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CASE STUDY

Accommodating Religious Beliefs in the ICU: A Narrative Account of a Disputed Death

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Abstract. Despite widespread acceptance in the United States of neurological criteria to determine death, clinicians encounter families who object, often on religious grounds, to the categorization of their loved ones as “brain dead.” The concept of “reasonable accommodation” of objections to brain death, promulgated in both state statutes and the bioethics literature, suggests the possibility of compromise between the family’s deeply held beliefs and the legal, professional and moral values otherwise directing clinicians to withdraw medical interventions. Relying on narrative to convey the experience of a family and clinical caregivers embroiled in this complex dilemma, the case analyzed here explores the practical challenges and moral ambiguities presented by the concept of reasonable accommodation. Clarifying the term’s meaning and boundaries, and identifying guidelines for its clinical implementation, could help to reduce uncertainty for both health care professionals and families and, thereby, the incremental moral distress such uncertainty creates.

Keywords. Brain death, clinical ethics, ethics consultation, reasonable accommodation, religious conflict.

Sarah and Rebekah were as close as sisters could be. They were close in age, in their late-twenties, with Rebekah being older by two years. But more significantly, they viewed each other as best friends. The bonds between them ran so much deeper than their common blood; their connection was emotional, religious, and spiritual. Both were professional women—Sarah a lawyer in a small firm, Rebekah an adjunct history professor at a city college. Atypically within their Orthodox Jewish community, neither Sarah nor Rebekah was married. Their apartments were only a few blocks apart, and they often met for dinner during the week. Every Friday evening, they cooked a traditional Shabbat (Sabbath) dinner for their widowed father after he returned from shul (synagogue).

The tragedy occurred on a weekday. The sisters had not met for dinner and, according to their routine on such evenings, Rebekah telephoned Sarah at about 7:00 p.m. After four rings Sarah’s answering machine was activated on her land-line. A few moments later, Rebekah’s call to Sarah’s mobile phone went immediately to voice mail. Rebekah waited ten minutes—perhaps she was in the shower—but reached only message systems on both telephones. Something is wrong, thought Rebekah, as she...
rushed to Sarah’s apartment building while continuing to try to reach her by phone. After Rebekah ran up four flights of stairs, her persistent and loud knocking on Sarah’s apartment door received no response. She had a key and let herself in while calling Sarah’s name. Lights on, briefcase on the table, jacket on the back of the chair, and Sarah lying on the floor, unconscious. Rebekah dropped to Sarah’s side, dialing 911 as she searched desperately for a pulse.

Only later would Rebekah learn that Sarah probably had lost consciousness after a sudden cardiac arrhythmia. The Emergency Medical Squad had arrived within minutes and had started cardiopulmonary resuscitation (CPR). In the hospital’s Emergency Department Sarah was placed on a ventilator. How long had she been “down”, and how much time had passed since she had taken a breath on her own? How many minutes had gone by without oxygen to her brain? No answers.

After two weeks in an intensive care unit (ICU), Sarah remained unresponsive even to what the doctors described as “painful stimuli” such as rubbing Sarah’s sternum bone. High doses of medications were initially needed to maintain her blood pressure. A tracheostomy was performed to protect her vocal cords from being damaged by the endotracheal tube, but she remained ventilator dependent at high oxygen settings. A few of the nurses had begun to talk openly about the likelihood of severe brain damage, and Rebekah overheard a doctor say that “the patient might be trending toward brain death.”

Rebekah and her father consulted their Rabbi. He counseled that because Sarah was still breathing and her heart beating, she was very much alive and must be treated as such. The Rabbi strongly recommended that Sarah be transferred to a “specialty” hospital, given the absence of signs of improvement, and he offered to use some of his contacts to help make this happen. Rebekah and her father agreed with the Rabbi’s recommendation, and initiated the transfer process.

Upon arrival by air ambulance at the receiving hospital, health care personnel set about assessing Sarah medically and neurologically. Chest x-ray, head CT, electroencephalogram of the brain, pupil reactivity, a Transcranial Doppler test. The tests strongly indicated severe anoxic brain injury and possible brain death.

Within a few hours of transfer Rebekah arrived at Sarah’s bedside. She had notified her Dean that she might need someone to teach her courses for the next few weeks, and she became Sarah’s constant companion, advocate, and protector. Their mother had modeled for them the value of being assertive and insistent, and of taking control of challenging situations. Rebekah resolved to be this kind of person for Sarah just as she knew that Sarah would do the same for her. Rebekah felt very strongly that Sarah would not want the doctors or the hospital or her family giving up on her as long as her heart was still beating.

As of their father’s arrival at the new hospital a day later, Sarah’s doctors had proposed an apnea test to ascertain damage to her brain. Rebekah feared the results and how they might be interpreted—that the doctors would say that her sister was “brain dead”—so she categorically refused to allow the test to be done. Bolstered by her religious beliefs and the teaching of Orthodox Rabbis that death only occurred when a person’s heart ceased to beat, Rebekah held out hope that Sarah would awaken from this comatose state and return to the happy life she had been enjoying a few weeks before.

After Sarah had been at the new hospital for three days, a neurologist who had examined Sarah multiple times reviewed the results of all the diagnostic tests. She placed a progress note in Sarah’s medical record that concluded, “Unfortunately the patient is dead based on neurological criteria. I will meet with the family today to inform them about this unfortunate news.” Informed by her own Jewish background, the neurologist was aware of a profound irony as she wrote this chart note: she would communicate this tragic information on the eve of Rosh Hashanah, when Sarah and her family should have been preparing to celebrate the Jewish new year. It certainly was not a time to be grappling with the death of a youthful and vibrant loved one.

An hour later, at the request of the neurologist and the ICU physician, a social worker approached Rebekah and her father at Sarah’s bedside and asked them to attend a meeting with the doctors that afternoon. The social worker explained with
intentional vagueness, “They want to share with you the test results and make recommendations for next steps.” Rebekah feared the worst. She could barely hold back her tears. In her panic she momentarily closed her eyes in silent prayer, seemed to gain strength, and agreed to attend the meeting, recommittting herself to fight for Sarah’s life. After Rebekah calmed herself, she began to telephone local synagogues to find an Orthodox Rabbi who could attend the family meeting and provide her and her father the religious support she intuitively knew they would need.

The meeting took place as scheduled. Rebekah and her father were accompanied by a Rabbi whom they had met a few minutes earlier. In addition to the neurologist, attendees included the ICU physician, the social worker, and a representative from the hospital’s ethics consultation service (ECS).

Rebekah’s fears were realized. The neurologist began the conversation by stating that she was very sorry to have to give Rebekah and her father such bad news. She then relayed that Sarah had died, despite all bedside observations to the contrary—acknowledging that her heart was still beating and she was breathing and looked alive. Rebekah and her father objected. They explained their belief that Sarah was very much alive and would remain so until her heart and breathing stopped. The Rabbi supported them by reviewing the opinions of highly respected and learned Rabbis.

The ICU physician proposed that, at a minimum, a Do-Not-Resuscitate (DNR) order should be written. The Rabbi countered that any treatment or intervention that could provide even one day of additional life was obligatory. In his view CPR must be attempted, and only if Sarah’s heart did not re-start would discontinuing life-saving measures be appropriate. The ECS representative mentioned that transfer back to the originating hospital or to another acute care facility might be a possible resolution. The meeting took on a schizophrenic tone, with the physicians using clinical, diagnostic, and neurological terms depicting Sarah as dead, and Sarah’s family members and the Rabbi invoking religious doctrine that characterized her as alive and requiring continued life-sustaining treatment.

Fairly quickly it became clear that agreement would not be reached. The ECS representative then recommended what he judged to be a reasonable short-term accommodation to the family’s religious beliefs. Because Rosh Hashanah had such religious significance for Sarah’s family, thus weighing against forced decision making, and its observance precluded them from exploring transfer options, he suggested that everyone reconvene in 48 hours, after Rosh Hashanah had concluded. In the meantime, the level of ICU support for Sarah should continue unchanged.

This recommendation was accepted by Sarah’s family. The ICU physician accepted the recommendation but expressed concern that a new set of issues could arise in the interim if another patient needed ICU admission. This statement angered Rebekah and her father. Rebekah responded that they might need to inform their religious community about the hospital’s willingness to trade one life for another; “Certainly you don’t want it known how disrespectfully we are being treated because of our religion!”

Over the next two days, the clinicians caring for Sarah struggled with their own moral uncertainty, confusion, and commitments related to what was happening and what they were being asked to do. This was especially true of the bedside nurses. While they acknowledged Sarah’s death, she remained a person—or at least a former person—who deserved quality care and respect. Sarah was young, close in age to many of the nurses, heightening their sympathy for Sarah’s family. The nurses had seen families in similar situations cope with bad news and experience grief in many different ways, and so they tried to be understanding and accepting of how Sarah’s family was responding to this tragedy. Some took consolation in the fact that what was being done to Sarah—much of which they themselves were doing—could not hurt or harm her; after all, she was already dead. One nurse wondered whether what they were doing was disrespectful to Sarah’s body, and she questioned whether the temporizing delay reflected kindness toward Sarah’s family or actually harmed them by obscuring the reality of her death. The ICU nurse manager kept anxious watch on the ICU census, grateful that they would not likely need Sarah’s bed for another
patient within the next few days but aware that the situation could change at any moment.

As the end of the 48 hours drew closer, many nurses grew more distressed because, in their judgment, the two most obvious options for resolution seemed equally unsatisfactory: either continue Sarah’s ICU care indefinitely, or defy her family, violate their religious beliefs, and discontinue the ventilator. The inherent inconsistency of providing prolonged and intensive care for someone who had died was taking a toll.

During the days and hours of Rosh Hashanah, Rebekah and her father kept vigil at Sarah’s bedside. They felt a growing mistrust toward the doctors and nurses. They began to monitor the machines and alarms and changing numbers, scrutinizing care providers with watchful eyes. Rebekah had become sufficiently educated during the past three weeks at Sarah’s bedside to interpret the ventilator settings, blood pressure and electrolyte measurements, sodium levels, and medication drips. Her frequent and assertive questioning of the clinicians’ activities earned her the labels of “manipulative” and “intimidating.” Both family and nurses became more cautious around each other.

Although the ICU physician remained committed to honoring the 48-hour accommodation, he worried about what would be next. He interpreted the family’s position of wanting continued ICU treatment as inflexible and unlikely to change. In anticipation of what he projected to be an irresolvable conflict, the physician requested that a formal multidisciplinary ethics team convene as soon as possible after the 48-hour period. The social worker notified Rebekah and her father about this plan and invited them to attend the ethics consultation meeting scheduled for the day after Rosh Hashanah’s conclusion. Once again Sarah’s family felt panic and feared that the physician would issue an ultimatum. After all, the ethics consultation team would be comprised of other hospital personnel, and wouldn’t they be more inclined to side with the ICU physician and his medical team than with an out-of-town family?

In bedside conversations with the social worker and some nurses, Sarah’s family weighed the option of transferring Sarah to another specialty hospital or the hospital that initially received her ambulance. Financial cost was an issue for Sarah’s family, especially if this would be an out-of-pocket expense, but they quickly concluded that this cost would be outweighed by saving Sarah’s life and being faithful to their religious tradition. More important would be finding a hospital willing to accept her.

Rebekah and her father once again turned to their Rabbi at home. His influence in their community never ceased to amaze them. Before the ethics team meeting took place, word came that the hospital back home would accept Sarah—or, in the view of the ICU doctors and nurses, Sarah’s body. Transfer occurred just over 24 hours later. An ultimate confrontation had been avoided.

But was this a desirable and appropriate conclusion to a situation that had been highly distressing and discordant for everyone involved? Would more conversation, discussion and negotiation have resulted in a different and better resolution? Had the hospital’s accommodation to Sarah’s family been reasonable or unreasonable, beneficial or harmful? Should the final resolution of the case be viewed as “win-win” for the disagreeing “sides” entangled in the complexities of a true ethical dilemma?

“Unfortunately the patient is dead based on neurological criteria.”

While clinical and ethical debate continues about the validity and implications of “brain death” (Bernat, 2009; Shah & Miller, 2010; Macdonald, Liben, Carnevale, & Cohn, 2008), determining death by neurological criteria is a widely accepted, if not routine, element of clinical practice in the United States (Siminoff, Gordon, Hewlett, & Arnold, 2001). Since the issuance of a landmark report, Defining Death, by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, medical and secular communities in the United States have largely accepted a “whole brain standard” for determining death, that is, death occurs when all functions of the entire brain, including those of the brain stem, are irreversibly lost. Urging the need for a uniform
and practicable standard for clinical determination of when death occurs, the report influenced the Uniform Determination of Death Act (UDDA), a statutory template drafted by the National Conference of Commissioners on Uniform State Laws. The UDDA provides:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. . . .

Identifying neurological criteria as one of two methods for establishing death, the UDDA (or a version with slight modifications) has been adopted in most of the 50 United States (Olick, 1991). Despite the legal clarity, clinicians continue to encounter families who object to the categorization of their loved ones as “brain dead,” and to struggle, as Sarah’s case exemplifies, with the moral ambiguity of how to respond.

“. . . because Sarah was still breathing and her heart beating, she was very much alive. . . .”

Sarah’s family adopted the objection to the concept of brain death espoused by traditional Orthodox Jewish doctrine. Halakha, literally “walking” or “the way”, is the collective body of laws and rules of Judaism, derived from scripture, rabbinic commentaries and customs of the Jewish people (Swa-tos, 1998). According to halakhic law, death ensues only after the cessation of respiratory and circulatory function. Under this perspective, the beating heart and breath of a patient, even if artificially maintained, belie the conclusion of death by neurological criteria; the patient remains alive (Bleich, 1995). Orthodox Jewry recognizes within its own community regarding the moral and religious acceptance of brain death criteria (acher, 2008). Some rabbinic authorities find modern brain death criteria analogous to decapitation and therefore a tolerable standard for determining death (Tendler, 1990). However, those who oppose the concept of brain death pose a significant challenge for clinical caregivers because withdrawing mechanical support from a patient deemed dead by neurological criteria is, from an Orthodox believer’s perspective, tantamount to murder (Zweibel, 1989).

“Certainly you don’t want it known how disrespectfully we are being treated because of our religion!”

Reflecting the prevalence of Orthodox Jewish populations within their borders, the states of New York and New Jersey have modified their legislative approaches to the determination of death in an attempt to accommodate religious objections. The two states’ policies differ, but both concede that religious or moral objections to neurological criteria may outweigh societal interests favoring uniformity in determining death.

New Jersey’s law offers the strongest protection of religious dissent, providing actual exemption to a determination of death by neurological criteria. If a physician has reason to believe “that such a declaration would violate the personal religious belief of the individual” (N.J. Stat. § 26:6A-5, 1991) death is pronounced only upon irreversible cessation of heartbeat and respiration. Thus the statute does not alter the methods by which death can be declared under the UDDA, but permits religious rejection of the neurological standard. Clinicians operating under this approach must continue to provide cardio-respiratory support for the patient until cardiac and respiratory function has irreversibly ceased.

In New York, recognition of religious objection appears in regulations requiring reasonable accommodation of religious or morally-based rejection of neurological criteria for determination of death. The law clearly legitimizes whole-brain death as a legal standard, asserting that death shall be deemed to have occurred upon the completion of neurological confirmatory tests specified in 10 N.Y.C.R.R. § 400.16. However, prior to final determination and notation of death, i.e., while the patient remains legally alive, hospitals must inform the patient’s legal representatives that the determination of death “will soon be completed”, enabling them to assert an objection. Importantly from a secular health care ethics perspective, according to New York State Department of Health (DOH) guidelines supplementing the regulation, the accommodation provision applies only to religious or moral objections; neither psychological denial nor a generally-stated
conscientious objection suffices to support accommodation (New York State Department of Health Guidelines for Determining Brain Death, 2005).

“. . . a reasonable short-term accommodation. . .”

In clinical practice, “reasonable accommodation” remains an important but ambiguous concept. Direction from states with codified mechanisms for addressing religious or moral objections is minimal. While New York law specifically references “reasonable accommodation” of religious objections to a determination of brain death, it offers no explanation of what the phrase actually means. New York DOH regulations require hospitals’ written policies to include:

a procedure for the reasonable accommodation of the individual’s religious or moral objection to the determination as expressed by the individual, or by the next of kin or other person closest to the individual.

Thus, New York law explicitly requires hospitals to delineate a procedure oriented toward accommodating a patient’s religious beliefs and values, but offers little guidance on exactly what that means for clinicians: “the meaning of accommodation and its ethical parameters are subject to interpretation and may vary across New York hospitals” (Olick, Brian, & Potash, 2009). The determination of death is delayed during the period in which reasonable accommodation takes place, and the requirement of a written policy identifying a procedure suggests that institutions must assert their own plan for clinical management of patients being reasonably accommodated. The New York DOH Guidelines for Determining Brain Death advise that hospital policies “may include specific accommodations, such as the continuation of artificial respiration under certain circumstances, as well as guidance on limits to accommodation,” but provide no more specific basis for justifying an institution’s boundaries.

In New Jersey, legislation effectively asserts that religious objections to brain death criteria can be reasonably accommodated only by negating their applicability to opposed patients. The approach neglects the practical and clinical challenges posed by extending somatic support of these patients, and ignores clinicians’ ethical struggle with treating patients they perceive to be dead. Regardless of whether reasonable accommodation is legally required, the concept is an ill-defined target within clinical practice.

“. . . the clinicians . . . struggled with their own moral uncertainty, confusion, and commitment. . .”

Once Sarah’s condition met criteria for death by neurological criteria, clinicians questioned how they ought to respond to the family’s directives, particularly the extent to which they should accommodate family insistence on continued medical intervention. Throughout the three days of Sarah’s subsequent ICU stay, they continued to examine whether they were acting ethically in delaying withdrawal of the ventilator from her. Though no law or regulation required “reasonable accommodation,” compassion for the family and recognition of their need for time to grieve Sarah’s devastating injury compelled a desire to avoid antagonizing them. The religious foundation of the family’s objection heightened the moral uncertainty and emotional distress that accompany, under any circumstances, the prospect of disregarding family wishes for continued medical intervention. Rebekah’s threats to inform the local Orthodox community about the confrontation further exacerbated tensions.

Contemporaneously though, the clinicians experienced moral distress about whether accommodating the family was a beneficent act, or whether continued medical intervention muddled a message the family needed to accept. Monitoring and performing medical treatments on a dead body for several days, they weighed their own professional integrity and values against the justifications offered for continued accommodation of the family’s demands (White & Brody, 2011).

“In the meantime, the level of ICU support for Sarah should continue unchanged.”

Once Sarah’s health care team committed to accommodating the family’s opposition by delaying further decisions during Rosh Hashanah, they con-
fronted practical ambiguities produced by the delay. The published literature offers substantial direction on sustaining brain-dead bodies. However, this guidance is usually oriented toward maximizing the value of organs intended for transplantation, an accepted goal in American society. The ethical justification for organ transplantation itself supports the act of maintaining the body, i.e., anticipated benefit accruing to the transplant recipient justifies resource expenditures to preserve organs and the potentially undignified or unusual treatment of a dead body. Organ preservation not only defines a morally acceptable goal of care but clarifies the clinical parameters for the care itself.

In contrast, the absence of a uniformly accepted goal in Sarah’s care precluded clear guidelines for her clinical management. Rosh Hashanah provisionally offered a definitive boundary for the term and scope of accommodation, ameliorating some team members’ discomfort with maintaining somatic support. However, the two-day window only temporized the ethical dilemma and decision making because uncertainty remained about what course of action would follow. Moreover, while the question of “reasonable accommodation” and its possible limits would need to be addressed after two days, caregivers faced immediate uncertainties. What should be Sarah’s target blood pressure? Should the team add antibiotics not already in use? Should platelets or other high-cost interventions be provided? Would they resuscitate if Sarah’s heart stopped?

Caregivers could not detach these clinical questions from their ethical concerns. The inherent inconsistency of the situation was palpable. As had been asserted to Sarah’s family, Sarah was dead, yet the caregivers found themselves doing interventions they would not have done if she were dead, such as maintaining electrolytes or responding to changes in blood pressure. Awareness that Sarah was dead by neurological criteria exacerbated discomfort with these interventions as caregivers felt they were treating a corpse disrespectfully. These day-to-day aspects of Sarah’s support then became matters of further dispute as Rebekah monitored and challenged the nurses’ activities. Rebekah’s focus on such details fueled concerns that the family’s rejection of Sarah’s death reflected psychological denial along with religious opposition to the concept of brain death.

“. . . a new set of issues could arise in the interim if another patient needed ICU admission.”

From the outset of questions about reasonable accommodation in Sarah’s case, consensus among the medical team members and ECS representative was clear and explicit that, even within the two-day window, an immediate need for an ICU bed for another patient would prevail over the family’s claim to accommodation. Their consensus and the family’s angry response to it exemplify the ethical hazard of allowing a negotiated standard for determining death. For the hospital, a fundamental professional threshold not to be crossed in accommodating the family’s religious perspective was depriving another patient of potentially therapeutic intensive care. Notably, the Regulatory Impact Statement for Initial Proposal of 10 N.Y.C.R.R. § 400.16 issued with New York’s “reasonable accommodation” regulation indicates that accommodation would not be acceptable in, “instances when maintenance of a brain dead person would result in harm to another patient for whom meaningful life could be saved.” For the ICU staff, allocating a bed to a patient with a reversible medical condition rather than to a corpse would be an obvious choice to preserve life. However, merely acknowledging this possibility manifested to Sarah’s family a willingness to allow her to die for the sake of another. From their perspective, this was a moral horror exacerbated by the implication that Sarah’s ICU stay was wasteful.

Even absent such a clear need for the resources consumed by Sarah’s ICU stay, stewardship obligations and possible violations occupied her caregivers. The long-held tenet against bedside rationing references living patients. No such proscription applies after death; no sanctity of life principle is protected by funneling health care resources into a dead body. In addition to the tangible resources Sarah’s support required, the physicians and nurses
questioned whether and how their training and energy ought to be allocated under the circumstances. When even indirect benefit to a patient by comforting or “treating” the family could not be surmised, the basis for continuing support diminished. Additionally, some caregivers questioned whether accommodating Rebekah and her father’s request for delays actually served the family’s best interests; they worried that accommodation instead fueled their non-acceptance of Sarah’s fate and impaired the family’s progression through anticipated and necessary stages of grief.

Offending a family member by unilaterally withdrawing life-sustaining treatment might be construed as a wrong against a dying patient who, if he or she could express a desire, would not wish family members to suffer. The ongoing “medical futility” debate reflects the affront to professional integrity posed by aggressive treatment administered to imminently dying patients, and raises questions similar to those raised by Sarah’s continued ICU treatment. Is placation of family members a sufficient reason to justify resource expenditures and the imposition of burden on patients who will not benefit? While some might assert that Sarah, embedded in her family’s religious and cultural beliefs, would support her family’s desire to sustain her body after a declaration of death by neurological criteria, assertions grounded in individual autonomy and nonmaleficence fail to abate concerns about expending resources on a dead body.

“...the physician requested that a formal multidisciplinary ethics team convene...”

Sarah’s medical team proactively consulted the hospital’s ECS and invited a representative to participate in the initial family meeting after Sarah’s death by neurological criteria had been determined. Anticipating that the family would continue to object to Sarah’s characterization as dead after the conclusion of Rosh Hashanah, the medical team sought further consultation with a multidisciplinary ethics consultation team. Had that occurred, the focus of the ethics team’s deliberation would likely have been to assess whether the accommodation of Sarah’s family’s perspective reflected an optimal balance among competing values, or whether additional accommodation was ethically warranted. Specifically, the consult team would have considered whether unilateral withdrawal was ethically justified. If the ethics team had recommended further accommodation, it would likely substantiate its position with additional advice on what further action or inaction ought to occur, and where outer boundaries of accommodation might rest.

As is the case with most ECSs in the United States, the ethics team’s conclusions and recommendations would have been advisory (Fox, Myers, & Pearlman, 2007). Ultimate decisions about whether and when to discontinue somatic support would require the individual actions of the respective clinical team members, who dreaded the prospect of confronting Sarah’s family under those circumstances. Moreover, an ethics opinion would not have resolved practical ambiguities and confusion about how to proceed. Following a decision to withdraw, would the ICU physician have had to write medical orders to discontinue life-supports for a patient who was already dead? Similarly, would the ICU physician have had to write a DNR order in Sarah’s medical chart? Regardless of whether actual medical orders were necessary, the ICU physician would have needed to authorize discontinuation of the ventilator and other medical interventions. The physicians and nurses would then have carried out this process, presumably with Sarah’s family present. An ECS’s support and opinion of ethical justification would not likely dispel the anguish that would result.

“Sarah and Rebekah were as close as sisters could be.”

Throughout this ordeal, Sarah’s caregivers were struck by the degree of love and commitment Rebekah manifested toward her sister. While the exact nature of their bond could only be surmised, its force permeated care providers’ anxieties about how she would respond to the ultimate outcome of the situation. Rebekah’s motivations to protect and preserve the life of her sister were likely multiple,
intertwined, and even conflicted. Strict fidelity to tradition and rabbinic authority has sustained the Jewish Orthodox community through thousands of years of being a persecuted minority. Rebekah and her father standing in solidarity with this tradition enabled them to affirm their identity within this close community and experience the security deriving from membership. Rebekah’s religious faith and commitments likely provided her with a sense of existential meaning and identity when she was confronted with the frightening boundary between life and death. For many persons, religious faith takes on particular value during such a life crisis, perhaps explaining why a believer would refuse to abandon religious tenets no matter the countervailing arguments and evidence.

At the same time, Rebekah shared with Sarah the distinction of being an unmarried woman in a male-ordered community in which the roles of wife and mother are primary vehicles for religious expression and obligation. Together they had grieved the loss of their mother, and since then had shared the duty of caring for their father. As well, they had merged their day-to-day lives—their schedules, their dinners together, the proximity of their homes—as modern professional women. These common and personal characteristics may have further solidified their emotional and spiritual bond during life, and exacerbated Rebekah’s pain and grief when faced with the possibility of being left without her younger sister. Should Sarah die, Rebekah’s potential loss, suffering, and grief would have been deep, profound, and seemingly without relief. It may have been nearly impossible for Rebekah to accept any other perspective than the belief that Sarah was alive.

An Epilogue

In the case narrated and analyzed here, an ultimate confrontation was avoided between a deeply religious family and deeply committed health care professionals. Akin to a deus ex machina intervention in a classical Greek tragedy, a transfer to the hospital back home relieved the intensifying distress and conflict over Sarah’s “disputed death.” For most of the principal stakeholders in the case, the resolution may have been optimal under the circumstances. As tragic as Sarah’s outcome was, her family was not forced to condone the termination of their still-living loved one. The health care team perhaps temporarily compromised values and commitments by maintaining a dead body in an ICU, but was not forced to abandon them indefinitely.

The serendipitous resolution of this one case at this one hospital should not diminish the importance of proactive planning for future and similar cases. Assuming “reasonable accommodation” of objections to brain death is ethically appropriate in some cases, health care organizations and institutions, and their ethics committees, should clarify the term’s meaning within their facilities. Clinicians need practical guidelines for such cases, geared toward both medical management of patients and interactions with patients’ families. Institutional policies offering explicit guidance about how to handle the conflict and identifying the bounds of reasonable accommodation could help to reduce uncertainty for both health care professionals and families, and, thereby, the incremental anxiety such uncertainty creates.

Moreover, reasonable accommodation policies implicitly anticipate an endpoint, whether it be a “natural” one, when somatic support fails, or when accommodation extends beyond “reasonable,” however it might be determined. Without the transfer, the case described here might have been intractable, i.e. reaching a dramatic denouement in which the hospital either conceded to maintain Sarah’s body until cardiac death, or ceased its accommodation and withdrew Sarah’s ventilator despite her family’s objection. Thoughtful planning for such a potentiality cannot eliminate moral regret that all the values at stake cannot be upheld or the distress of decision-making. Nevertheless, even in situations of irresolvable dilemmas, processes can be implemented that increase the likelihood of clear, respectful, and emotionally sensitive communication; the extension of compassionate care; and the availability of education, guidance and counseling for those navigating the conflict.
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