Bioethical Issues Related to Limiting Life-Sustaining Therapies in the Intensive Care Unit

Debra L. Wiegand, PhD, RN ❍ **Marian S. Grant, DNP, RN**

Decisions to limit life-sustaining therapy occur often in the critical care setting. Bioethical dilemmas may occur as decisions are made to withhold and/or withdraw life-sustaining therapy. Even when the decision to limit life-sustaining therapy is ethically appropriate and clear, there can be issues. A case will be presented to illustrate dilemmas that can arise as these difficult decisions are made. The following bioethical issues will be discussed: (1) When is it ethical to limit life-sustaining therapy? (2) Who should make decisions when a patient is unable to make his/her own decision? (3) What should be done if a patient's previously stated wishes are not honored? (4) What should be done if a patient is suffering? It is essential that bioethical issues are identified and addressed.

KEY WORDS

bioethics, life-sustaining therapy, life-sustaining treatment, life support, moral distress

Of those patients who die in the intensive care unit (ICU), most do so after decisions are made to limit life-sustaining therapies (LSTs). Withholding or deciding not to initiate LST may include decisions not to perform cardiopulmonary resuscitation (CPR) if an individual's heart stops or not to start renal dialysis if a person's kidneys fail. Decisions to withdraw or remove LST may include decisions to stop mechanical ventilation, vasopressor therapy, and a ventricular cardiac assist device or deactivate an implanted cardioverter defibrillator. Ethical dilemmas may occur as these sensitive, complex decisions are made and during the process of limiting LSTs. Even when the decision to withhold or withdraw LSTs is ethically appropriate and clear, there can be issues. The following case will illustrate some of them.

MRS SMITH

Mrs Smith is a 90-year-old woman with a history of heart failure, chronic renal insufficiency, hypertension, type 2 diabetes, atrial fibrillation, and arthritis. Her husband died in the hospital 10 years ago after he had a myocardial infarction. Mrs Smith has 3 adult children. After her husband's death, she sold the family home and moved into a small apartment. Two years ago, her oldest daughter, Karen, who was divorced and had no children, moved in with her. Mrs Smith was hospitalized several times over the last 2 years, and her functional status has progressively declined. Karen kept her own home, so has been maintaining both her mother's apartment and her home, working full-time, and helping her mother. Mrs Smith's middle son, Bob, lives in the area with his wife and 4 children. He comes to see his mother occasionally so that Karen can get a break. Mrs Smith's youngest child, Susan, lives more than 1000 miles away with her husband and 2 children. She visits her mother a couple of times a year.

Mrs Smith is frail, yet is cognitively intact and continues to participate in all decisions regarding her medical care. Her wish at her last hospitalization was to not have CPR if her heart were to stop. She also did not want to be intubated. She has an advance directive that says she would want comfort care should she suffer a devastating neurological injury or be in a terminal medical condition. Her advance directive lists all 3 children as her health care proxies and names Karen first. She has separately told her children she would not want to be "kept alive on machines" and recently told them and her primary care provider that she would not want to be on hemodialysis if her kidneys were to fail.

Mrs Smith awoke in the middle of the night struggling to catch her breath. She called out to Karen, who connected her home oxygen for her. Karen gradually increased the oxygen from 2 L/min to 6 L/min per nasal cannula. When her mother's breathing problems worsened, she called 911. The paramedics arrived and placed a 100% nonrebreather mask on Mrs Smith, started an intravenous line, and transported

---

Debra L. Wiegand, PhD, RN, is assistant professor, School of Nursing, University of Maryland, Baltimore.

Marian S. Grant, DNP, RN, is palliative care advanced practice nurse, University of Maryland Medical Center, and assistant professor, School of Nursing, University of Maryland, Baltimore.

Address correspondence to Debra L. Wiegand, PhD, RN, School of Nursing, University of Maryland, 655 W Lombard St, Baltimore, MD 21201 (Wiegand@son.umaryland.edu).

The author has no funding or conflicts of interest to disclose.

DOI: 10.1097/NJH.0000000000000049

her to the hospital. The physician in the emergency department informed Karen that her mother was having an acute exacerbation of her heart failure and that intubation may be necessary. The physician thought that her mother would only need to be intubated for a few days. After discussing the pros and cons of intubation, Karen gave her consent. Mrs Smith was intubated, mechanical ventilation was started, and she was transferred to the ICU. Her fluid status was very tenuous, and her kidney function was poor. Her ICU team managed her care, using intravenous diuretics, a dobutamine infusion, and an insulin infusion. Mrs Smith's creatinine level increased, and her team expressed concern that Mrs Smith might need renal dialysis.

Mrs Smith could not participate in decision making during this hospitalization because of being intubated and occasionally sedated. Karen stayed at the hospital every day and provided informed consent for her mother's various procedures. Susan called the hospital daily and verbalized her concerns about the treatments that her mother was receiving as she felt that her mother would not want them. She had been expecting her mother's decline and was not surprised to hear how critically ill she now was. She was angry that her mother was intubated and told her mother's primary critical care nurse, Carl, that her mother would not want all of these treatments done. Bob was somewhere in the middle; he was able to see both of his sisters' view points, but was personally unclear what the next steps should be. Karen, Bob, and the team met on hospital day 7, and everyone agreed that ICU care and treatments would continue. During the meeting, the attending physician (intensivist) recommended that if Mrs Smith's heart should stop he did not feel that CPR should be started. He wanted to change her code status from "attempt CPR" to "do not resuscitate." Karen would not agree to this, and Bob was unsure what to do. The physician decided not to change Mrs Smith's code status.

Mrs Smith's critical care nurse, Carl, is concerned because several times Mrs Smith tried to pull out her endotracheal tube. Soft wrist restraints were ordered, but he and the other nurses tried not to use them unless it was absolutely necessary. Instead, the nurses administered small amounts of sedation, as prescribed, to keep Mrs Smith from becoming restless. The attending physician did not want to use a lot of sedation as then Mrs Smith became too drowsy and was unable to participate in spontaneous breathing trials. Carl feels that Mrs Smith is suffering by being awake enough to know she is both intubated and restrained. He tried to advocate for better sedation from the attending physician, but the physician felt that additional sedation was not needed. Carl also shared his concerns with Mrs Smith's daughter, Karen, but she did not have a problem with the restraints. Karen feels that the restraints are needed so that her mother will not pull any of the tubes out and that she needs all of the tubes as they are going to help her mother to get better. Carl also verbalized his concerns that Mrs Smith's previously stated wishes are not being honored. The team listened to Carl, but feels that because her family is not in agreement, all treatments should be continued.

Ten days after Mrs Smith was admitted to the hospital, the attending physician and medical team rotated off service, and a new medical team was in charge of Mrs Smith's care. The ICU nurse, Carl, approached the new attending physician, Dr Shaw, and shared his concerns with her. Carl expressed his concern that Mrs Smith's condition was not improving and that Mrs Smith would not want the treatments continued. Carl feels Mrs Smith's daughter, Karen, has been making decisions based on what Karen wants, not based on the decisions her mother would make. Dr Shaw listened carefully to Carl's concerns and asked Carl if he would work with the social worker to set up a family meeting.

The social worker called Karen and Bob and asked them if they would come in for a family meeting. Karen said that she would like to delay the meeting for a couple of days as her sister, Susan, would be in town then. The meeting was set up for 3 days later, which was hospital day 14. All of Mrs Smith's children attended. Mrs Smith's critical care nurse, social worker, and the chaplain also attended the meeting, and Dr Shaw led the meeting. Dr Shaw asked everyone to introduce themselves. She discussed her concerns regarding Mrs Smith's medical history, current weakened cardiac status, dependency on mechanical ventilation, declining kidney function, and her professional prediction of a poor prognosis. Dr Shaw provided several care options and gave the rationale for the option that she felt was best, which was to transition care to a palliative care approach. She then asked the family members to share their perspectives. Susan and Bob said that they were supportive of a palliative approach. Karen, on the other hand, adamantly disagreed. Karen did acknowledge that mechanical ventilation and dialysis were things that her mother never wanted, but might be something her mother would be willing to try for a temporary period of time. Dr Shaw discussed her concerns that she did not believe that extubation would be possible. She did not think a decision to begin dialysis was needed today but that it would more than likely be needed within the next several days. Carl also verbalized that he was concerned as he knew that Mrs Smith had said in the past that she did not want CPR, intubation, or dialysis. He asked the family to seriously consider what decision Mrs Smith would make if she were in the room and could speak for herself. After some discussion, the family members were able to agree that CPR should not be started if their mother's heart stopped. Karen was reluctant, but eventually agreed. However, the siblings were not able to agree on anything else. Because they could not decide, the team agreed to continue all current care. The team also asked Mrs Smith's family if it would be OK to call the palliative care service to see if they could help to support the patient, family, and the team further. The family agreed that involving palliative care would be all right.

The next day, the advanced practice nurse (APN) from the palliative care service talked with the team and then met Mrs Smith's children. She encouraged each of them to talk about what their mother would want. Bob and Susan feel that their mother would not want dialysis and would not want to be on the ventilator this long. They feel that everything should be stopped. Karen said that she would not give up on her mother and feels that all treatments should be continued and that a dialysis catheter should be placed so that dialysis could be started. Karen said that she would feel too much guilt if she had to make a decision about stopping treatments. The palliative care nurse asked the social worker and the hospital chaplain to continue to support the family during the decision-making process. The palliative care nurse also worked with the team to ensure that Mrs Smith was not anxious and more comfortable in between the breathing trials by using short-acting opioids.

The family was provided with daily updates. Several days later, Karen told the palliative care nurse that she was now comfortable making a decision not to start dialysis, but that she could not make a decision to stop other treatments. Two days later, Mrs Smith developed sepsis, septic shock, and multisystem organ failure. Another family meeting was held, and the palliative care nurse was part of this meeting. The team supported the family as they were told that Mrs Smith was dying, despite all their efforts. Dr Shaw recommended stopping all aggressive interventions, including infusions (diuretics, insulin, dobutamine) and mechanical ventilation. Susan and Bob supported this recommendation. Karen was distraught and would not agree. She said she wanted to go home and think about it. Late that evening (hospital day 20), Mrs Smith took a turn for the worse; her blood pressure dropped suddenly and continued to drop despite attempts at administering fluid boluses and increasing Mrs Smith's vasopressor infusions. Her family was called in and made it to her bedside before she died. Morphine was infusing at 5 mg/h. Mrs Smith was unconscious and showed no signs of distress.

BIOETHICAL DILEMMAS

This case raises several bioethical dilemmas. Those that will be discussed include (1) When is it ethical to limit LST? (2) Who should make decisions when a patient is unable to make her own decisions? (3) What should be done if a patient's previously stated wishes are not honored? (4) What should be done if a patient is suffering? It is important that the nurse and other members of the health care team identify and address ethical issues as they arise.

When Is It Ethical to Limit LST?

Life-sustaining therapy is defined as interventions that are focused on increasing the life span of the patient.[1] Decisions to withhold or withdraw LSTs are commonly made in the ICU setting. Withholding LST involves deciding not to initiate treatment with the understanding that the patient will probably die without the intervention, whereas withdrawal of LST involves deciding to stop or remove treatment that with the knowledge that the patient will die following the change in therapy.[1] Limiting LST is ethically appropriate if a patient makes an informed decision that he/she does not want the treatment(s). It is also legal and ethical for a patient's surrogate decision maker to make life-limiting decisions.

There is no ethical distinction between withholding and withdrawing LST, and in many situations, it is ethically appropriate to do either. Despite being ethically acceptable, from a practical perspective it often feels different to withhold and withdraw LST. This difference is felt by both families and providers. Deciding not to start CPR if a patient's heart stops feels different than actually removing mechanical ventilation and extubating a patient. Withholding CPR is perceived as a passive or natural process, whereas removing mechanical ventilation and extubating a patient are perceived as an active process. Often decisions are made as part of a 2-step process with decisions to withhold LST preceding decisions to withdraw LST.[2]

Who Should Make Decisions When a Patient Is Unable to Make Her or His Own Decisions?

It is always preferable for patients to make their own decisions if possible. This supports the principle of autonomy and respect for the individual. However, because of illness, intubation, and sedation, the patient, Mrs Smith, is unable to participate in the decision-making process about her preferences for care and treatments. This is, unfortunately, the case for many ICU patients.[3] If patients are unable to participate in the decision-making process, decisions are made by a surrogate decision maker.[4]

The surrogate decision maker may be a person that the patient designated as her health care proxy or durable power of attorney. If the patient never delegated a health care proxy, then the legal next of kin is responsible for decision making. In the case presented, Mrs Smith had an advance directive. In her advance directive, she identified her 3 adult children as the individuals who should make decisions on her behalf. Her oldest child, Karen, was listed first, but because she identified all 3 of her children as health care proxies, all of her children would be responsible for making decisions for their mother. Mrs Smith may not have anticipated that her children would struggle making decisions.

What Should Be Done if a Patient's Previously Stated Wishes Are Not Honored?

The principle of autonomy is the foundation of self-determination. The voluntary choice of an informed patient with decision-making capacity should determine whether any treatment, including life-sustaining treatments or symptom management, should be initiated, continued, or withdrawn.[1]

Surrogate decision makers should make decisions based on patient's previously expressed wishes. These wishes may have formally been written in a living will document or may have been communicated to the surrogate. If the surrogate decision maker and the patient never discussed end-of-life preferences, then the surrogate makes decisions based on what is the best decision for the patient given the situation. Thus, patient autonomy is supported as decisions are made based on the decision that the patient would have made if she was able to communicate preferences.

In the case presented, Mrs Smith had an advance directive that stated that she would want comfort care should she suffer a devastating neurological injury or be in a terminal medical condition. Upon her arrival to the emergency department, she did not have a devastating neurological injury, and it was not clear that her medical condition was terminal. Thus, it was important to know that she had the advance directive and to know what it said, but the advance directive information was not relevant to Mrs Smith's medical status on admission to the hospital.

Before her current hospitalization, Mrs Smith stated that she would not want CPR, to be intubated, or have dialysis. Based on this knowledge, her critical care nurses, including her primary nurse, Carl, and both her attending physicians felt that CPR should not be started if Mrs Smith's heart was to stop. Initial support was not provided by Mrs Smith's oldest daughter, but later support was given, and a do-not-resuscitate order was written. Mrs Smith's family was also initially divided on making a decision about whether to start dialysis, but eventually all agreed to withhold dialysis based on their mother's previously stated wishes.

When Mrs Smith was emergently admitted to the ED, a quick decision was needed, and her oldest daughter, Karen, consented to intubation. The ED physician thought that intubation might be needed for a few days until Mrs Smith's condition stabilized. Some members of her family and her medical team questioned if intubating Mrs Smith in the first place and continuing mechanical ventilation were the right thing to do. Even as it became clear that Mrs Smith was not going to survive, her oldest daughter, Karen, was not willing to agree to stop mechanical ventilation.

What Should Be Done if a Patient Is Suffering?

Carl was concerned that Mrs Smith was not adequately sedated. He and the other nurses tried not to use the soft wrist restraints, but when Mrs Smith tried to pull out her endotracheal tube, they applied them as prescribed. He asked the physicians to increase Mrs Smith's sedative medication so that she was not as restless. The physician was fine increasing sedation at night but not during the day as he wanted Mrs Smith to be more alert than to participate in daily weaning trials. Carl was concerned as Mrs Smith was not doing well with weaning and was restless most of the day. He felt Mrs Smith was suffering.

The team followed the recommendation by the APN from the palliative care service to prescribe short-acting opioids during the day in between weaning trials. Mrs Smith was less restless and appeared more comfortable during the day.

MANAGING AND RESOLVING BIOETHICAL DILEMMAS

The environment in which nurses work can block nurses from being effective patient advocates.[5] Mrs Smith's primary critical care nurse, Carl, did his best to address the ethical dilemmas in the case. He tried to advocate on her behalf, but was frustrated by the process. He was uneasy that both the ED physician and the first ICU attending physician were very aggressive in managing Mrs Smith's medical problems. Both physicians thought that Mrs Smith would stabilize and that her medications and mechanical ventilation would be weaned. Carl was relieved when the new ICU medical attending physician, Dr Shaw, came on service as he felt she was willing to listen to his concerns, understood them, and was willing to address the ethical issues. Both the nurses and physicians were frustrated when Mrs Smith's family members were not able to reach decisions together as a family.

This family, like other families of the critically ill, struggled with concern that they were doing the right thing.[6] The team kept the family updated and provided support. Eventually, the family was able to make decisions with the team regarding withholding CPR and dialysis. Carl was sorry that Mrs Smith died without other treatments withdrawn. He and other members of the nursing and medical team felt satisfied that they were able to support some of Mrs Smith's wishes, yet were frustrated that they were not able to support all of them. Carl was also concerned that although Mrs Smith's family members may have felt that everything was tried, they may feel guilty later that they did not support their mother's wishes.

LESSONS LEARNED

The team had a debriefing meeting the day after Mrs Smith's death. This meeting provided an opportunity for the team to come together and review the case. It also provided a safe environment for team members to share the ethical burden that each team member experienced.[7] Carl verbalized how upset he was that Mrs Smith died intubated. Some of the other critical care nurses and Dr Shaw also shared their frustrations. Carl was thankful that at least they did not have to perform CPR. The palliative care APN helped the team to realize that Mrs Smith did not die in pain and seemed very comfortable. The social worker also said that all 3 siblings were able to spend time together at their mother's bedside and were able to tell her goodbye. The family thanked the staff for everything they did and hugged everyone before they left. Mrs Smith's children verbalized their gratitude for the care that their mother received. The chaplain said that the family was at peace and knew that their mother and father were now together.

The team discussed what they might have done to change the situation. Carl thought that it might have been helpful to discuss the case with the ICU's medical director. Carl also said that he wished he had talked with his clinical nurse specialist and his nurse manager sooner. They may have been able to help to support the team earlier, and perhaps they might have been able to consult palliative care earlier. Carl and Dr Shaw both thought they should have involved the ethics committee. An ethics consult would have been an important resource to bring the family and the team together to discuss Mrs Smith's earlier stated wishes and focus discussions more on Mrs Smith and her wishes and not on family wishes. Additional resources such as consulting grief counseling may have been helpful to provide additional support and guidance for Mrs Smith's children.

Caring for patients who receive overly aggressive and futile treatments can lead to nurses experiencing moral distress.[8-10] Thus, it is essential that these ethically distressing situations are thoughtfully addressed. It is important that nurses discuss ethical concerns with members of the interdisciplinary team, unit leadership, and ethics experts.

CONCLUSION

Decisions to limit LST occur often in the critical care setting. When bioethical dilemmas occur, they need to be discussed by the interdisciplinary team. The nurse and other members of the team should consider consulting the ethics committee early in the process as their assistance may help to honor patient wishes and provide important guidance and support to families and health care providers.

References

1. Berlinger N, Jennings B, Wolf S. *The Hastings Center Guidelines for Decisions on Life- Sustaining Treatment and Care Near the End of Life: Revised and Expanded Second Edition*. New York, NY: Oxford University Press; 2013.
2. Wiegand DL. In their own time: the family experience during the process of withdrawal of life-sustaining therapy. *J Palliat Med*. 2008;11(8):1115-1121.
3. Cypress BS. Family conference in the intensive care unit: a systematic review. *Dimens Crit Care Nurs*. 2011;30:246-255.
4. Hospice and Palliative Nurses Association. *HPNA Position Statement: Withholding and/or Withdrawing Life-Sustaining Therapies*. Pittsburgh, PA: HPNA; 2013.
5. Cox KM. Moral distress: strategies for maintaining moral integrity. *Perioper Nurs Clin*. 2008;3:197-203.
6. McAdam J, Puntillo K. The intensive care unit. In: Ferrell BR, Coyle N, eds. *Textbook of Palliative Nursing*. 3rd ed. 2010. New York: Oxford University Press.
7. Santiago C, Abdool S. Conversations about challenging end-of-life cases: ethics debriefing in the medical surgical intensive care unit. 2011;22(4):26-30.
8. Browning AM. Moral distress and psychological empowerment in critical care for adults at end of life. *Am J Crit Care*. 2013;22(2): 143-152.
9. Ferrell BR. Understanding the moral distress of nurses witnessing medically futile care. *Oncol Nurs Forum*. 2006;33(5):922-930.
10. Wiegand DL, Funk M. Consequences of clinical situations that cause critical care nurses to experience moral distress. *Nurs Ethics*. 2012;19(4):479-487.