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When the Patient Just Says No

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Stem Case and Key Questions Content

A 19-year-old male is brought to the emergency room after being struck by a car. He is tachycardic to 140 and hypotensive to 85/55. His oxygen saturation is 95% on a NRB which he frequently removes. He is conscious, but combative with medical personnel and there is the odor of alcohol on his breath. He has contusions to his abdomen and chest wall, as well as an apparent fractured femur. Based on radiographic studies there is concern for active abdominal bleeding and a moderate hemothorax on the left. No obvious injuries to the head or neck are appreciated. Intravenous access is obtained with difficulty in the ER and a left chest tube is placed which continues to drain blood. He is taken to the operating room for an emergent exploratory laparotomy and thoracotomy.

After being transferred to the operating room table, he states, “Don’t you dare put a tube in my throat. I know what I’m saying.”

1. What are the additional questions that should be asked, if any before inducing anesthesia?
2. How would you determine if the patient had capacity?

3. Would the situation be different if he were 17 rather than 19?

Anesthesia is induced with a rapid sequence technique, and the airway is secured. The operation begins and the patient requires escalating doses of vasopressors to maintain adequate hemodynamics. Blood products are being prepared when a nurse enters the room and states that she has just had a conversation with the patient’s mother in the waiting room who states that he is a devout Jehovah’s witness, and would never want to receive exogenous blood products.

4. Is the patient’s mother an appropriate surrogate decision maker?

5. What questions, if any, should be asked of the patient’s mother before blood products are administered?

6. Would the approach be different if the patient’s hemodynamic status was more stable, but his hematocrit was falling?

7. Would the situation be different if he were 17 rather than 19?

The patient is resuscitated in the OR with vasopressors, fluids, and blood products. Bleeding is surgically controlled. However, he remains tachycardic and hypotensive. A TEE probe is inserted into the esophagus and a transgastric view reveals an ejection fraction of approximately 30%. An inotrope is started before he is transferred to the ICU and hemodynamics improve. The following morning, he continues to recuperate and is extubated. A member of the anesthesia team visits the patient for postoperative evaluation. He appears completely alert and seems angry. He asks, “Why did you put a tube in my throat when I told you not to? You have assaulted me.”.

8. How should the patient’s concern be addressed?

9. Had assault been committed?

The patient’s wife comes into the room and tries to calm him. Outside the room, she reports that the patient had been very depressed prior to his accident because of a recent diagnosis of nonischemic dilated cardiomyopathy. She believes this may have made him suicidal. She also reports that the patient was raised as a Jehovah’s witness, but is no longer observant, which has caused a conflict with his mother.

10. How should the wife’s concerns regarding depression be addressed?

11. How might depression or other psychiatric illness affect the determination of capacity?

12. If he is found not to suffer from depression, should medical care be removed if he requests?

Although the patient cooperates with most of his care, he continues to intermittently refuse blood draws and medication. A psychiatric consult is obtained, and he is found to have medical decision making capacity, but to be suffering from depressive symptoms secondary to his recent diagnosis of heart failure. With continued daily visits from a psychiatrist and the initiation of antidepressants, his mood seems to marginally improve and he is more cooperative with his care. However, he continues to remain dependent on vasopressors and inotropes. He shows signs of renal failure and volume overload. A repeat TEE shows an ejection fraction of 10-15%. An intra-aortic balloon pump is inserted with minimal improvement. A cardiac surgeon is consulted and recommends left ventricular assist device insertion as a bridge to transplant. The patient refuses and states he doesn’t want to, “become a machine”.

13. Should his wishes be honored?

14. What if he loses consciousness and his wife who is his proxy consents to LVAD placement?

The patient decides to undergo LVAD implantation after all. He returns to the ICU and gradually recovers until discharge. Three months later, he receives a heart transplant and initially does well, however, then develops persistent cough and fever. He is placed on isolation for concern of possible tuberculosis infection. He is not compliant with isolation and often is found wandering about the halls. After several days, he demands to be allowed to go home.

15. Can he sign out against medical advice (AMA)?

16. How can his right of autonomy be reconciled with his infectious risk to the public?

17. What if he had an infection that was not a risk to public health?

The patient is treated for TB with antituberculins, however, again begins to demonstrate signs of heart failure. A diagnosis of subacute rejection is made and after rapid deterioration, biventricular assist devices are inserted with his consent. He is then confined to the ICU because of his devices, but he is extubated and able to communicate with family. He returns to the OR several times for chest washouts, debridements, and revisions of his VADs. Over the next several months, his heart makes a modest recovery in terms of biventricular function. His prospects of receiving a second heart transplant are poor due to antibodies from repeated transfusion. The cardiac surgeon and ICU attending determine his best course is VAD explant. The patient refuses, stating, “You’re just trying to turn me off”.

18. Should his devices be explanted?

19. Is there a limit to the health care resources that should be spent for this patient?

Model Discussion Content

Modern medical practice is rife with ethical dilemmas that only increase in complexity with advances in biomedical technology[1,2]. For example, how do we allocate advanced life sustaining technologies, such as ventricular assist devices (VADs)? When is it appropriate to withdraw care? How do we make decisions for critically ill patients who cannot communicate their wishes? As perioperative physicians, anesthesiologists may feel somewhat shielded from these issues. After all, by the time we encounter our patients, the thorny ethical decisions have already been made. It may seem that our course of action to adhere to good ethical practice is always clear: take care of the patient to the best of our ability, see them safely through their procedure, and return them to their other medical caregivers.

However, things are not always so simple, and even an anesthesiologist whose practice is strictly limited to the operating room cannot afford to ignore the principles of bioethics. Specifically, anesthesiologists need to be particularly well versed in the ethical guidelines surrounding informed consent. As we are usually the last to communicate with patients and their families before they submit to an invasive procedure, we are in a unique position as the final protector of patient autonomy in the perioperative arena[3].

Although the majority of adult patients are able to provide consent for procedures independently, others are not able to make these critical decisions for themselves, so a surrogate provides consent on their behalf. Some of these patients are unable to communicate at all. Others lack decision-making capacity, but agree with the plan to proceed with a procedure. In other words, these patients provide their *assent*, although they are not able to provide *consent*. But what about when the patient just says ‘no’? What if the patient disagrees with their surrogate? When, if ever, is it ethical to force someone to go under the knife?

The anesthesiologist faced with hashing out these less common, but critical decisions has to be prepared to address the issue quickly and in a manner that adheres to both ethical and legal principles. To resolve such a dilemma, the first question to address is whether the patient has the capacity to make medical decisions. Some people clearly lack medical decision-making capacity such as those in a coma, the frankly psychotic, or young children. Other times it is less clear. For example, a patient may be able to carry on a normal conversation yet lack capacity, while another may not be completely oriented and have it. The determination of capacity has three components[4]:

1. Understanding: The patient must be able to understand the relevant information about the disease, treatment options, and recommendations of the physicians. The patient must also be able to communicate a choice.2. Evaluation: The patient has a framework of values that will enable him to judge whether a particular health care decision will accomplish what he considers good for himself.3. Reasoning: The patient can deliberate and reason about how available courses of action will affect him. An important factor in this determination is that decision-making capacity is situation specific. For example, one may have the capacity to make medical decisions, but not financial ones. However, once a determination of medical decision-making capacity has been established, it is absolute, and a person cannot be found to have the capacity to make some medical decisions, but not others. Furthermore, a patient found to have medical decision-making capacity is free to act autonomously and make their own decisions based on their values, however irrational those decisions may appear to someone else[5].

An appropriate evaluation of whether someone has capacity is not trivial, and usually requires more time than we have with our patients prior to surgery. Psychiatrists are considered among the best evaluators of capacity, and then only after a thorough examination. Capacity can also wax and wane with a patient's mental status, further complicating assessment. It should also be appreciated that physicians, other clinicians, and family members have their own biases regarding a treatment plan, and it is all too common for even those with good intentions to only question capacity after the patient has ceased to agree with that plan[6].

Furthermore, when a patient does not have capacity, we cannot simply do whatever we want. A surrogate must make decisions on behalf of the patient, preferably a proxy selected by the patient prior to the loss of capacity. However, if this is not the case, then an alternate person can be appointed. In New York State, the Family Health Care Decisions Act delineates how to select a surrogate in such circumstances. Other states have similar statues that usually give priority to spouses followed by other family members or acquaintances[7]. In the absence of an appropriate or willing surrogate among the patient's family or friends, one must be appointed in a court of law, if time permits. Only in the urgent or emergent setting may physician representatives bypass the court to serve in this roll[8].

Once a proxy is determined, this person should follow two principles to guide decision-making on behalf of the patient: substituted judgment and best interests. The principle of substituted judgment simply means that the proxy makes decisions as the patient would were they able to

do so based on their values and thinking. Ideally, this is based on advanced directives written by the patient or detailed conversations the patient had with the proxy prior to their loss of capacity. Often patients have proxies, but no advanced directives, so the proxy must either rely upon what they know of the patient's values to make decisions that they think they would have made, or to act in their best interests. The principle of 'best interests' is somewhat more nebulous and open to interpretation as it refers to the obligation of the surrogate to make a decision that would lead to the best possible outcome for the patient[4,6].

Additionally, a patient without medical decision-making capacity still has rights of autonomy and their expressed wishes should be respected even if contrary to decisions made by a surrogate. New York's Family Health Care Decisions Act specifies that if a patient without capacity either disagrees with the assignment of a surrogate or decisions made by that surrogate in the non-emergent setting, the case must go to court to be settled[8]. There are, however, limits to the patient's right of autonomy, regardless of their decision-making capacity. For instance, a patient who poses a threat to society either because of psychiatric instability or infection cannot simply walk out of a hospital, and clinicians are bound by the ethical principle of justice in preventing them from doing so[12].

Anesthesiologists can expect to find themselves in situations in which they must address an ethical quandary in clinical practice, frequently when time is of the essence. We must, therefore, be adept at using a systematic approach to these issues and have a working knowledge of both bioethics and the law. Critical to the approach of ethical dilemmas that arise in the perioperative period are timely decision-making, communication between different interested parties, and a team-based approach.

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