family. A brother (with whom the patient and wife live) is the family spokesperson.

The patient started asking to go home early in his course of therapy. He consented to stay because Medicaid declined to cover home I.V. therapy. He was receptive to conventional therapy, but did refuse his fifth weekly spinal tap. When told that the test was necessary to monitor improvement, he agreed to a final one at the end of his 6 weeks of therapy.

Since his recent setbacks, his family have asked to take him home to pursue ethnic treatments (application of leaves and lotions to his skin; taking of homemade herbal mixture by mouth) believing that hospital treatment has failed to cure him. They have not been antagonistic. Their

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cultural beliefs include spirits of deceased relatives as the cause of illness and/or failure to respond to conventional therapy. They also put faith in dreams, and the family reports that some dreams about this patient and his course of illness have come true.

Psychiatric consultation has confirmed that the patient does not now have decision-making capacity. The infectious disease consultant states that he will surely die if he leaves the hospital, and may even with continued treatment. The most recent neurology note states that his prognosis is guarded, even with treatment, since he is not responding to treatment, presumably on the basis of immunosuppression. His vision will not improve, and his cognitive recovery is questionable. On exam, he is somnolent and appears to be in no distress.

Discussion:

We traditionally allow competent patients to refuse treatment, even life-saving treatment, as long as they understand the consequences of their decision. We are more reluctant to honor such requests from surrogates. When working with surrogate decision-makers, the primary questions are: (1) is the proxy making the decision which the patient would make, and (2) is the proxy acting in the patient's best interests? It is often helpful to articulate the goals of therapy before judging a particular decision about a particular modality.

These matters become even more complex when dealing with patients from another culture. Requests for unorthodox therapies can sometimes be accommodated without compromising conventional therapy; other times this is not possible.

This patient (and his family) apparently chose a goal of cure and accepted conventional medical therapy. Now that he has worsened and has lost decision-making capacity, his caring family still want to pursue that goal of cure through other means. At the same time, the care team believes that the possibility of cure (restoration of previous level of impaired function) with continued therapy is fading.

Recommendations:

If the proposed ethnic interventions are not recognized as toxic and can be administered in hospital in conjunction with continuation of conventional therapy, this option should be offered to the family. If this is acceptable to them even for a few days, his prognosis may become even more clear.

In light of his poor prognosis for recovery (and for survival) even with continued therapy, if the proxy making the decision which the patient would make is not possible, or if they insist on his discharge, a non-adversarial meeting with them should be held in an effort to determine whether the patient would choose this move. They must clearly realize that it is our understanding that he will die if they take him home. If the care team is convinced that the family is making a truly informed substituted judgment, it would be ethically permissible to allow them to take him home "Against Medical Advice"[4] since they appear to be acting in his best interests.

If this cannot be determined, or if the responsible physicians are not willing to do this, the only alternative would be an adversarial court proceeding.

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Follow-Up:

The patient's neurologist permitted the family to apply the topical therapies, but could not be convinced by the family or the nurses to allow the internal herbal mixture. He initially seemed to show some improvement and was a bit more alert. However, his fever continued and his kidney function deteriorated, probably from the prolonged use of Amphotericin. The spinal fluid tests monitoring his progress initially improved, then bounced up and down. His mental capacity also fluctuated considerably. Phone consultation with a nationally known expert in cryptococcal infections offered no other options. His family considered flying him back to Samoa, but the cost was prohibitive. Nearly 4 months after the consultation (over 5 months after admission), he was found unresponsive in bed. No resuscitation was attempted.

Comment:

Would it have been better to either allow his family to take him home, or at least to allow the administration of the herbal mixture in hospital? It is difficult to know. The administration of unknown chemicals might have adversely affected the antibiotics, worsened his failing renal function, or caused other unexpected side effects. They might have had no effect at all. Could they possibly have helped? While this latter possibility seems unlikely, in a patient with a very poor prognosis it might have been helpful to the family as they looked back on the sequence of events if they were able to think they had fulfilled their duty to the patient.

Editor's Comment:

Occasionally, at end-of-life situations, the medical team seems to appropriately focus on the wishes of the patient (or the health care proxy), sometimes not giving gracious thought to the intentions of the family in attendance at the bedside. Whereas this may occur for a variety of reasons, one may well be because the goal-oriented team does not recognize the importance of cultural preferences and—perhaps—makes the assumption that these carry no recognized medical contribution. A less directive-oriented team may be more open to cultural options of unproven but (likely) nonharmful effects. "First, do no harm" has broad latitude in such a situation.

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REFERENCES

1. The article, as originally published, was untitled, and is reprinted by permission of the publisher. Robert Orr, *Medical Ethics and the Faith Factor: A Handbook for Clergy and Health-Care Professionals* (Grand Rapids, MI: Eerdmans, 2009), 280–83.
2. A life-threatening infection around the brain, in this case caused by a fungus rather than by the more typical bacteria or virus.
3. A decrease in the body's ability to resist or fight infection; can be caused by many things including illness (e.g., diabetes), infection (e.g., AIDS), or drugs (e.g., steroids).
4. Documentation in a patient's hospital chart that a discharge is Against Medical Advice (often called an AMA discharge) is a standard procedure when a patient insists on leaving the hospital but his physician believes this is medically unwise.

Robert D. Orr, MD, CM, practiced family medicine in Vermont for 18 years before receiving a post-doctoral fellowship to study clinical ethics at the University of Chicago. Thereafter, he served as consultant and professor of medical ethics at Loma Linda University (CA), Trinity International University (IL), the Graduate College of Union University (NY), and the University of Vermont before his passing in 2021.

Column Editor: Ferdinand D. Yates, Jr, MD, MA (Bioethics), is a retired pediatrician who has contributed to bioethics education in medical schools, colleges, hospitals and through professional societies. He earned his MA in Bioethics from Trinity International University and was Professor of Clinical Pediatrics at the State University of New York at Buffalo.

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