

Virtual Mentor

American Medical Association Journal of Ethics
November 2002, Volume 4, Number 11: 341-344.

VIEWPOINT

Cultural Differences Intensify End-of-life Care Challenges

Linda MacDonald Glenn, LLM and Faith Lagay, PhD

Evonne, an intelligent and appropriately mature 16-year-old, is suffering from systemic scleroderma, a chronic, autoimmune disease of the connective tissue, generally classified as one of the rheumatic diseases. She has extensive gastrointestinal and myocardial involvement and has been admitted to the pediatric intensive care unit (PICU) because of fluid build-up around her heart. Evonne is malnourished because her bowels are not functioning properly due to scarring from the disease. She has been treated with methotrexate and prednisone over the last 6 years. Her primary care physician describes her condition as "pre-terminal" because Evonne is at imminent risk of heart failure.

Evonne's parents, Mr. and Mrs. B, immigrated to the United States from West Africa, and Evonne and her younger sister were born and raised in the southern US. Evonne's mother suffered cognitive impairment following head trauma from a motor vehicle accident several years ago and is unable to participate meaningfully in discussion of her daughter's care. Mr. B holds to his cultural/religious belief that to talk about death is to invite it. He has adamantly refused to discuss the inevitable course of Evonne's disease and has suggested treatments such as heart/lung transplant. Evonne's physicians respond that her chronic systemic disease would soon reproduce the current damage to those organs. Moreover, the heart/lung transplant would not mitigate Evonne's mal-absorption problems. Her father insists that "everything possible" be done and has refused to discuss a DNR order.

Evonne is a socially active, happy teenager and an A+ student despite her disease. She tells her primary care physician, Dr. T, a pediatric rheumatologist, that she has researched her disease extensively on the Internet's Juvenile Scleroderma Network [www.jsdn.org/]. She has learned about the treatment and is aware of her prognosis. Evonne's father is by her side continuously so that the doctors or nurses cannot speak with Evonne alone. In the presence of Dr. T and her father, Evonne asks, "Am I going to die?" Mr. B quickly intervenes with "Don't be silly—you are not going to die, Tell her, doctor." The doctor somewhat caught off guard, replies, "I don't want to lie to you—it's certainly possible." Upset by this response, Evonne's father has told everyone involved with Evonne's care that they are not to speak about death in front of him or Evonne and that by doing so, they are "inviting the Devil."

Evonne's primary care physician would like to talk to Evonne alone and determine her wishes. He believes Evonne is mature enough to exercise decision-making capacity and would like to know how much she wants to talk about her present situation, her prognosis, and her future treatment. At the same time, Dr. T is aware that Evonne does not want to distress her father. Dr. T believes that intubation and resuscitation would be inappropriate in Evonne's case. His colleagues agree; the pediatric surgeon points out that normal intubation is impossible, due to the narrowing of airways, caused by the disease. Dr. T consults the ethicist about approaching Evonne alone.

Discussion

The serious medical, ethical, and cultural challenges in this case are complicated by the fact that the patient, 16-year-old Evonne, is "pre-terminal," ie, expected to die soon, and apparently discussion of truth-telling and end-of-life medical treatment has not been broached with Evonne's father. Her father does not want Evonne to know of her prognosis, he wants no mention of death in her, or his own, presence, and he wants "everything done" to save her life. The cards seem so stacked against a "good" outcome in this case that Evonne's medical care givers may have to be satisfied with good process rather than good outcome, that is, proceeding on a medical and ethical course that avoids "worst" outcomes.

The outcomes to be avoided include (1) causing Evonne pain by subjecting her to medical interventions that will neither lengthen her life nor make her remaining life more comfortable and satisfying; (2) angering her father and giving him no "face-saving" choice but to remove Evonne from the current clinical setting; (3) setting Evonne and her father at odds with each other so that her last days (and his last days with his beloved daughter) are filled with pain and strife.

The challenges in Evonne's case can be broadly separated into treatment issues on the one hand, and issues of cultural difference in information-sharing, truth-telling, and autonomy, on the other, although these, of course, overlap and affect each other. The cultural/communication/ truth-telling issues highlight the differences between the culture of Western biomedicine and Mr. B's West African American culture. They infuse the treatment dilemmas and need to be resolved, or at least addressed, first.

Mr. B fears that if he, or Evonne, or Evonne's medical care givers discuss death, they will be inviting it or, worse, inviting the Devil, a view that most Western biomedical theory dismisses as unscientific and superstitious. Evonne's best interest will not be served, however, by attempts on the part of her care givers or ethicists to overturn her father's belief system overnight or to ignore it completely, so that they can approach Evonne and talk to her about death. Enrolling the help of hospital chaplains or other spiritual advisors could be effective if a representative familiar with Mr. B's religious tradition can be summoned. If such a person is found, his views must be expected to conform more closely with those of Mr. B than with those of Western medicine.

The fact that Evonne is an unemancipated teenager, that is, one who is still living with her parents and subject to their authority, limits the choices available to those who wish to improve end-of-life care for Evonne without her father's cooperation. The course that may produce greatest peace and comfort during Evonne's final hospitalization may be to honor her father's ban on discussion of death. When Mr. B trusts that no one will talk to Evonne about death, he may allow them to discuss other matters with her, probably in his presence.

There is much to talk to Evonne about besides death. Dr. T can ask her how she is feeling, what causes her pain or relieves it, who she would like to visit with, how she would like to spend her time while in the hospital. Though this course denies Evonne the opportunity to talk about death outright, it may be the only way to avoid contentious division between Evonne and her father or Mr. B and Evonne's care givers and may prevent more severe curtailments of her autonomy. Some cultures approach end-of-life discussions metaphorically¹ and, although this is frowned upon by recent thinking about truth-telling in US bioethics, the approach should not be overlooked. (Recall that the trend to tell patients the truth about their prognosis and "how long they have left" is recent, and many US patients, particularly the elderly, do not want to know the specifics of their prognoses.) Evonne is intelligent and mature. Discussion of what "you would like to happen while you are here in the hospital" may well be understood by Evonne, who has researched her disease and knows she how sick she feels, to mean exactly what it is intended to mean—while you are still *here*. This level of interchange between Evonne and her medical care givers would amount to a not-so-bad outcome, given her father's strongly held beliefs, even though frank discussion of death is absent.

With the cultural impasse banning any discussion between Evonne and her caregivers sidestepped, talk can focus on treatment. In this area, physicians at least have the right to exercise medical judgment in a way that they could not exercise overriding cultural judgment. A surgeon can say, "I will not perform surgery on Evonne because of her current compromised physical condition and because her chronic disease will quickly attack the transplanted organs." Mr. B's refusal of a DNR order is more difficult to manage, although no physician can be coerced to commit what he or she considers to be torture on a patient. Here again, what care givers want to avoid at all costs is causing Mr. B to move Evonne from place to place in search of medical staff who will agree to resuscitate her under all circumstances. Ultimately, medical staff may have to continue dialogue with Mr. B, hoping to convince him to sign a DNR order and hoping that Evonne does not code before they succeed in persuading him. Other treatment questions—eg, intubation—have arisen, and others are likely to arise. Mr. B may ask that an enteral feed tube be placed, for example. Again, physicians must proceed along a medically and ethically justifiable course, attempting to convince Mr. B that these interventions will not buy Evonne time and explaining why they will not.

In sum, then, the least worst outcome that can be expected in Evonne's case is good medical and ethical *process*—open dialogue with Evonne and her father and non-

abandonment of either of them by Evonne's medical care givers. At best, the opportunity may open to talk metaphorically with Evonne about her eventual death and allow her to express her wishes about her time "while she is in the hospital."

References

1. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end-of-life: "You got to go where he lives." *JAMA*. 2001;286(23):2993-3001.

Linda MacDonald Glenn, LLM is a fellow at the AMA Ethics Standards Group. Faith Lagay, PhD is managing editor of *Virtual Mentor*.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2002 American Medical Association. All rights reserved.