

Palliative and End-of-Life Ethical Dilemmas in the Intensive Care Unit

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ABSTRACT

Critical care nurses and advanced practice registered nurses frequently face bioethical dilemmas in clinical practice that are related to palliative and end-of-life care. Many of these dilemmas are associated with decisions made concerning continuing, limiting, or withdrawing life-sustaining treatments. The purpose of this article is to describe common ethical challenges through case

study presentations and discuss approaches that critical care nurses and advanced practice registered nurses in collaboration with the interdisciplinary team can use to address these challenges. Resources that may be helpful in managing ethical dilemmas are identified.

Keywords: bioethics, end of life, ethical dilemma, intensive care unit, palliative care

Critical care nurses (CCNs) and advanced practice registered nurses (APRNs) frequently face ethical dilemmas in clinical practice, and many of the dilemmas are related to palliative and end-of-life care. Decisions are commonly made in the intensive care unit (ICU) about whether life-sustaining interventions and treatments should be continued, limited, or stopped. Nurses are intricately involved in difficult and often complex ethical discussions and situations involving seriously ill patients, their families, and other members of the interdisciplinary team. Addressing ethical issues and resolving ethical dilemmas take time, commitment, and collaboration. Unresolved ethical dilemmas can contribute to nurses experiencing moral distress.¹⁻⁴

An ethical environment is essential in the provision of palliative and end-of-life care. Nurses play an important role in the provision of palliative and end-of-life care that includes supporting each patient's right to self-determination, supporting surrogate decision makers and families of patients who are unable

to participate in palliative and end-of-life decisions, assisting the interdisciplinary team to recognize and address medical futility, participating in the decision-making process, and supporting decisions to withhold and withdraw life-sustaining therapy.

Bioethical Dilemmas

Classic legal cases, including the cases of Karen Ann Quinlan,⁵ Nancy Cruzan,⁶ and Terri

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Schiavo,⁷ have set legal precedence that patients have a right to self-determination and designated surrogates and family members have the authority to make decisions (including end-of-life decisions) on a patient's behalf. These decisions are made on the basis of previously known or stated patient values and wishes. In Karen Quinlan's case, her family was supported in its request to withdraw ventilator support, and in Nancy Cruzan's and Terry Schiavo's cases, the Cruzan family and Terry Schiavo's husband were supported in their request to withdraw artificial nutrition.

The circumstances that present bioethical issues and dilemmas entail decisions to do the right thing, when the right thing may not be clear or agreed upon by all.⁸ Ethical issues and dilemmas commonly arise and are resolved in acute care settings. Ethical dilemmas present difficult choices and opportunities to seek acceptable options based on moral imperatives of involved patients, family members, nurses, physicians, and other members of the team.⁹

Ethical principles are used as the basis for ethical discussions and in the critical care setting frequently include autonomy, beneficence, and nonmaleficence.¹⁰ Autonomy is centered on respect for the individual. Care must be patient centered and given on the basis of each patient's values and preferences. Beneficence is based on the concept of doing good and refers to actions done for the benefit of others.¹¹ Nonmaleficence is focused on avoiding harm and minimizing the risk of harm. Additional ethical considerations include honesty and integrity. Health care providers must be honest with patients and families and provide them with the information that they need so that they can make the best decisions. It is of utmost importance that nurses practice with integrity, which involves consistently upholding and standing firm in one's values and advocating for patients and families.¹¹

Several resources are available for CCNs and APRNs to help resolve bioethical dilemmas (Table 1). Resources used will vary on the basis of the dilemma. When faced with situations that are ethically challenging, CCNs and APRNs should consider collaborating with the interdisciplinary team in a stepwise approach to delineate the dilemma and identify options to address it (see Table 2).

The following case studies provide examples of bioethical dilemmas related to palliative and end-of-life care situations commonly

Table 1: Resources Available to Help Resolve Ethical Dilemmas

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| 1. Reach out to the team.
- Ask colleagues for help (social work, clergy, intensivist, counselors). |
| 2. Set up a meeting to discuss the ethical dilemma with the entire interdisciplinary team. |
| 3. Set up a meeting to discuss the ethical dilemma with the patient and family and interdisciplinary team. |
| 4. Consult palliative care. |
| 5. Consult ethics experts. |

encountered by nurses in critical care settings. Moral concerns and ethical principles are identified and approaches that CCNs and APRNs in collaboration with the interdisciplinary team might use to address the ethical challenges are discussed.

Case 1: Is Stopping Treatment the Right Thing to Do?

Jill is a 34-year-old single woman who was brought to the emergency department after she attempted suicide by taking an overdose of her mother's pain medication. Her mother found her unconscious with an empty medicine bottle next to her and called 911. Jill was admitted to the medical intensive care unit (MICU) unresponsive, intubated, and receiving intravenous fluids and vasopressors to maintain her blood pressure. Jill's mother informed the clinical team that Jill had struggled with depression since she was in her early teens and that she had attempted suicide several times in the past.

Jill's mother gave her nurse a copy of Jill's advance directive. As documented in the advance directive, Jill's mother was designated as her health care proxy. The advance directive also stated that Jill would not want life support

Table 2: Steps to Consider When Faced With Situations That Are Ethically Challenging

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| 1. Review the case/scenario/issue. |
| 2. Identify the bioethical dilemma. |
| 3. Explore options to resolve the dilemma. |
| 4. Determine the best action and take it. |
| 5. Evaluate the outcome. |

if there was “no hope for recovery.” The advance directive document was completed 3 years ago. Jill’s mother asked the nurse whether she could speak with the attending physician as she felt that all treatment should be stopped. She was emotionally distraught and tearful.

The APRN coordinating Jill’s care in the MICU met with Jill’s mother and her CCN to review Jill’s condition and care. Jill’s mother stated that Jill would not want to be kept alive if there was “no hope of recovery.” The APRN clarified that he believed that Jill would recover from the overdose. He felt that time was needed to allow the medication to clear from Jill’s body. Jill’s mother stated that her daughter’s depression was a “terminal illness,” and there was “no hope for her mental recovery.” She repeatedly asked whether the ventilator could be removed and her daughter be allowed to die. She emphasized that her daughter had suffered for 2 decades and as her mother she could not bear to see her suffer anymore. As the CCN and APRN did not believe the condition criteria in the advance directive had been met, the APRN suggested that an ethics consultation may be helpful.

Jill’s mother, her friend, the CCN, APRN, resident, attending physician, consulting psychiatrist, social worker, and 3 members of the ethics committee met to discuss Jill’s condition and treatment plans. The team reviewed her medical and psychiatric history, current condition, treatments, and advance directive. They gave Jill’s mother time to discuss her view that treatments should be stopped. After a long discussion, the ethics consultative team recommended that Jill’s current treatment should be continued. They understood that Jill’s mother believed that her daughter’s advance directive was not being followed. They, however, made the recommendation that treatments be continued as the medical team anticipated that Jill would recover; thus the condition set in the advance directive (no hope for recovery) was not met. The team members offered to meet again if Jill’s condition did not improve or worsened.

Jill’s condition continued to improve and 3 days later her level of consciousness increased, the vasopressor infusions were titrated off, and

steps were made to begin ventilator weaning. Jill’s mother was supportive of ongoing treatments and agreed to further psychiatric care for her daughter. Jill’s mother was supported throughout her daughter’s hospital stay by the MICU team. She participated in daily rounds and helped the CCNs with some of her daughter’s personal care. A social worker met with her daily. The consulting psychiatrist met with her, and they developed a follow-up mental health plan for her daughter. Jill’s mother also was encouraged to seek help from a psychologist if she felt she needed additional support after her daughter was discharged from the hospital.

Case 1 Analysis

The bioethical dilemma presented in this situation was based on determining whether stopping treatment was the right thing to do. The patient’s mother wanted treatment stopped and the CCN and APRN did not think that stopping treatment was the right thing to do.

The patient’s right to self-determination is based on the ethical principle of autonomy. Health care providers have an obligation to respect the right of each person to make his or her own decisions.⁹ In this case, Jill’s mother was the decision maker. She was designated by Jill in her advance directive as her health care proxy. The role of the health care proxy (also referred to as durable power of attorney for health care) is to make decisions on the basis of the decision that the person would make. Thus, as health care proxy, Jill’s mother was expected to make decisions on the basis of what Jill would want. The APRN and Jill’s CCN did not believe that Jill’s current condition met the criteria set in Jill’s advance directive to stop treatment. Jill’s mother disagreed.

The APRN was proactive in initiating an ethics consultation. He invited key members of the interdisciplinary team to attend the meeting with the ethics experts. The patient’s advance directive stated that the patient would not want life support if there was no hope for recovery. The directive provided guidance about what the patient would want should she be near the end of her life. Of utmost importance in this dilemma was for the ICU team with the help of the ethics experts to determine whether the patient met the criteria set forth in her advance directive—that is, was she near the

end of her life with no hope for recovery. Because the criteria set in the advance directive, no hope for recovery, was not met, treatments were not stopped.

Case 2: What Should the ICU Team Do When a Child's Parents Do Not Agree to Recommendations to Stop Treatment?

Adam was a 2-year-old child with congenital acute myeloid leukemia. He was admitted to the pediatric intensive care unit (PICU) after receiving an allogeneic bone marrow transplant. One week after transplant, a severe pulmonary infection developed, resulting in irreversible lung injury; he was ventilator dependent. Adam was a patient in the PICU for 2 months and he had good and bad days. On his bad days, the PICU staff struggled to manage his hypoxemia, hypercapnia, and hemodynamic instability. He had several close calls with death, including being resuscitated twice after having cardiac arrests. Neurologically at times he opened his eyes; he had limited motor ability. When he became restless, he was given sedative drugs.

Several family meetings occurred over his 2-month PICU stay. The palliative care team was consulted 5 weeks into his stay. At the most recent meeting, the palliative care APRN reviewed Adam's illness trajectory, discussed his current condition, and told Adam's parents that the team would like to consider a change in the focus of Adam's care. The pediatric intensivist discussed Adam's poor prognosis and his parents were given time to ask questions. The palliative care APRN discussed the possibility of focusing Adam's care on comfort and suggested that it was time to consider decisions such as withholding cardiopulmonary resuscitation if Adam's heart were to stop again. She asked Adam's parents whether they would support this decision. Adam's mother said that she agreed that CPR should not be started if her son's heart stopped. Adam's father became angry and stated that the staff were giving up on his son. He absolutely wanted all treatment continued, including CPR. He got up and stormed out of the conference room.

Adam's PICU nurse was not sure whether to stay in the meeting or leave. She decided to leave and look for Adam's father. She found him sitting at his son's bedside crying. He told her that he needed a little time alone, so the nurse left and gave him time with his son. When she returned, she acknowledged how difficult it must be to participate in these types of decisions. Adam's father told her that he did not want to give up on his son. The nurse reinforced what good parents that both he and his wife were. Adam's father said that he needed time to think about everything. He had hoped that his son would recover and he was just starting to realize that he might not. The PICU nurse emphasized that Adam would continue to receive the best care possible, regardless of what decision was made, and that the team was there to help not only Adam but also his family.

Case 2 Analysis

The ethical dilemma in this case involves deciding what should be done when the ICU and palliative care team would like to change the focus of care to comfort care and the family (in this case the child's parents) do not agree or are unable to agree. This dilemma can cause distress within the family, between the family and the ICU team, and within the ICU team. Each person has his or her own perspective of what should be done. The child's mother is willing to forgo CPR if her son's heart stops again; the child's father feels that this is giving up and he is not ready to do that. Professionals who are part of the ICU team want what is best for the patient (beneficence) but do not want to provide care that may be harmful (nonmaleficence). CPR would be considered harmful if the child is not expected to survive.

In this example, health care providers should continue to provide honest information to Adam's parents and to closely collaborate with them as decisions are made. Decisions made on Adam's behalf should be made by his parents and the team through a process of shared decision making.^{12–14} Because Adam's father was not in agreement with the recommendation made by the ICU team, if Adam's heart were to stop, the team would initiate CPR. This action may be difficult and create moral distress for some members of the ICU team. In time, Adam's father may change his

mind and agree that not performing CPR is the best decision for his son. Until this happens, family meetings must continue to be scheduled, and communication between the family and ICU and palliative care team must be open and supportive.

Health care providers need to meet families where they are, taking the time to explore what family members understand about their loved one's condition. Families need time to process the situation and the barrage of information they receive, and the time needed by families and family members varies. They should be informed and supported throughout the process. It is less burdensome to families if end-of-life decisions are made in phases, with decisions to withhold life-sustaining therapy (eg, CPR) as one decision and decisions to withdraw life-sustaining therapy (eg, vasoactive medications) as a separate decision.¹⁵ At a future point in time, Adam's parents may make a shared decision with the PICU and palliative care team about withholding CPR and also may consider stopping additional treatments, such as ventilator support.

If parents (or other members within a family) have conflicting wishes about the direction that a child's (or family member's) care should go, providers must continue to support both parents (or all family members). The PICU and palliative care team should continue to meet with the parents on a routine basis and continue to assess their understanding of their child's condition, provide accurate information, and answer questions. Including additional team members, such as pastoral care and bereavement counselors for support, and consulting the ethics committee for additional guidance may be helpful. Staff also may need support during these difficult situations. Setting up debriefing meetings between the ICU staff and the members of the palliative care team, clergy, and/or counselors can provide a safe environment for the ICU staff to talk and receive support and guidance.

Case 3: Should a Neuromuscular Blocking Medication Be Stopped?

Jessie Blackwell was a 42-year-old man with a history of a degenerative neuromuscular disease. He was on a ventilator in the neurological ICU for 1 week after being diagnosed with necrotizing pneumonia. His condition deteriorated to

the point that he required pressure-control ventilation with high oxygen levels; several infusions were started, including a neuromuscular blocking agent (cisatracurium), a sedating agent (midazolam), and an analgesic agent (fentanyl). Multiple family meetings took place to keep his wife updated on his tenuous condition and declining status. Before his hospitalization, Mr Blackwell had conversations with his wife, primary care provider, and neurologist about his end-of-life wishes. Eight months ago he completed a medical order for life-sustaining treatment (MOLST) document with his neurologist. As documented in his MOLST, he did not want prolonged life-sustaining treatments, including ventilator therapy, dialysis, or artificial nutrition if it was not expected that he would live more than 6 months. The MOLST also noted that Mr Blackwell wanted medication to promote comfort, especially if his life was nearing the end. The APRN facilitated an ICU team and family meeting to discuss the possibility of withdrawing ventilator support. Mr Blackwell's wife agreed with the team that it was time to support her husband's wishes, withdraw life-sustaining treatments, and allow him to die peacefully.

The CCN was unsure if the neuromuscular blocking infusion should be stopped. She discussed her concern with the APRN and the resident. The APRN thought that the medication should be stopped, whereas the resident thought that the medication should be continued. After further discussion among the team members, including the unit intensivist, it was agreed that the APRN would place an order to discontinue the neuromuscular blocking agent. The APRN discussed Mr Blackwell's care with his CCN. The plan included increasing the dose of the sedative and analgesic medications, waiting an hour, and then gradually decreasing the dose of the neuromuscular blocking medication until it was titrated off. The APRN told the nurse to closely monitor the patient and to call her immediately if there were any signs of discomfort.

The CCN carefully observed for signs of discomfort, including grimacing, restlessness, and breathing changes, such as an increase in respiratory rate and labored breathing. The nurse noted that Mr Blackwell began to have labored breathing, which was relieved by increasing the dose of the fentanyl and the midazolam. The neuromuscular blocking agent was gradually discontinued, and time was permitted for

the medication to clear from Mr Blackwell. The team then progressed to withdrawal of ventilator support, and orders were placed for further titration of both medications if any signs of discomfort were noted.

Case 3 Analysis

The CCN was faced with the ethical dilemma of whether a neuromuscular blocking agent should be continued or discontinued before withdrawal of life-sustaining therapy. The CCN discussed her concerns with the APRN and the resident and further input was sought from the intensivist. After the decision was made to discontinue the medication, a plan was discussed to carefully assess and manage potentially distressing symptoms.

This case demonstrates the important role of the CCN as a patient advocate. To make certain that pain and other potentially distressing symptoms are managed, nurses should be able to accurately assess for signs and symptoms of distress. If a neuromuscular blocking agent was infusing, the patient would not be able to exert any respiratory effort and may experience respiratory distress, anxiety, and pain that would not be able to be detected.

This case also provides an example of how a MOLST document can be effectively used to guide end-of-life care. Many states have MOLST legislation (some states have Physician/Provider Orders for Life-Sustaining Treatment, or POLST, legislation). These documents are completed by individuals with serious illnesses and specify the types of treatments that a person would or would not want toward the end of life. Depending on the state, these medical orders are signed by the patient's physician, APRN, or physician's assistant.

Case 4: Should the Patient Receive Pain Medication?

Mr Grier is an 84-year-old man who was admitted to the surgical intensive care unit (SICU) after surgery to repair a perforated bowel. He was diagnosed with peritonitis and sepsis. He was placed on a ventilator for respiratory support and required a vasopressor infusion to support his blood pressure. His caring wife, son, and daughter were at his bedside daily. They participated in unit rounds and asked many appropriate questions. After 5 days in the SICU, a family meeting was held. The APRN asked Mrs Grier if it would be okay to

invite a member of the palliative care team to join them in the meeting. The intensivist asked the family members how they thought Mr Grier was progressing. The family members were very concerned and worried, and Mr Grier's son asked whether his father was going to die. The intensivist and the APRN gave the family an update on Mr Grier's condition and shared their concerns about his uncertain prognosis. Mr Grier did not have a living will and had not designated a health care proxy. His wife did not think Mr Grier would want to live in his current state if his health did not improve; his adult children agreed. After much discussion, Mrs Grier and her children agreed with the APRN's recommendation not to initiate resuscitation if Mr Grier's heart were to stop.

The intensivist and the APRN also recommended limitation of further treatments (ie, additional vasopressor infusions) and asked the family to consider withdrawal or stopping the ventilator. Mrs Grier said that she could not agree to stop the ventilator. She knew how serious her husband's condition was but she still was very hopeful that her husband's condition would improve. She shared that earlier that day the renal physician told the family that Mr Grier's kidneys were better. She was hopeful that additional signs of improvement would follow. The team and the family agreed that resuscitation and additional vasopressors would not be initiated and all current treatments would be continued. After the meeting ended, the CCN and the palliative care nurse stayed with the family to provide additional family support.

Mr Grier did not designate a health care proxy. Legally his next of kin, his wife, was responsible to make decisions on his behalf. These decisions are made on the basis of the principle of substituted judgment; thus, decisions are made on the basis of the decision her husband would make if he was able to. Mrs Grier verbalized that she was not sure what her husband would want done and she decided to continue treatments. Although this was difficult for the ICU team caring for Mr Grier, they did their best to understand that Mrs Grier was the legal decision maker and that she needed more time.

Unfortunately, Mr Grier's condition declined. He continued to have signs of severe sepsis with hypotension and multiorgan failure. The nurses caring for Mr Grier felt increasingly

uncomfortable as they felt that the treatments were becoming futile. Any mention of limiting additional treatments was not received well by Mrs Grier. She was often tearful, distraught, and overwhelmed. She did not want to lose her husband; they had been married for 45 years. The ICU nurses were upset as they felt that Mr Grier was suffering. Mr Grier grimaced during turns and dressing changes. When a nurse tried to give him morphine for pain, Mr Grier's family objected. Mrs Grier and her son did not want Mr Grier to receive pain medication; they insisted that his pain was "not that bad." The CCNs became more and more frustrated.

Mr Grier's CCN discussed her concerns about his pain with the intensivist. He suggested a palliative care consult and if that did not help to consider an ethics consult. The palliative care nurse and physician talked with Mrs Grier and her son about the pain medication. They were able to clarify the importance of the medication and dispel concerns that the Grier family had about addiction to medication. A member of the palliative care team also came to see Mr Grier and his family every day. One week later, the Grier family agreed with the ICU team's recommendation to stop aggressive treatments and focus on his comfort.

Case 4 Analysis

The ethical dilemma that most distressed the CCNs in this case was that they were blocked from administering pain medication to a patient in pain. Nurses have an ethical obligation to prevent and manage discomfort. If a nurse assesses signs of discomfort, the nurse needs to use pharmacological and nonpharmacological interventions to promote comfort. The principle of nonmaleficence is important as nursing's goal is to minimize harm and promote beneficence or good. If faced with a complex case such as this, nurses should consult with additional members of the team to help. In this case, the CCN asked the intensivist to intervene. The palliative care nurse and the physician were able to educate the patient's family, clarify misperceptions, and increase their understanding of the importance and necessity of managing pain.

This case is similar to an earlier case demonstrating the difficulty faced by the family and SICU team when there is disagreement about goals of care. In this case, the ICU team wanted to withhold and withdraw treatments. The

patient's family was willing to agree with the ICU team's recommendation to withhold CPR and additional vasopressors, but they were not in agreement with the team's recommendation to withdraw the ventilator. When the renal physician gave the family good news in relation to the patient's improving kidney function, the information was not put in the larger context of Mr Grier's overall condition. When family members are given different messages, confusion ensues, which can contribute to family distrust of the medical team.¹⁶

Case 5: Should the Patient Have Surgery?

Sarah Smith is a 77-year-old widow with a history of an aortic aneurysm and hypertension. She was admitted to the cardiac care unit with hypertensive crisis and midsternal chest pain radiating to her neck and mid-scapular region. Nitroglycerin and nitroprusside infusions were started. Diagnostic testing done in the emergency department revealed that her aneurysm had increased in size. Her cardiologist consulted the cardiothoracic team to discuss the possibility of aneurysm repair surgery. Mrs Smith informed the team that she did not want surgery. Before this hospitalization she had consistently told her primary care physician that she did not want surgery. She understood that she might die without surgery.

The next day, Mrs Smith had midsternal chest pain. She had episodes of nonsustained ventricular tachycardia accompanied by hypotension and hypoxia. She was sedated and intubated. The medical team believed that her aneurysm was leaking and that a decision about surgery was needed. Despite knowing Mrs Smith's previously stated wishes, the cardiothoracic surgeon said that he was willing to perform the surgery and would take her immediately to the operating room if her family was willing to consent. Because Mrs Smith was unable to make decisions for herself, her family was asked to make the decision. Her daughter, Katrina, and son, Karl, met with the cardiac care unit team. They were not certain what to do; they were leaning toward her having surgery, but they wanted more time to consider the options. They did not want their mother to die and they did not want to be responsible for her death, but they knew she did not want the surgery. Katrina was crying at her mother's

bedside. The CCN entered the room to talk with Katrina. She asked the nurse what she would do if this was her mother. The nurse replied, "That is a difficult question to answer. I would need to think about what my mother would want. If your mother could talk with us right now, what do you think she would want?" Katrina knew the decision that her mother would have made, but both she and her brother struggled with the enormous responsibility that was placed on their shoulders.

Several hours later, Katrina and Karl, despite being urged by the cardiothoracic surgeon to consent for surgery, decided not to have the aneurysm repaired. They felt that they needed to support their mother's wishes. Unexpectedly, she gradually improved, was able to be extubated, and decided herself not to have the surgery, which was now no longer emergent.

Case 5 Analysis

The ethical dilemma in this case was whether the patient should have surgery. When the patient was able to make her own decisions, she clearly and consistently stated that she did not want surgery. When the patient's condition declined and she was no longer able to speak on her own behalf, her son and daughter were asked to make difficult decisions on their mother's behalf.

Beneficence, the duty to do good, and non-maleficence, the duty to avoid harm, can collide when caring for a patient without decision-making capacity. Determining what is good for another person and what decision to make is difficult. Both the family and the ICU team wanted to do good. The family wanted to support their mother's wishes, but they also did not want her to die. The surgeon wanted to repair the patient's aneurysm and was hoping that she would survive and be able to continue to live a productive life. Of utmost importance in cases such as these is to assist the family as they participate in the surrogate decision-making process and to help the family to focus on the wishes of their loved one. The role of the surrogate decision maker is to make the decision that the patient would make if she was able to speak.

In this case, the CCN and APRN could have immediately intervened and set up a meeting that included the family, the patient's attending cardiologist or primary care physician (who could have called into the meeting), and the

patient's cardiothoracic surgeon. This meeting could have focused on what the patient wanted with everyone present for the discussion. The ethics committee also could have been consulted.

Case 6: Can an Adolescent Make Her Own Decisions?

Jennifer Lee was a 15-year-old girl with advanced cystic fibrosis. She had been hospitalized 6 times in the last 8 months with respiratory distress. A year ago her pulmonologist recommended that it was time to seriously consider lung transplant surgery. Jennifer and her parents were thoroughly informed of the need for a transplant and were educated about the care that she would receive before and after the lung transplant. Jennifer had consistently refused to consider lung transplant as an option. She knew other children from her cystic fibrosis support group who had received lung transplants. She did not feel that the quality of her life would be better. Jennifer's mother and father were supportive of surgery. They tried to convince her to have the surgery, but she consistently stated that she would not agree to it.

Jennifer was admitted to the pediatric pulmonary step-down unit with dyspnea. Her nurse observed that her respiratory rate was increased and her respirations were labored. Her lung sounds were coarse and her oxygen saturation was 89%. The nurse removed her nasal cannula and placed a face mask on Jennifer with an albuterol breathing treatment as prescribed. The treatment helped Jennifer expectorate some secretions and improved her breathing rate, pattern, and oxygen saturation. Once Jennifer was breathing comfortably, her pulmonologist assessed her and then sat down in her room to talk with Jennifer and her parents. Jennifer's nurse remained in the room. The pulmonologist reviewed Jennifer's condition. He asked Jennifer whether she had changed her mind about the lung transplant. She said that she did not want to have it. She realized that she might die without it. The pulmonologist told Jennifer that he would like to consult the palliative care team. He thought that the palliative care team could support Jennifer and her parents. Jennifer's mother asked the pulmonologist whether she and Jennifer's father could consent for their daughter. She said that Jennifer was just a child and should not be allowed to make such a life-and-death decision.

The pediatric palliative care team was consulted. A meeting was set up with Jennifer, her parents, and her PICU team (primary nurse, APRN, respiratory therapist, and intensivist) and the palliative care APRN and physician. At the meeting, Jennifer explained to everyone that she did not want to have the transplant surgery. Jennifer and her parents were in agreement that they were open to having visits from the different members of the palliative care team. Over the next 2 weeks each of the members of the palliative care team, including the nurse, physician, social worker, child life specialist, and psychologist, met several times with Jennifer, her parents, and with all 3 family members together. The palliative care psychologist recommended that Jennifer's desire not to have surgery should be supported. Her parents were very involved and, although not the decision they would make, were eventually in support of their daughter's wish not to have surgery. Jennifer was discharged home and arrangements were made to coordinate her follow-up pulmonary physician appointments with appointments for ongoing care from the palliative care team on an outpatient basis.

Case 6 Analysis

The ethical dilemma in this case was that the teenage patient was refusing to have transplant surgery, a decision with which her parents disagreed. Ideally the adolescent, her parents, and the medical team should communicate and participate in the decision-making process together. The American Academy of Pediatrics Committee on Bioethics recommends that children should be included in decisions about their care to the greatest extent possible.¹⁷ The team should review the teenager's options for care with her and her family. The teenager has the right to have her views and to express those views especially about her own care.¹⁸ Thus, the teenager has the right to make a decision not to undergo lung transplant surgery. In this case, the palliative care team was consulted to provide additional support to both the patient and her family.

Conclusion

Critical care nurses and APRNs frequently encounter and identify ethical dilemmas and are in the ideal position to collaborate with the interdisciplinary team in creating a plan to address these often complex issues. Of

utmost importance is that the patient's wishes are known and respected. Communication must be clear, open, and honest, not only within the team but also between the team and the patient and family. Nurses can seek assistance from members of the palliative care team and the ethics committee in especially complex and difficult cases. Identifying and addressing ethical dilemmas can take time and effort, but patients, families, and providers will benefit.

REFERENCES

1. Gutierrez KM. Critical care nurses' perceptions of and responses to moral distress. *Dimens Crit Care Nurse*. 2005;24(5):229-241.
2. Lutzen K, Dahlqvist V, Eriksson S, Norberg A. Developing the concept of moral sensitivity in health care practice. *Nurs Ethics*. 2006;13(2):187-196.
3. Wiegand DL, Funk M. Consequences of clinical situations that cause critical care nurses to experience moral distress. *Nurs Ethics*. 2012;19(4):479-487.
4. American Association of Critical-Care Nurses. *Moral Distress Position Statement*. Aliso Viejo, CA: American Association of Critical-Care Nurses; 2006.
5. In Re Quinlan 355 A.2d 647 (NJ. 1976)
6. Cruzan v. Director, Missouri Department of Health, 760 S.W.2d 408 (Mo. Banc 1988), 497 U.S. 261 (1990).
7. Shindler v Schiavo, 792 So2d 551, 557 (Fla Dist Ct App 2001).
8. Wiegand DL, Russo MM. Ethical considerations. In: Dahlin C, Lynch M, eds. *Core Curriculum for the Advanced Practice Hospice & Palliative Registered Nurse*. Pittsburgh, PA: Hospice & Palliative Nurses Association; 2013:39-59.
9. Hamric AB, Hanson CM, Tracy MF, O'Grady E, eds. *Advanced Practice Nursing: An Integrative Approach*. 5th ed. St Louis, MO: Saunders Elsevier; 2013.
10. Beauchamp TL, Walters L, Kahn JP, Mastroianni AC, eds. *Contemporary Issues in Bioethics*. 8th ed. Belmont, CA: Thomson Wadsworth; 2013.
11. Beauchamp TL, Childress JF, eds. *Principles of Biomedical Ethics*. 7th ed. New York: Oxford University Press; 2012.
12. Himelstein BP. Palliative care for infants, children, adolescents, and their families. *J Palliat Med*. 2006;9(1):163-181.
13. Michelson KN, Steinhorn DM. Pediatric end-of-life issues and palliative care. *Clin Pediatr Emerg Med*. 2007;8(3):212-219.
14. Valdez-Martinez E, Noyes J, Bedolla M. When to stop? Decision-making when children's cancer treatment is no longer curative: a mixed-method systematic review. *BMC Pediatr*. 2014;14:1-25.
15. 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.
16. Chow K. Ethical dilemmas in the intensive care unit: treating pain and symptoms in non communicative patients at the end of life. *J Hosp Palliat Med*. 2014;16(5):256-260.
17. Mercurio MR, Adam MB, Forman EN, Ladd RE, Ross LF, Stiber TJ. American Academy of Pediatrics Policy statements on bioethics: summaries and commentaries: Part 1. *Pediatr Rev*. 2008;29(1):e1-e8.
18. Wellesley H, Jenkins IA. Withholding and withdrawing life-sustaining treatment in children. *Pediatr Anesth*. 2009;19(10):972-978.