case study

Duty, Distress, and Organ Donation

A man of twenty-two is admitted to an intensive care unit (ICU) after intentionally overdosing on Tylenol. Prior to the overdose, he was physically well, and most of his organs are still healthy, but his liver failure is severe, and his mental status has declined to the point that he needs intubation and multiple vasoactive medications to stay alive. His family is at the bedside round the clock. His condition continues to worsen over the course of twenty-four hours, and he begins exhibiting signs of worsening cerebral edema. A CT scan of his head reveals impending herniation, which could quickly lead to brain death.

The local organ procurement organization has been following his case; however, no one from the agency has spoken to the family about the possibility of organ donation. Overnight, it becomes clear that the patient will not survive. The OPO's representative is no longer on site. The nurse caring for the patient is busy at the bedside managing his unstable condition and his increasingly distraught family.

The nurse asks the intensivist on call if someone from the OPO should be called in to speak to the family, given the worsening clinical picture and the likelihood that the patient will progress to brain death. The patient's condition is such that multiple organs, including his heart and lungs, could be donated. The intensivist instructs the nurse not to call, as he wishes to have an end-of-life discussion with the parents. He believes that the parents should know that death is imminent and that further interventions will not save their son. He argues that introducing the OPO at this point will cause the family more distress. He wants the parents to be able to give their son a peaceful death without additional stressors.

What are the broader implications of not calling the OPO at this juncture? Does the nurse involved have an ethical obligation to override the intensivist's instructions by calling the OPO? Should the fact that multiple healthy organs could be harvested from this patient's body have any bearing on the decision to call the OPO?

commentary

by Aimee Milliken

This case presents a challenging scenario in which multiple competing interests are at play. Health care providers can feel a powerful emotional responsibility toward patients' families, and, in this case, both the nurse and the intensivist have an instinctual desire to provide comfort to the patient's family. Yet in his desire to protect the parents from further pain, the intensivist unilaterally makes a decision that not only prevents certain potential benefits to other patients but that also may cause the family more harm than good.

The nurse in this case has an ethical obligation to call the organ procurement organization, despite the intensivist's objection. A referral to this organization can be made by any member of the care team (the referral is, in fact, a legal obligation in cases of imminent death according to the Conditions of Participation set by the Center for Medicare & Medicaid Services). In the case of this patient, the referral has already been made, but the OPO should be notified of the new clinical decline. Notifying the agency early enables any potential discussions to be planned out, not rushed or hastily done, and for plans to be communicated to the entire care team. It is up to the OPO to ensure that, once the end-of-life discussion has been had, the follow-up organ donation discussion is sensitive to the distress the family is experiencing.

The opportunity to make the decision to donate their son's organs may provide this family with a sense of closure and a sense that at least some good came from his death. Alternatively, the family may not perceive it this way, but this is not up to the intensivist to decide. Regardless of what decision the family ultimately comes to, depriving them of the opportunity to make this decision is depriving them of the ability to make one final, autonomous decision on behalf of their son.

On a broader level, the decision not to notify the OPO is detrimental to potential recipients of this patient's organs. While the sheer number of organs to be donated should not be a deciding factor in this case—even one kidney can save a life—the decision not to call has potential consequences far beyond this case.

Since the National Organ Transplant act of 1984, there have been many efforts to increase organ donation rates in the United States. Challenges remain, and opportunities for organ donation discussions are often missed, as this case elucidates. As long as there continues to be an "us against them" mentality, families will continue to be deprived of the opportunity to have these discussions by providers who consider the conversation

to be an additional burden upon the family. OPOs and hospital care providers need to work in conjunction with each other in these cases to achieve what is best for the patient and family, whether this means donation or not.

Policies to facilitate this, such as the Massachusetts Organ Donation Initiative, are crucial in educating providers. Provider education helps ensure that these difficult conversations be held in a timely manner and that they are led by trained professionals sensitive to the distress experienced by families in situations like the one in this case.

As we have seen in recent, widely publicized cases on brain death, the medical bases for the determination of death remain misunderstood by the general public. The ethical questions surrounding organ donation and the determination of death are also unchartered territories for most people. Public dialogue is necessary to shed light on these topics so that misinformation does not lead to fear and mistrust of health care providers. Lifting the veil of secrecy and incorporating conversations about organ donation into everyday discussion will help patients and providers to talk frankly about patient wishes. Further, widespread information about what organ donation involves and what the decision to be a donor means may even contribute to families' initiating of these difficult conversations.

commentary

by Anji Wall

This case holds the potential to cause the nurse moral distress. The above commentary argues that the nurse has both an ethical and a legal obligation to call the organ procurement organization about her patient's decline despite the express direction by an attending physician not to do so. While calling the OPO appears to be the right action, the nurse may well be conflicted about doing this because of the directions given to her by a superior. The right thing to do in this case is clouded by the unequal power relationship between the nurse and the attending physician and by the consequences that going above the express directives of this attending could have on the nurse's work environment and perhaps even her employment.

Moral distress occurs when a person knows what he or she considers the right action to take but is restrained from taking it. It is important to distinguish between moral distress and an ethical dilemma. When an individual experiences an ethical dilemma, he or she recognizes that two or more ethically justified but mutually opposing actions can be taken. However, in a situation that generates moral distress, the individual believes that a particular course of action is right but is unable to act on that belief. A key element in moral distress is the actor's sense of powerlessness. The nurse is not empowered to contact the OPO because she has been instructed against this course of action by a superior.

When someone is placed into a morally distressing situation, it is often difficult, if not impossible, for this person to perform what he or she considers the ethically right action. The internal distress can be emotionally draining. The nursing literature describes many strategies for dealing with moral distress. The American Association of Critical Care Nurses describes a strategy of four As: Ask, Affirm, Assess, and Act. Individuals, or actors, should first ask themselves if they are actually feeling moral distress. In this case, it appears that the nurse believes that the OPO should be called because she brings this question up to the attending physician. Actors should next affirm the aspect of their moral integrity that is being threatened. In this case, the nurse is being forced to deny the family the opportunity to donate their son's organs. We can imagine that the inability to give the family this option is the source of her distress. In the affirmation process, she could validate her feeling of moral distress with coworkers and get their input regarding next steps for action.

The final element of the affirmation stage is to determine whether one is under an obligation to act. The nurse should ask herself, "Is this situation distressing enough that I should act to change it?" If the answer is yes, then she has to determine her options for action. The nurse could try to convince the attending to call, she could call herself, or she could talk to a superior about calling. Alternatively, she could refrain from calling but make it a priority to change the policy surrounding contacting an OPO when there is a potential organ donor in the ICU. The goal of affirmation is to make a commitment to address the moral distress.

The next step in evaluating moral distress is to assess the situation more thoroughly. The assessment stage reconfirms the source of distress, quantifies the severity of distress, and gauges readiness to act. We have imagined that the nurse has already identified the source of her distress, but its severity is unclear. Contributing factors could include this physician's history of not contacting OPOs, the ICU's culture with respect to communicating with OPOs, and prior experience of other families' interactions with an OPO. The action the nurse chooses should reflect the severity and source of the distress. For example, if this situation is consistent with this attending physician, the nurse may choose to address the problem at a higher institutitonal level with an initiative to have nurses be the contact point for the OPO. If this is a one-time occurrence, she might reapproach the attending about contacting the OPO or ask her charge nurse to approach him. (Note that implementing the four As is not always a linear process. For example, if the severity of distress turns out to be minimal during the assessment stage, it is important to revisit the affirmation stage to determine if action is obligatory.)

The final, and most difficult, step in addressing moral distress is action. As discussed, the nurse could choose a myriad of actions. Ultimately, whether she calls the OPO, urges the attending to, talks to another superior, or takes initiative to change the hospital's policy on and culture surrounding contacting the OPO, the nurse is justified because of her vulnerable position in this scenario.

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