daughter served as the family spokesperson, although she stated that her eldest brother who lived in another state had often considered himself to be the family decision-maker. The patient’s community-based primary care physician was advised of his patient’s clinical status, but did not meet with the patient’s family.

The family was advised of the extremely poor prognosis at the time of admission. On the second day following admission, the attending suggested non-aggressive management, but indicated that everything would be provided to assure comfort and dignity for the patient. Pain management and other symptom management concerns were not prominent issues since the patient was deeply comatose within two hours of admission. The family was encouraged to visit at the bedside, and to consult with ICU staff for periodic updates in addition to regularly scheduled discussions.

The patients’ children requested that “everything possible be done” for their mother, and that they believed God would decide when to take her. The family declined a DNR order for their mother even after 24 hours of continued clinical deterioration. Her condition had worsened to requiring full ventilatory support. The family’s minister joined in subsequent discussions, and suggested to the family that “a miracle could happen,” concurring with the family’s request that “everything possible be done.”

At that time, an EEG showed only trace electrocortical activity, with absence of any remnant of physiological rhythm. Although the record was not consistent with a diagnosis of brain death, her prognosis for neurological recovery remained extremely poor. The family was again advised that there was no expectation for neurological recovery, and that death was virtually certain within a few days.

The team felt that they were being asked to provide treatment that they deemed medically futile, and that no meaningful survival of this patient could be expected. An ethics consultation was requested by the attending physician to help resolve what the health care team considered a moral and ethical dilemma.

The Ethics Committee convened and recommended continued discussion with the family in order to reach a care plan acceptable to the family and healthcare professionals. Members of the Ethics Committee supported the concept of not providing further aggressive medical interventions, and indicated the appropriateness of a DNR order, based on medical futility.

Within 36 hours of admission, all four adult children concluded that “nature be allowed to take its course.” They agreed to a DNR order, and simply requested that their mother be allowed to die in peace, with no additional interventions to prolong the dying process. They still requested that she be cared for in the ICU setting, and not be transferred to the floor. On day 4 of admission, all four children with the concurrence of grandchildren agreed that mechanical ventilation could be withdrawn. But very importantly, they did not want ventilatory support withdrawn until the eldest son arrived the following day. His plane arrived the next morning.

The eldest son appeared depressed. He had not seen his mother in over ten years, but had recently talked with her on her birthday. He was dismayed at the family’s decision to withdraw life support, and insisted that “everything be done—we love our mother, and we can’t play God.” He was steadfast in his insistence that aggressive support be continued.

Commentary:
Miracles and Medicine: Helping Families Navigate the Course
LaVera M. Crawley, MD

This scenario could easily represent the narrative of many African-American families. Mortality and morbidity from hypertension, diabetes, and coronary artery disease are high among blacks, all too often leading to presentations at hospital emergency rooms with cerebrovascular events or other acute sequelae of these longstanding serious and eventually fatal diseases. Many African-American patients arrive having not completed advance directives or, when they have completed them, expressing a desire for resource-intensive care.
Once patients arrive at the hospital, staff may find themselves overwhelmed by the accompanying presence of large numbers of family members or other extended support persons who keep watch over their loved one. For some African-Americans, that watch may entail prayer vigils or other expressions of spiritual faith that are central to cultural belief and practices. The appeal to miracles or other forms of divine intervention thought necessary for the patient’s recovery and survival may accompany such demonstrations of faith. It is not always clear what families are asking for when they use the language of miracles. Awaiting a miracle may not always mean belief in an unrealistic cure but rather may simply represent the language of hope.

The medical care system, itself, is complicit in creating expectations for miracles. Technological breakthroughs are often heralded as modern day miracles and hospital or managed care marketing campaigns use slogans such as “miracles happen here.” The central issue in this case, however, stems from differences in treatment goals between doctors and the patient’s surrogates. The medical team deemed Mrs. A.B.’s case to be one of medical futility and “that no meaningful survival of this patient could be expected.” The concept of futility, however, is controversial. How one defines when life begins and ends will vary among and within different cultural groups—including among practitioners of medicine—and what constitutes the quality of a meaningful survival is similarly subjective. For some African-Americans, the quality of life may extend beyond health-related outcomes measured by functional status. What may appear to outsiders as acts that prolong suffering may be seen by others as efforts to ensure equality. At a minimum, given evidence that blacks often receive less processes of care than do whites, the family’s request that everything be done is understandable. At best, it can be reasonably justified.

Issues of trust and trustworthiness may have been central to this case, further complicated by the lack of involvement of a continuity provider. The case was referred for ethics consultation, in which “continued discussion” with the family was suggested. Given the issues raised above, how might such a discussion have accommodated the differences in treatment goals between the medical team and the patient’s family in a manner to foster trust? There are numerous heuristics for approaching conflicts in end-of-life decision-making. Most stress the need to elicit information regarding patients’ or families’ explanatory models of illness and to determine their expectations for care. In this case, consultation or assistance from other African-American health care workers, community leaders, and religious leaders might have facilitated this process. The family should have been asked how they perceived the meaning of suffering. Not only might this have allowed them to give voice to their values and to perceive that the doctors cared by asking, but the answer may have also provided the medical team with new insights that could later guide decision-making. At that point in the discussion, the family’s understanding of Mrs. A.B.’s preferences could have been elicited, referring to earlier statements about her friends being “kept alive on those machines.” In general, the focus of these kinds of family discussions needs to remain grounded in shared goals and values. By so doing, both families and medical teams might be facilitated to modify strongly held positions in order to reach a mutually acceptable solution.

Despite the medical team’s apparent attempts to communicate with the family, this case was complicated by dynamics that were independent of the patient’s race or ethnicity. The absent and estranged son entered the scene bringing seemingly unresolved issues in his relationship with his mother. It would be important for the medical team to recognize this as perhaps a concomitant but indeed separate issue from the spiritual concerns addressed earlier.

Although this case has been interpreted in light of racial or ethnic issues, the problems raised are not unique to African-American patients and families. Understanding the roles of surrogates and other supports for patients; respecting the importance of spiritual and religious beliefs; recognizing the limits of concepts of futility; and fostering good communication and trust are essential elements needed for effective end-of-life care for all persons.

References


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Commentary:
Beyond Ethnicity
Jerome E. Kurent, MD, MPH

This case illustrates the complex interplay of factors relating to goals of care, trust, medical futility, family dynamics, and ethnicity as they impact on ethical medical decision-making at the end-of-life.

Elements of the challenging clinical scenario illustrated in this report are familiar to most experienced physicians entrusted with the care of patients during the end of life; a critically ill patient whose family has difficulty withdrawing what most clinicians would consider futile care. This case is nuanced, however, because these generic concerns take on the additional complexity of crossing ethnic and cultural boundaries. While these ethnic and cultural dimensions are important, it is important to acknowledge that these challenges are not unique to one specific culture and that many of the dynamics encountered in end-of-life care transcend the particularities of ethnicity and race.

To review the case: Mrs. A.B. was an 84-year-old woman who experienced the acute onset of a devastating neurologic event. The large left putaminal hemorrhage with associated mass effect, intraventricular extension, and hydrocephalus caused deep coma that required aggressive medical support to maintain the patient. Only minimal brainstem function was evident on neurological examination, indicating an extremely grave neurological prognosis. Most patients with such a massive intracerebral insult rarely survive for longer than several days even with aggressive medical support. The rare survivor usually exists in an unresponsive neurovegetative state, with no expectation for meaningful quality of life. Hypertensive hemorrhages of the basal ganglia associated with severe neurological deficits are generally not considered surgically treatable lesions given the resulting poor clinical outcomes.

In an era preceding intensive care units and mechanical ventilation, patients like Mrs. A.B. would not have survived for more than a few hours. Prior to the advent of intensive care units, mechanical ventilation, and the technological imperative to support life at any cost, many decision-making issues experienced with this patient would have been rarely encountered.

In this case, end-of-life decision-making was complicated by the lack of a long-standing patient–physician relationship between the attending neurologist and patient at time of presentation to the tertiary medical center. Neither the patient nor family were known to the physician. There had been no previous opportunity to discuss advance care planning.

While African-American patients may be more likely to experience discontinuity of care, this is not a shortcoming that is uniquely experienced by members of that community. Instead, the absence of a long-standing and trusting relationship between the patient, family and physician may be a generic barrier to discussing care plans during an acute life-threatening crisis. The lack of an established relationship in this case may have contributed to a lack to formally engage in advance care planning. That is, while the patient had previously expressed an aversion to being maintained on machines and being connected to tubes in the event of severe irreversible illness, she had not completed a formal advance directive expressing her preferences and avoidances in the event of terminal illness or loss of decision-making capacity.

That failure to formalize advance care planning was further complicated by conflict within the family. Although Mrs. A.B.’s four adult children were in agreement regarding the decision to withdraw life support, these surrogate decision-makers preferred to defer their deci-