

EPEC

Education for Physicians on End-of-life Care

Participant's Handbook

Module 11

Withholding, Withdrawing Therapy

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Abstract

The withholding and withdrawing of life-sustaining therapies is ethical and medically appropriate in some circumstances. Physicians need to develop facility with general aspects of the subject, as well as specific skills and approaches. In this module, general aspects are discussed first. Then, 3 areas where this general knowledge frequently needs to be applied are covered: cessation of artificial nutrition/hydration, ventilator withdrawal, and resuscitation.

Key words

artificial fluids, artificial food, cardiopulmonary resuscitation (CPR), do-not-resuscitate (DNR) orders, hydration, informed consent, nutrition, ventilator withdrawal, withdrawing, withholding

Objectives

The objectives of this module are to:

- know the principles for withholding or withdrawing therapy
- apply these principles to the withholding or withdrawal of:
 - artificial feeding, hydration
 - ventilation
 - cardiopulmonary resuscitation

Clinical case on trigger tape

A patient with chronic pulmonary obstructive disease is currently in the intensive care unit (ICU) on a ventilator and is requesting that it be removed. The physician and nursing staff are discussing the situation.

Introduction

Facilitating decision making and implementing decisions about life-sustaining treatments are essential skills for physicians. Impediments to good care include misconceptions about legal and ethical issues, as well as unfamiliarity with the practical aspects of implementation.

This module discusses approaches to determine and implement treatment preferences to withhold or withdraw therapy. First, general principles and approaches are covered as they relate to this subject. Then, 3 specific therapies that many physicians discuss with patients are covered in more detail: artificial nutrition or hydration, ventilatory withdrawal, and CPR. Ethical and legal issues are covered in more detail in Plenary 2: Legal Issues, Module 7: Goals of Care, and Module 10: Common Physical

Role of the physician

The physician plays an essential role in defining and implementing the medical care plan, and providing continuity of care as the goals evolve and change over time. The physician will often take the lead in initiating discussions about life-sustaining treatment, educating patients and families, helping them deliberate, and making recommendations about the treatment plan. As part of this role, the physician is responsible for ensuring that the patient's wishes, and/or the parents' wishes if the patient is a child, are documented and supported by the appropriate medical orders. Advance directives may be in place and helpful, but may not necessarily make clear how to translate general goals or treatment preferences into treatment of the present medical conditions. Consequently, it is critical that physicians have the knowledge and skills necessary for discussions, negotiations, and implementation of decisions related to life-sustaining treatments.

All states in the US have statutes covering issues related to withholding or withdrawing life-sustaining treatments. Institutional policies of many hospitals or other health care institutions tend to include considerations, perhaps drafted by ethics committees, to protect patient's rights and interests and considerations, perhaps crafted by risk management officers, to protect the institution from risk. Often, institutional policies are written in response to the general legal imperative to, when in doubt, provide treatment to prolong life. If the appropriate goals of care are other than "life at all costs," then the physician needs to write orders that are specific enough to accomplish the intended goals.

Emergency medical technicians (EMTs) are regulated by statute, and sometimes by city ordinance. Although requirements vary, in general EMTs are required to provide all resuscitative and life-prolonging treatments unless a physician's order is in place to the contrary.

The physician is the only member of the health care team who can ensure appropriate care, if the goals of care are other than the default mode. It is the physician's responsibility to ensure that the patient's wishes (or parents' if the patient is a child) are followed across care settings. In the hospital, one major study demonstrated that the majority of patients in intensive care unit settings die without attention to issues of life-sustaining treatment. Many of these patients have undergone some form of invasive medical treatment against their previously stated wishes.

All too often, patients are transferred to the acute-care setting where life-sustaining measures are administered because the appropriate treatment plan and physician's orders have not been completed and placed in the patient's chart. One study demonstrated that fewer than 25% of advance directive orders were carried from the nursing home to the acute care hospital. The fact that physician's orders may not transfer across settings (eg, nursing home, ambulance, acute care hospital) also exacerbates the problem.

Common concerns

There are several common concerns that impact decisions about life-sustaining treatments in general and withdrawal of ventilator support in particular:

- **Are physicians legally required to provide all life-sustaining measures possible?**
No. In contrast, patients have a right to refuse any medical treatment, even life-sustaining treatments. There are few exceptions to this rule. Mechanical ventilation and life-sustaining treatments are not exceptions.
- **Is withdrawal or withholding of treatment euthanasia?** After decades of discussion in society, there is strong general consensus that withdrawal or withholding of treatment is a decision/action that allows the disease to progress on its natural course. It is not a decision/action actively to seek death and end life. Euthanasia actively seeks to end the patient's life.
- **Are you killing the patient when you remove the ventilator and treat the pain?**
The intent and the sequence of actions are important, as are the means chosen. If the intent is to secure comfort, not death; if the medications are chosen for (and titrated to) the patient's symptoms as ventilator weaning proceeds; if the medications are not administered with the primary intent to cause death, then ventilator withdrawal and pain treatment are not euthanasia. Usually, actions intended to provide comfort and freedom from unwanted intervention result in a slower progression to death than do actions intended to euthanize.
- **Can the treatment of symptoms constitute euthanasia?** For patients who have been using opioids for pain, it is in fact very hard to give such high doses of opioids that death is caused (or even hastened) in the absence of a disease process that is leading to imminent death, particularly if accepted dosing guidelines are adhered to. Patients tend to sleep off the effect if they get too much medication. However, for the rare circumstances when opioids might contribute to death, provided the intent was genuinely to treat the symptoms, then opioid use is not euthanasia. Be careful to avoid the rationale that says, "death is the treatment!" Symptom treatment alleviates symptoms; it does not intentionally cause death.
- **Is it illegal to prescribe large doses of opioids to relieve symptoms of pain, breathlessness, or other symptoms?** Even very large doses of opioids are both permitted and appropriate, if the intent and doses given are titrated to the patient's needs.

Life-sustaining treatments

There is a wide range of life-sustaining treatments that might be considered by an individual patient and family. These include CPR, elective intubation and mechanical ventilation, surgery, dialysis, blood transfusions or blood products, artificial nutrition

and hydration, diagnostic tests, antibiotics, other medications and treatments, and future hospital or ICU admissions.

After determining the general goals of care, discuss each specific treatment with your patients and families, as appropriate. At a minimum, try to discuss an invasive and a noninvasive intervention to get a general idea of a patient's priorities for treatment. Decisions about surgery and antibiotics are often strongly predictive of other invasive and noninvasive decisions, respectively.

8-step protocol to discuss treatment preferences

An 8-step protocol is suggested to guide the discussion of treatment preferences, particularly when considering withholding or withdrawing a life-sustaining therapy:

1. Be familiar with policies and statutes
2. Appropriate setting for the discussion
3. Ask the patient and family what they understand
4. Discuss the general goals of care
5. Establish context for the discussion
6. Discuss specific treatment preferences
7. Respond to emotions
8. Establish and implement the plan

Module 7: Goals of Care presents an approach to determining the general goals of care. Module 1: Advance Care Planning presents a general approach to the discussion of advance care planning. Module 2: Communicating Bad News presents guidelines on how to conduct discussions related to communicating bad news. This module integrates the principles from these modules to the discussion of specific treatment preferences, particularly to discussion about withholding or withdrawing therapy.

Reasonable physicians may disagree about the extent to which specific treatment preferences ought to be discussed, if such treatment will not help achieve the overall goals. As a rule, the discussion of general goals of care should precede the discussion of specific treatment preferences.

The physician usually conducts discussions of treatment preferences. Other appropriate members of the health care team may enhance the discussion and prevent subsequent conflict within the team. They will have additional time to carry on the dialogue with the patient and family. The team will also be able to provide valuable emotional support to the patient, family, and each other.

Even though other members of the health care team participate and/or conduct the discussion, implementation of any decision requires a physician's order. The attending physician must sign the documentation and assume full responsibility for its accuracy.

Become familiar with pertinent policies and statutes

Physicians must familiarize themselves with the policies of the institution and pertinent statutes where they practice. Unfortunately, many physicians presume that, because their hospital has a specific policy (eg, all patients will have CPR unless otherwise ordered) this practice reflects state or federal law. Relatively few states have laws that address specific treatments, such as the law in New York that addresses CPR. Most states leave specific treatment decisions to be decided between patient and physician. Each institution will have its own policies, and may have developed standard forms regarding life-sustaining treatment.

Communicate effectively

When starting a discussion of treatment preferences, follow the approaches to communication outlined in Module 2: Communicating Bad News. Establish the appropriate setting. Ask what the patient, family, or surrogate understands about the current health situation, and would like to know, before imparting new information.

Determine/reconfirm goals of care

Determine or reconfirm the general goals of care. Examples are, “Can we review our overall goals for your care?” or, “Let me tell you what I understand you want as we plan your care.” Once the general goals of care have been confirmed, specific life-sustaining treatment preferences can be discussed.

Establish the context of the discussion

Be sure to establish the context in which or for which treatment planning is being discussed. The classic misstatement on the part of well-meaning physicians is, “Do you want us to do everything?” This highly euphemistic and misleading question fails to acknowledge context. When are we talking about? Today, when the patient is quite healthy, or at the very end of his or her life when facing death? “Everything” is much too broad and is easily misinterpreted by families, especially when they feel “everything” has not, in fact, been done.

Discuss specific treatment preferences

Discuss specific treatment preferences. Use language that the patient will understand. Use a translator, preferably someone trained in these skills, if necessary. Give information in small pieces. Reinforce the context in which the decisions will apply. Stop frequently to check for reactions, to ask for questions, and to clarify misunderstandings.

Reasonable physicians may argue that it is unnecessary and potentially confusing to patients and families to ask them to decide about specific treatment preferences. Patients and families may be ill served if physicians regard the principle of autonomy as meaning

that physicians must offer all possible therapies from which patients and families choose, as though they were choosing items from a menu in a restaurant. Nonetheless, it is often useful to discuss and recommend withholding or withdrawing specific treatments in light of the general or overall goals that have previously been established.

Aspects of informed consent

Informed consent is a fundamental ethical principle that underlies contemporary medical care. Patients, and parents if the patient is a child, deserve a clear, complete understanding of all therapies that are being proposed for them. Some will want to know all the details. Others will prefer not to know anything.

Be prepared to describe in simple, neutral terms the aspects of each life-sustaining treatment in a manner that conforms to the principles of informed consent (see Module 8: Sudden Illness):

- the problem the treatment would address
- what is involved in the treatment or procedure
- what is likely to happen if the patient decides not to have the treatment
- the benefits of the treatment
- the burden created by the treatment

Information that could be provided to patients and families who are making decisions regarding artificial feeding and hydration, ventilator withdrawal, and cardiopulmonary resuscitation is provided in the appendix.

Respond to emotions

During these discussions, respond to patient and family anxiety, and acknowledge emotional content. Parents, if the patient is a child, are likely to be very emotional and need support from the physician and other members of the health care team. Patients, families, and surrogates may be profoundly disturbed by the subject matter being discussed. If a physician finds that emotions are too challenging, ask other colleagues and/or members of the health care team to assist.

Establish a plan

Establish and implement a plan that is well articulated and understood. The next steps may be as simple as planning to discuss the subject again at the next visit, or convening a family meeting to further discuss the proposed treatment plan. They may be as complex as organizing nursing, social work, and chaplaincy intervention, or assuring that a key family member living out of town is notified.

Document and disseminate the plan

Discuss treatment plans with other health care professionals so that the plans may be carried out in a straightforward and organized fashion. In health care institutions, this involves discussing the plan with nursing and house staff, at a minimum. Write the appropriate orders, document the discussion in the medical record, and talk about the plan with other members of the health care team.

Application of the protocol

Three common examples of the application of the protocol to discuss the withholding or withdrawing of therapy follow.

Example 1: Artificial feeding and hydration

Physicians frequently perceive the discussion about whether or not to use or continue artificial feeding and/or hydration to be difficult. Successful approaches are not customarily demonstrated during medical training. Food and water are widely held symbols of caring, so withholding of artificial nutrition and hydration may be easily misperceived as neglect by the patient, family, or other professional and volunteer caregivers. The following are key points, in addition to the general approaches described above:

Review goals of care

First, establish the overall goals of care. Talk about the general medical condition. Evaluate the ability of artificial hydration and nutrition to help achieve those goals, before discussing specifics. For example, if the patient has advanced cancer, establish an understanding of the overall situation. What is the expected course of the cancer? Is anything reversible? Second, how will artificial hydration and nutrition contribute to the overall goals of care, or improve the situation? If the patient and family hope to see improved energy, weight, and strength, then artificial fluid and nutrition may not help accomplish those goals. Help the patient and family to understand the goals for which artificial nutrition and hydration would be appropriate (see Module 7: Goals of Care).

Address misperceptions

During the discussion, listen for misperceptions expressed by patients and families. They may believe that lack of appetite and diminished oral intake of fluids is causing the patient's level of disability. Most then make the assumption that, if only the patient got more fluids and nutrition, he or she would be stronger. Use clear, simple language to help them focus on the true causes of the situation: eg, "The cancer is taking all of your strength" or, "The fact that your heart is so weak is what is causing you to lose your appetite and feel so fatigued."

If the patient is close to dying, make sure the family knows that a dry mouth may not improve with intravenous fluids. Relief is much more likely with attention to mouth care and oral lubricants (see Module 12: Last Hours of Living).

In some patients, delirium may be related to dehydration, so a clinical trial of intravenous fluids may be warranted. However, before starting, ensure that everyone is aware that there are other causes of delirium that may not respond to fluids, and there is a risk that fluids will only increase other physical symptoms (eg, edema, breathlessness) without relieving the delirium.

Urine output normally declines in the patient who is dying; it is not just an indicator of hydration. Urine output in the range of 300 to 500 mL/day is adequate. The large volumes (2 to 3 L/day) that physicians and other health care professionals associate with hospitalized patients are usually the result of intravenous infusions and do not reflect normal output with oral hydration. Both high-volume infusions and excessive urination may be a source of discomfort to the patient (see Module 6: Depression, Anxiety, Delirium; Module 10: Common Physical Symptoms; and Module 12: Last Hours of Living).

Help family with their need to give care

As part of the discussion, identify the emotional need that providing food and water meets, particularly for families. Don't just address issues of artificial hydration and nutrition. Help the family find ways to redirect their desire to be caring, and teach them the skills they need to be effective.

Normal dying

Loss of appetite and diminished fluid intake are a part of normal dying. Trying to counteract the natural trends may lead to more discomfort for the family without affecting the outcome.

Near the end of life, patients and families may be concerned that there will be suffering from thirst or hunger if the patient is not taking any fluids or nutrition. Help the patient and caregiving family to understand that dehydration is a natural part of the dying process. It does not affect the dying patient in the same way as a healthy person who feels thirsty on a hot day or becomes dizzy on standing.

Let family members know that if the patient is not hungry, artificial fluids and hydration will not help him or her feel better. Badgering the patient to eat or drink more will only increase tensions and may cause the patient to become angry, depressed, or withdrawn, if he or she cannot comply.

In addition, make sure that family members and caregivers know that artificial fluids and nutrition may make edema, ascites, pulmonary and other secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia.

Ensure that family and caregivers know that a state of dehydration in a patient who is bed-bound and imminently dying may have some benefits. Pulmonary secretions, vomiting, and urinary incontinence may be less. Dehydration may actually stimulate the production of endorphins and other anesthetic compounds that help to contribute to a peaceful, comfortable death for many patients.

Practical approaches to managing specific symptoms are covered in Module 6: Depression, Anxiety, Delirium; Module 10: Common Physical Symptoms; and Module 12: Last Hours of Living.

Example 2: Ventilator withdrawal

For many physicians, there is a relatively rare need to supervise withdrawal of a ventilator when death is expected. However, the withdrawal of ventilator support from a patient is one of the most challenging situations for patients, families, and their caregivers, and members of the health care team.

The purpose of this section is to describe an approach (based on the literature and expert opinion) that can guide the physician through such an encounter. While there are no tested protocols, if you are uncertain, seek the assistance of experienced colleagues and other health care professionals to help in the process.

In discussing whether to institute or withdraw artificial ventilation, follow the general outline for discussing life-sustaining treatments that began this module. Assess whether removal from the ventilator is appropriate and desired (elements of that assessment are described in the references). First, discuss the overall goals in light of the patient's medical condition. Then, consider the role that artificial ventilation might play in achieving those goals.

Techniques for ventilator withdrawal

If ventilator withdrawal seems appropriate to everyone involved, consider which of these two methods might be used:

1. Immediate extubation (removal of the endotracheal tube)
2. Terminal weaning

The clinician's and patient's comfort, and the family's perceptions, should influence the choice of the method to use.

Immediate extubation

In immediate extubation, the endotracheal tube is removed after appropriate suctioning. Humidified air or oxygen is given to prevent the airway from drying.

This is the preferred approach to relieve discomfort if the patient is conscious, the volume of secretions is low, and the airway is unlikely to be compromised after extubation.

While most authorities regard immediate extubation as ethically sound practice, some may be concerned that it is a form of direct killing of the patient. In such an action the intent becomes the primary concern. Secondary consequences can be dealt with, if they occur.

Terminal weaning

In what some have called terminal weaning, the ventilator rate, positive end-expiratory pressure (PEEP), and oxygen levels are decreased while the endotracheal tube is left in place. Terminal weaning may be carried out over a period of as little as 30 to 60 minutes or longer. CO₂ narcosis may stimulate endorphin release and further sedate the patient. If the patient survives, a Briggs T-piece may be used in place of the ventilator, if the endotracheal tube will be left in place. Alternately, patients may then be extubated.

Ensure patient comfort

When removing a patient from the ventilator, it is critical that the patient be comfortable throughout the procedure and afterwards. The most important and prevalent symptoms are breathlessness and anxiety.

Prevent symptoms

Breathlessness

Opioids (such as morphine) are the most effective medication for relieving the sense of breathlessness. They work through both central and peripheral mechanisms of action. The principle of intended vs unintended consequences governs their use in this setting.

Concerns about unintended secondary effects, such as shortened life, are exaggerated, particularly if established dosing guidelines are followed. Titrate the dose with the intent to achieve comfort. Increased doses beyond the levels needed to achieve comfort or sedation in order to hasten death would constitute euthanasia. Oxygen is helpful to correct hypoxemia, but not necessarily breathlessness (see Module 10: Common Physical Symptoms).

Anxiety

Benzodiazepines such as midazolam, lorazepam, and others are the most effective anxiolytic drugs in this setting. They are usually used in combination with opioids for severe breathlessness. Opioids only have transient and unreliable anxiolytic effects in opioid-naive patients and should not be used for this purpose (see Module 6: Depression, Anxiety, Delirium).

Preparing for ventilator withdrawal

If the patient is conscious, determine if he or she would like to remain conscious as the ventilator is withdrawn. This will determine the endpoints for initial medication and

guide the use of additional medication during the procedure. If the patient wishes to remain awake, institute opioids and benzodiazepines at low doses. Make plans to intervene if severe breathlessness or discomfort ensues after extubation. Determine, with the patient and family, how and when you would decide to titrate to an endpoint of sedation.

In planning for discontinuation, a skilled clinician must assess and reevaluate the patient's choice and situation. Anticipate potential discomfort and institute appropriate medical and nonmedical measures in advance to prevent these symptoms from occurring. Have medication immediately available at the bedside so that it can be rapidly titrated to the level appropriate to ensure the patient's comfort.

Before withdrawing the ventilator, ensure that the patient is comfortable. If the patient is naive to opioids and benzodiazepines, start by giving the patient a bolus dose of 2 to 10 mg of morphine IV to prevent breathlessness. For children, dose the medications with advice from a pharmacist or pediatric intensivist. Follow this initial dose with a continuous morphine infusion at 50% of bolus dose/h to maintain the desired effect. Also, bolus with a dose of 1 to 2 mg of midazolam IV and begin a midazolam infusion at 1 mg/h. Titrate these medications to minimize anxiety and achieve the desired state of comfort and sedation. Lorazepam may be used as an alternative. If these medications have been in use routinely and pharmacologic tolerance has developed, higher doses will be required. There is no need to increase the doses once comfort and the desired level of sedation have been achieved.

If distress ensues once the ventilator is withdrawn, aggressive symptom control is needed. Consider using morphine, 5 to 10 mg IV push q 10 min, and/or midazolam, 2 to 4 mg IV push q 10 min, until distress is relieved. Adjust both infusion rates to maintain relief.

The doses recommended here are for patients who were not previously taking anxiolytic medication or opioids.

Prepare the family

Ideally, the family will be involved in the decision to withdraw the ventilator. They will need to understand the procedure and be reassured about their roles. Since there is uncertainty involved, it is also important for the physician to prepare the family for the range of outcomes that might occur.

Never make assumptions about what the family understands. Describe the procedure in clear, simple terms and answer any questions. Assure them that the patient's comfort is of primary concern. Explain that breathlessness may occur, but that it can be managed. Confirm that you will have medication available to manage any discomfort. Ensure they know that you may need to put the patient to sleep. Assure them that involuntary moving or gasping does not reflect suffering if the patient is properly sedated or in a coma.

Explain how the family can show love and support through touch, wiping of the patient's forehead, holding a hand and talking to him or her. Ask the family what other concerns

they have. Explain that there is always some uncertainty as to what will happen after the ventilator is withdrawn. (Some patients die within several minutes, whereas others may live for longer periods.) Caution the family that, although death is expected, it is not certain. Data show that approximately 10% of patients survive and are discharged from the hospital.

A suggested protocol for ventilator withdrawal: immediate extubation, unconscious patient

This protocol demonstrates how care and planning can ensure that the process of withdrawing life support maintains the dignity of the patient, and involves the family appropriately. The protocol presented is for immediate extubation, but it can be adapted for other uses. Immediate extubation may be best reserved for unconscious patients. Key points are listed below.

Prior to withdrawal

In addition to fulfilling all the requirements of informed consent in a good decision-making process, there should be discussion and agreement with the patient if he or she is conscious and the family when to proceed with discontinuing life support. In addition, nurses, respiratory therapists and all professional staff on the unit should understand this development, and have the opportunity to discuss the plan of care. Encourage family to make arrangements for special music or rituals that may be important to them. If the patient is a child, ask parents if they would like to hold the child as he or she dies. Make arrangements for young siblings to have their own support if they are to be present. Document issues, clinical findings, and care plan on the patient's chart.

Withdrawal protocol—part 1

The physician should personally supervise that all monitors and alarms when possible in the room are turned off. Ensure that staff is assigned to override alarms that cannot be turned off if they are triggered. All restraints should then be removed. Clear a space for family access to the bedside. Before the family comes into the room, remove NG tube and any other needlessly disfiguring or unnecessary device that may be crowding the bedside. At this point, invite the family into the room to be with the patient. If the patient is an infant or young child, offer to have the parent hold the child. Then turn off the pressors. Maintain intravenous access for administration of palliative medications.

Withdrawal protocol—part 2

Establish adequate symptom control prior to extubation as described above. As the family has been told that tachypnea or periodic breathing can occur, but will be managed, the physician or assisting nurse should have a syringe of a sedating medication such as

midazolam, lorazepam, or diazepam in hand, to use in case distressing tachypnea or other symptoms occur.

Once initial symptom control has been established, set the FiO₂ on the ventilator to 21%, and observe the patient for signs of respiratory distress. Adjust opioids and benzodiazepines to relieve distress before proceeding further. If a patient is likely to develop CO₂ narcosis with a decrease in ventilator settings, there may be less need for sedating medications.

If the patient appears comfortable, prepare to remove the endotracheal tube. Try a few moments of “no assist” before the endotracheal tube is removed.

When ready to proceed, first deflate the endotracheal (ET) tube cuff. If possible, someone should be assigned to silence, turn off the ventilator, and move it out of the way. Once the cuff is deflated, remove the ET tube under a clean towel which collects most of the secretions and keep the ET tube covered with the towel. If oropharyngeal secretions are excessive, suction them away.

Withdrawal protocol—part 3

The family can now come forward to a loved one whose face is no longer encumbered by medical devices. A nurse should be stationed at the opposite side of the bed with a washcloth and oral suction catheter. The family and the nurse should have tissues for extra secretions, and for tears. The family should be encouraged to hold the patient’s hand and provide assurances to their loved one.

After the patient dies, follow the approaches discussed in Module 12: Last Hours of Living for expected death. There is no need to rush anyone. Encourage the family to spend as much time at the bedside as they require. Provide acute grief support.

Once they are ready to leave, provide the family with the physician’s name and phone number, if they have any questions. Offer follow-up bereavement support.

Send a bereavement card to family members (see Module 12: Last Hours of Living for details about caring for the patient during this period).

Example 3: Cardiopulmonary resuscitation

Many physicians perceive the discussion about whether or not to use CPR to be difficult. This may be due, in part, to the fact that successful approaches are not customarily demonstrated during medical training. Often, the attending physician conducted such discussions alone, behind closed doors. Sometimes, these discussions were assigned to a lone medical student or resident to do after rounds.

It is worth reflecting on the language that has developed around CPR and DNR status, particularly in hospitals. Getting the DNR order is an important goal for physicians. “Is he or she a DNR?” has become shorthand for the more pertinent question, “What are the

goals of care?” Too frequently, a DNR order is interpreted to imply a whole host of other decisions that, in fact, may or may not have been made about an individual patient.

The focus of this section and, in fact, of the entire EPEC curriculum is to place specific decisions about medical treatment into the context of whole-person care and respect for the individual. DNR status should never be addressed in isolation. The phrases, “She is a DNR” and, “He is a full code” betray the bizarre way in which decisions about resuscitation are sometimes treated in contemporary medical care.

One impetus to the current state of affairs is the emotional subtext related to “doing everything” for someone who is loved. It should be expected that everyone involved—patient, family, physician, health care team—wants to do everything possible to achieve the health and well-being of the patient. Cardiopulmonary resuscitation is but one medical treatment that may or may not help to achieve realistic goals related to the care of the patient.

It is helpful to first identify the goals of care. It is the physician’s role to facilitate the identification of those goals, and then help to determine the medical care that will best achieve them.

Then, in the setting of advanced progressive illness where the prognosis is limited, consider carefully whether CPR will help achieve the goals that the patient, the family, and the physician have collectively determined. Using this approach, the discussion of CPR and DNR status become deemphasized to the point that they almost disappear as important parts of the discussion (see Module 7: Goals of Care).

Discussing DNR status

Establishing DNR status is but one example of advance care planning. When undertaking to establish DNR status, the physician may want to consider a range of scenarios, not just the one that appears to be the most pressing. This may also give the discussion a greater sense of proportion.

As discussed in Module 1: Advance Care Planning, and Module 7: Goals of Care, start by establishing or reaffirming an understanding about the patient’s values and goals of care. Before discussing a DNR order, confirm the patient’s (or parents’ if the patient is a young child) understanding about the overall medical condition, and the context in which you are discussing the use of CPR. Engaging in a discussion that focuses only on CPR and DNR status may leave the patient and family confused and anxious, imagining the precipice toward which the patient is speeding.

During the discussion, use language that is understandable, such as, “If you should die in spite of our current therapy, do you want us to use ‘heroic measures’? To do CPR? To press on your chest and put a tube in your lungs to try to get your heart and breathing started again?” To a layman, when the heart and/or lungs stop, the patient dies. It may be helpful to use the word “death” to clarify that CPR is a treatment that tries to temporarily

stop death from occurring. If the patient and family want more information, move to specific descriptions of what is involved with CPR after the more general question is answered.

The convention of initially discussing CPR as “starting the heart” or “putting on a breathing machine” implies a false sense of reversibility, or suggests those heart and lung functions are isolated problems. Avoid implying that the impossible is possible. In discussing DNR status with a patient with a life-threatening illness, avoid introducing CPR as “shocking the heart if it stops, using a breathing machine if the lungs stop.” This reductionist approach fails to acknowledge the context in which CPR would be administered—to a patient who is dying of a disease. In the setting of advanced illness, circulation and breathing stop because of the relentless progression of the disease. If there were something to reverse, the medical team would do so long before the patient stopped breathing.

Further, avoid describing CPR as “doing everything.” It implies that not doing CPR is “doing nothing.” The issue of abandonment is implicit in discussions of CPR and DNR.

As part of the discussion, ask about other life-prolonging therapies. Put the discussion of resuscitation into the context of the host of life-prolonging therapies that need to be decided upon, including elective intubation and mechanical ventilation, dialysis, surgery, antibiotics, artificial fluids, etc. Consider describing various scenarios and eliciting the patient’s preferences. Avoid “getting the DNR” and leaving the patient.

Before ending the discussion, affirm what you will be doing for the patient. Confirm the active interventions that are or will be done for the patient. For many patients, full medical interventions to reverse disease and sustain life are appropriate even with a DNR order in place. However, if the patient dies in spite of all efforts, resuscitation will not be attempted.

So-called “slow codes” or “chemical-only” codes are unacceptable approaches to the issue of whether or not to offer emergency attempts to restore airway, breathing, and circulation. Their use promotes cynical approaches to decision making and hypocritical interactions between physicians and patients.

Write appropriate medical orders

DNR order

CPR involves the establishment of a patent airway, effective breathing, and cardiac output through assisted ventilation and external cardiac massage. If this is not appropriate or desired by the patient, the physician should write a DNR order. A DNR order does not address any aspect of care other than preventing the use of CPR. Some institutions prefer a do not attempt resuscitation (DNAR) to avoid the implication of success that DNR connotes.

DNI order

A do not intubate (DNI) order is sometimes used for patients who do not ever want a ventilator used, even if the machine could save their lives. For example, patients with chronic or progressive lung diseases may choose an isolated DNI order. Patients who choose to have a DNR order have implied a DNI order, as CPR requires the establishment of airway, breathing, and circulation.

Do-not-transfer order

Some long-term care institutions may permit a “do-not-transfer” order to indicate preferences not to be transferred to an acute hospital setting, in the event of clinical decline.

Other orders

Include all positive orders that relate to symptom control and those that guide intensity of care. Some institutions have special forms to facilitate communication and document orders. A good example is the POLST (Physician Orders for Life-Sustaining Treatment), which is being used extensively in Oregon (see appendix).

Summary

Withholding and withdrawing therapy challenge physicians to be excellent communicators with patients and families. Working to help patients and families achieve their goals and understand the limits of modern medical help can be rewarding when information and skills are learned.

Key take-home points

1. Patients have the right to refuse any medical treatment, even life-sustaining treatments.
2. Withdrawal or withholding of treatment is a decision/action that allows the disease to progress on its natural course. It is not a decision/action intended to cause death.
3. In rare circumstances, opioids and other drugs are rapidly titrated to treat physical symptoms following accepted dosing guidelines. They might be perceived to contribute to death. Provided the intent was genuinely to treat the symptoms, then such use is not euthanasia.
4. Physicians must familiarize themselves with the policies of the institution and pertinent statutes where they practice.
5. Impediments to good care include misconceptions about legal and ethical issues, as well as unfamiliarity with the practical aspects of withholding or withdrawing treatment.

6. Patients may be transferred to the acute care setting where life-sustaining measures are administered because the appropriate treatment plan and physician's orders have not been completed and placed in the patient's chart, or physician's orders may not transfer across settings.

Nutrition/hydration

7. If the patient and family hope to see improved energy, weight, and strength, artificial fluid and nutrition may not help accomplish those goals.
8. If the patient is close to dying, make sure the family knows that a dry mouth may not improve with intravenous fluids. Relief is much more likely with attention to mouth care and oral lubricants.
9. Dehydration is a natural part of the dying process. Artificial fluids and hydration will not help the patient feel better.
10. Artificial fluids and nutrition may make edema, ascites, pulmonary and other secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia.

Withdrawing ventilation

11. When removing a patient from the ventilator, it is critical that the patient be comfortable before, throughout, and after the procedure.
12. If the patient is conscious, determine whether he or she would like to remain conscious as the ventilator is withdrawn.
13. A combination of opioid and anxiolytic therapy should be used to ensure comfort.
14. Have medication immediately available at the bedside so that it can be rapidly titrated to the level appropriate to ensure the patient's comfort.
15. There is no need to increase the dosage of medication once comfort and the desired level of sedation have been achieved.
16. Since there is uncertainty involved, it is important for the physician to prepare the family for the range of outcomes that might occur. Explain that there is always some uncertainty as to what will happen after the ventilator is withdrawn. Caution the family that, although death is expected, it is not certain; the patient may survive.
17. Encourage the family to spend as much time at the bedside as they require.

Cardiopulmonary resuscitation/do-not-resuscitate orders

18. In the setting of advanced progressive illness where the prognosis is limited, consider carefully whether cardiopulmonary resuscitation (CPR) will help achieve the goals that the patient, family, and physician have collectively determined.

19. Establishing a do-not-resuscitate (DNR) order is but one aspect of advance care planning. Avoid discussing it as an isolated decision.
20. Before discussing a DNR order, confirm the patient's understanding about his or her overall medical condition, and the context in which you are discussing the use of CPR.
21. Before ending the discussion, affirm what you *will* be doing for the patient. Confirm the active interventions that are being or will be done for the patient. For many patients, full medical interventions to reverse disease and sustain life are appropriate even with a DNR order in place.
22. Beside a DNR order in the chart, include all positive orders that relate to symptom control and those that guide intensity of care. Communicate this to other caregivers.
23. DNR status should never be addressed in isolation. The phrases, "She is a DNR" and "He is a full code" betray the bizarre way in which decisions about resuscitation are sometimes extrapolated to presume an entire care plan.
24. CPR decisions are the least stable and least useful in inferring other wishes. They tend to make people more concerned rather than less about the moment of death.

Pearls

1. Discuss overall goals before discussing specific treatments.
2. Acknowledge emotional components of decisions.
3. Stress from symptoms may be the only thing keeping the patient alive.
4. Dehydration may stimulate the production of endorphins and other anesthetic compounds that help to contribute to a peaceful, comfortable death for many patients.
5. Carbon dioxide narcosis may stimulate endorphin release and further sedate the patient.
6. In the context of general goals and other treatment/care choices for a defined set of scenarios, it helps to avoid fear of immediate death.
7. When the patient and family are fearful of immediate death, it may be helpful in reestablishing perspective and control to discuss goals and treatment or care choices in a range of scenarios.
8. Avoid implying that the impossible is possible. The convention of initially discussing CPR as "starting the heart" or "putting on a breathing machine" implies a false sense of reversibility, or suggests that heart and lung functions are isolated problems.
9. Explicitly acknowledge the context in which CPR would be administered—to a patient who is dying.

Potential pitfalls

1. Avoid loaded slogans like “do everything,” “starve to death.”
2. Institutional policies may be written in response to the general legal imperative to err of the side of prolonging life in cases of uncertainty or in emergencies.
3. Not having the attending physician at the bedside when withdrawing the ventilator.
4. Forgetting anxiolytics. Opioids only have transient and unreliable anxiolytic effects in opioid-naïve patients and should not be used to relieve anxiety.
5. Describing CPR as “doing everything.” This implies that not doing CPR is “doing nothing.”

Resources

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Appendix

Cases for role play

Artificial feeding and hydration

D.W. is an 82-year-old widowed retired secretary with advanced dementia. She is cared for in the home of her married daughter, who is her power of attorney for health affairs. She requires assistance in all her domestic activities of bathing, feeding, toileting, ambulation, etc. She spends most of the day in bed, or lying on the sofa. She speaks very little, and not very intelligibly. She has recently stopped eating almost everything. She bites the spoon when it is brought to her mouth and/or pockets food in her cheeks without swallowing. She was admitted to the hospital several months ago for the treatment of aspiration pneumonia. The possibility of a feeding tube has been raised. You are discussing this with the daughter.

Resuscitation

K.E. is a 68-year-old truck driver with advanced esophageal cancer. Despite surgical resection and combination chemotherapy and radiotherapy, the disease has progressed. Although he denies pain or breathlessness, he does indicate overall fatigue. He has lost 10 pounds over the past month. Recent studies have demonstrated malignant pleural effusion and liver metastases. He knows these results. You are seeing him in the office to discuss further care.

Information for patients/families

1. Artificial fluids and nutrition

When is artificial feeding and nutrition most appropriate?

- if you have a temporary condition that prevents swallowing, artificial fluids and nutrition can be provided until you recover

What is involved in the procedure?

- an intravenous catheter may be placed in a vein in the skin for fluids, or sometimes nutrition
- alternately, a plastic tube called a nasogastric tube (NG tube) may be placed through the nose, down the throat, and into the stomach. It is approximately 1/8 inch in diameter. This can only be left temporarily
- if feeding by this route, a more permanent feeding tube may be placed into the wall of the stomach (PEG tube or G tube)

What happens if it is not administered?

- if a person is unable to take any food or fluids due to illness, he or she will eventually fall into a state much like a deep sleep. This process will take 1 to 3 weeks
- before entering the deep sleep, he or she will normally not experience any hunger or thirst after the first several days
- for a person who has an advanced illness, giving artificial hydration and nutrition may not prolong life

What are the benefits?

- a feeding tube may reduce hunger in someone who is hungry, but cannot swallow
- intravenous fluids may reduce some symptoms, such as delirium

What are the burdens?

- all feeding tubes are associated with significant risk. Around 30% of patients have signs of the liquid entering the lungs. This aspiration of fluid can cause coughing and pneumonia
- feeding tubes may feel uncomfortable. They can block the stomach, causing pain, nausea, and vomiting
- tubes for food and fluids may become infected
- physical restraints are occasionally needed so the patient won't remove the tube

2. Artificial ventilation

When is artificial ventilation best used?

- if you have a temporary condition that prevents adequate breathing, a breathing machine can be used until you recover

What is involved in the procedure?

- a tube is placed through the mouth or nose into the lung and is connected to a breathing machine

What happens if it is not administered?

- if a patient is unable to breathe, the patient may die

What are the benefits?

- the breathing machine allows the body time to recover
- it prolongs life

What are the burdens?

- the breathing tube is uncomfortable. Most patients require medicine to keep them comfortable while they are on the breathing machine
- it may prolong a state of dependence in a medical setting that the patient finds not worth the discomfort
- it may prolong dying

3. Cardiopulmonary resuscitation (CPR)

When is CPR most important?

- when the heart or lungs stop working unexpectedly (eg, after an accident or when you are walking down the street)
- when there is a possibility that the underlying problem can be fixed

What is involved in the procedure?

- involves vigorous pressing on the chest and electric stimulation to the chest
- medications may be administered and a tube to assist breathing may be used
- typically lasts for 15 to 30 minutes

What happens if it is not administered?

- the loss of consciousness will be followed by death in 5 to 10 minutes

What are the benefits?

- for a patient with an advanced life-threatening illness who is dying of the underlying disease, there is no benefit
- for patients with good overall health status, younger age, and administered within 5 minutes of cardiac or respiratory arrest, it may permit prolonged life

What are the burdens?

- chest compressions could result in a sore chest, broken ribs, or a collapsed lung
- most people who need CPR also need to be on a mechanical ventilator in an intensive care unit to support their breathing for a period of time
- fewer than 10% of all hospitalized patients survive CPR and return to their previous state (most of these people were already in a coronary care unit when the procedure was done). Most patients live for a short period after CPR, but still die in the hospital
- only 1% to 4% of patients with multiple chronic illnesses survive to leave the hospital
- almost no one with cancer survives to leave the hospital
- of those who survive, many continue to live in a weaker state, or with brain damage. Half the people who survive are chronically dependent

Appendix: reprinted documents

Physician Orders for Life Sustaining Treatment (POLST Form), reprinted by permission of the Center for Ethics in Health Care, Oregon Health Sciences University, Portland, Oregon, USA.