



CHAPTER 11

Ethics Conflicts in Rural Communities: **End-of-Life Decision-Making**

Denise Niemira, Tom Townsend

DISCLAIMER

Dartmouth Medical School's Department of Community and Family Medicine, the editor, and the authors of the *Handbook for Rural Health Care Ethics* are pleased to grant use of these materials without charge providing that appropriate acknowledgement is given. Any alterations to the documents for local suitability are acceptable. All users are limited to one's own use and not for resale.

Every effort has been made in preparing the *Handbook* to provide accurate and up-to-date information that is in accord with accepted standards and practice. Nevertheless, the editor and authors can make no warranties that the information contained herein is totally free from error, not least because clinical standards are constantly changing through research and regulation. The authors and editor therefore disclaim all liability for direct or consequential damages resulting from the use of material contained in this book.

Although many of the case studies contained in the *Handbook* are drawn from actual events, every effort has been made to disguise the identities and the organizations involved.

The *Handbook for Rural Health Care Ethics* provides general ethics information and guidance. Due to complexities and constant changes in the law, exceptions to general principles of law, and variations of state laws, health care professionals should seek specific legal counsel and advice before acting on any legal-related, health care ethics issue.

Additionally, we have sought to ensure that the URLs for external Web sites referred to in the *Handbook* are correct and active at the time of placing this material on the home Web site. However, the editor has no responsibility for the Web sites and can make no guarantee that a site will remain live or that the content is or will remain appropriate.

Handbook for Rural Health Care Ethics: A Practical Guide for Professionals

Dartmouth College Press
Published by University Press of New England
One Court Street, Suite 250, Lebanon NH 03766
www.upne.com

Copyright © 2009 Trustees of Dartmouth College, Hanover, NH

Edited by William A. Nelson
Cover and text design by Three Monkeys Design Works

Supported by NIH National Library of Medicine Grant # 5G13LM009017-02

Ethics Conflicts in Rural Communities: End-of-Life Decision-Making

Denise Niemira, Tom Townsend

ABSTRACT

Caring for people at the end of their lives can be one of the most challenging and personally rewarding aspects of primary care. The proximity to death intensifies and transforms the medical encounter calling upon both the emotional and the clinical competence of the medical provider. As people live longer with chronic illnesses, and as life-prolonging interventions become routine, death frequently involves a decision to forgo or limit care. Such decisions can generate moral conflict, even when the ethical and legal principles governing decisions are well defined and widely accepted. Family members, may feel that withdrawing life support is morally different than withholding such therapy in the first place. Surrogates named in advance directives may want to keep their loved ones alive rather than follow directives, even when the patient's wishes are clearly articulated. The clinician's responsibility is to support the autonomy of the dying person, while recognizing the emotional needs of the family. This has become more challenging in cases where there is no ethical consensus about either the decision to be made, and/or the legal requirements for its enactment, such as the withdrawal of artificial nutrition or terminal weaning from a ventilator. Ethical challenges in end-of-life care are heightened for rural providers who often have multifaceted relationships with patients and their families. Rural providers are sometimes the sole recipients of oral directives, and may have less experience than urban providers with complex end-of-life care. Rural clinicians should enact procedures to help their patients and patient's families prepare for the end-of-life process to reduce both ethics conflicts and undue stress for all parties involved.

CASE STUDIES

CASE 11.1 | Surrogate wishes run counter to advance directives

Dr. Mark Townes, a family practitioner, returns from a vacation to find Frank Foote, a 72-year-old patient with multiple illnesses, including heart failure and end-stage COPD, on a ventilator in intensive care. Brenda Foote, Frank's wife of 48 years, greets Dr. Townes, saying, "I'm so glad you're back. His breathing got so bad I had to call 911. Your partner put in a breathing tube, and now he's been on the ventilator for six days. The antibiotics for the pneumonia aren't working so well. Your partner told me he should go to the University Hospital, because his breathing isn't getting better and he may need a tracheotomy. I'm so scared I might lose him. They say he's not responsive, but he seems to calm down when I speak to him and act up when they poke him to draw blood." A reading of the medical record confirms Mrs. Foote's story. Dr. Townes' partner, following Mrs. Foote's lead, has pursued aggressive care and Mr. Foote is in full code. The chart indicates that Mr. Foote had no advance directive, although Dr. Townes and Mr. Foote had discussed it at his last visit, and Mr. Foote assured Dr. Townes that an advance directive had been completed, but had not yet been witnessed. Two unsuccessful attempts have been made to wean Mr. Foote off of the ventilator. Based on previous discussions with the patient, Dr. Townes knows that continued care including intubation is not what Mr. Foote would want. However, Mrs. Foote is also Dr. Townes' patient, and he knows that she has a hard time confronting death — both her own and her husband's. Dr. Townes also knows that withdrawing Mr. Foote's ventilator will not be a typical procedure at his small hospital, and that there exists no policy for terminal weaning. The doctor is uncertain as to how to proceed.

CASE 11.2 | Colleagues disagree with end-of-life decisions

Dr. Rachel Dennis, a general internist, has recently discharged Mr. Coulter to a nursing home for permanent placement, following a hospitalization for complications related to a fall. Mr. Coulter, 80

years old, has end-stage Alzheimer's disease, with a swallowing disorder that has been worsened by his recent illness. Prior to discharge, Dr. Dennis had conducted a lengthy discussion with the Coulter family about Mr. Coulter's condition, specifically regarding his swallowing problems. At that point, the doctor had discussed the option of a feeding tube with Mr. Coulter's wife of 50 years, but Mrs. Coulter, the Durable Power of Attorney for Health Care, had rejected this option. Dr. Dennis believed that she had been clear in her description of the benefits and risks of the feeding tube, and she had felt that the family was clearly committed to a palliative care course, without supplemental nutrition, by the time that she had discharged Mr. Coulter to the local nursing home. The nursing home is generally known for its commitment to end-of-life care, and his staff understood the proposed plan of care. The administrator did tell Dr. Dennis that a new medical director had just been employed, and that he would need to review the proposed plan of care.

Several days after the hospital admission, Dr. Dennis receives a frantic call from Mrs. Coulter, who has just authorized the transfer of her husband to the hospital emergency room for evaluation. This has followed a discussion with the nursing home medical director, who thinks Mr. Coulter is dehydrated and probably has elevated sodium. Mrs. Coulter is upset following this conversation, and by remarks she has overheard from other staff members about her husband starving to death. She wants to reconsider her decision to withhold a feeding tube. Her family is confused by this abrupt change in plans, especially since it seems that their father might not be allowed to return to the nursing facility without a feeding tube.

OVERVIEW OF ETHICS ISSUES

Providing care for those at the end of life can be one of the most challenging yet rewarding tasks in medicine. It requires health care providers to competently address and manage the broad array of clinical, emotional, social, and spiritual issues that frequently arise in the dying process. It also requires providers to address many potential ethics issues in the end-of-life decision-making process. Despite the intensity of such challenges, providing competent, quality care at the

end of life can be professionally fulfilling and reflects the health care professional's respect for their patient's life and values.¹

Modern medicine is highly specialized, and technological interventions are commonplace, allowing people with chronic illnesses to live longer lives. As illnesses progress and the burdens of life-maintaining interventions increase, patients often exercise their autonomy by refusing continued treatment or requesting that current therapy be withdrawn. Clinicians who are aware of illness trajectories should initiate these discussions as part of the informed-consent process, when new treatments are proposed, or when reviewing the patient's current status in end-stage disease.²⁻⁶ In either case, clinicians should respect and maximize the patient's present autonomy, and anticipate and arrange for a future in which the patient may lack decision-making capacity. Such discussions form the heart of advance-care planning, and the preferences that patients express about future care constitute advance directives.^{7, 8}

Advance Directives

Advance Directives are oral or written instructions regarding an individual's choices for what medical care is to be given during a future illness when the person articulating such choices is no longer able to express his or her desires.⁷ The three general categories of advance directives are noted in Box 11.1.

BOX 11.1

ADVANCE DIRECTIVES

- Oral statements made to family, friends, or providers
- Written statements or documents
- Naming a proxy or surrogate to make health care decisions

Both the fields of health care ethics and the law generally recognize these various forms of advance directives as an extension of a competent person's autonomy, to be used in those situations when a person lacks competence or decision-making capacity. Advance directives seek to respect patients' values and preferences to direct

their care when they no longer may be capable of making health care decisions. Written directives are preferable, since they are less easily challenged and, if executed properly, have legal standing. Written advance directives may take several forms, as noted in Box 11.2.

BOX 11.2

TYPES OF WRITTEN ADVANCE DIRECTIVES

Living Will

| An expression of a person's desires regarding their own future treatment when death is imminent

Durable Power of Attorney for Health Care

| Naming a specific person as a surrogate decision-maker

Terminal Care Document

| A document which names a decision-maker and expresses choices about specific treatments, often including choices of mechanical ventilation, nutrition, and hydration

Patients may supplement these typical forms with more extensive expressions of values or desired treatment in specific clinical situations.³ Almost all states have laws that specifically address the right of a competent adult to make known his or her wishes about medical treatment through some form of legal document. While states vary in their laws, preferences expressed in living wills are most often upheld and referred to in court decisions regarding end-of-life care, even in states that do not recognize this specific document. Withholding certain therapies, such as hydration and artificial nutrition, however, may be subject to specific requirements in some legal jurisdictions. States may also define the necessary conditions, such as witnessing requirements, for a legally binding advance directive document. The state-specific law may define or limit the scope of the surrogate decision-maker, including who cannot be a surrogate, and which decisions a surrogate may not make without specific written instructions. In most states, the patient's health care providers are excluded from being appointed as surrogate decision-makers. Rural health care professionals are urged to be aware of their state's statute.⁹

Providers are expected to assist surrogates in making the most appropriate decisions based on their medical knowledge and understanding of the patient's desires and health care values.⁶ As extensions of their patients' autonomy in decision-making, clinicians are expected to treat advance directives with the same respect as they would with other patient choices. If the provider disagrees with the patient's choices, he or she has an ethical obligation to inform the patient when the document is executed, and to either resolve the conflict, or arrange for transfer of care. The same is true if the surrogate decision-maker presents the document at a later stage.

Surrogate Decision-Makers

Chronically ill or dying patients often lose their decision-making capacity prior to death, when care is ongoing and decisions still need to be made. For those who have executed a Durable Power of Attorney for Health Care (DPOAHC) according to the statutes of their state, the agent named is their legal surrogate decision-maker. Other potential surrogate decision-makers are listed in Box 11.3.

BOX 11.3

SURROGATE DECISION-MAKERS

- Agent named in Durable Power of Attorney for Health Care (DPOAHC)
- Guardian
- Spouse (may include domestic partners, depending on legal status or custom)
- Adult children
- Parents
- Siblings
- Other relatives or friends

Unfortunately, the option to formally identify a surrogate decision-maker in a DPOAHC is not often exercised. Therefore, other mechanisms for establishing surrogate decision-makers have evolved.³ In most states, statutes list the individuals who can consent in the absence of an appointed agent or guardian with health powers, and in what order of pri-

ority. In some states, legal statutes define the need, the role and the process for establishing guardianship in certain end-of-life decision-making situations. In other states, the law is silent or defers to kinship. Barring a legal requirement, most health care providers rely on those people who are most intimately knowledgeable with their patient's wishes, usually spouses and family members. When state law does not define a kinship hierarchy, many institutions will have a policy defining such a hierarchy for surrogates that usually lists, in the following order: spouse, adult children, parent, sibling, other relative or friend. The role of non-spousal domestic partners is often ambiguous in states where such relationships have no legal standing, and providers should strongly encourage people in such relationships to execute a proxy document if they wish to have their partner, rather than their family, be their decision-maker.

However surrogates are chosen, their role in decision-making is to represent the values and wishes of the person for whom they are deciding. The surrogate's decisions must be guided by standards that have a basis in law as well as in ethics.^{2, 3, 9} Rural health care professionals should be aware of their state's related statutes.

There are generally two recognized standards for surrogate decision-making, as indicated in Box 11.4.

BOX 11.4

STANDARDS FOR SURROGATE DECISION-MAKING

Substituted Judgment

Based on the patient's clear and specific previous expressed values, desires, actions, or beliefs

Best Interest

Based on a comparative assessment of the burdens and benefits of the current treatment options in relationship to the patient's condition

The first standard for surrogate decision-making is an autonomy-based standard, which includes clear, specific, previously expressed oral and

written directives that reflect the decision the patient would chose. The decision-maker's role is to make decisions based on the patient's expressed desires. These desires form the basis for what is known as "substituted judgment."

The second level of surrogate-decision-making standard is the best-interest standard. This standard attempts to maximize the net benefit of treatment by weighing the burdens versus the benefits of treatment options, given the patient's current condition. Surrogates are directed to make decisions on the basis of the first standard, unless there are no reliable expressed wishes or actions from which to make a substituted judgment.

Unless specifically stated in the DPOAHC or guardianship document that legally authorizes them, surrogates do not have the authority to make treatment decisions based on their own personal values or desires. Physicians caring for the dying have an ethical obligation to their patients to gently but firmly challenge the decisions of surrogates who ignore advance directives and instead base decisions on their own values or emotional reactions to impending loss. Providers should review treatment options with dying patients who retain decision-making capacity, or with surrogates. Clinicians must honor their ethical commitments to truthfulness, fidelity and respect for all people. Many of these commitments have been reviewed in Chapter 8 of this *Handbook*.

End-of-Life Decision-Making

End-of-life care decisions are challenging, because emotions and ethics are attached to actions that can lead to the hastening or perceived hastening of death.^{7, 10} There are fairly universal legal and ethical prohibitions for certain actions, such as active euthanasia, which is the direct killing of a person. However, other actions, such as physician-assisted suicide, are now legal in Oregon and Washington. In addition, there are other actions that are legally and ethically permissible, but are considered morally objectionable by certain individuals or groups, often centered in faith and/or geographic communities. These actions include withdrawal of nutrition and hydration,¹¹ withdrawal of ventilator support, and use of sedation for extreme pain and other symptom control (known as palliative sedation, previously called terminal sedation).¹²

What makes end-of-life decision-making even more challenging for the provider, especially during discussions with patients and surrogates, is that the end-of-life terminology that is often used, (such as allowing to die, euthanasia, assisted suicide, physician-assisted death, etc.) can have different meanings to different people. Providers need to be clear in their use of terminology, ensuring that the patient or surrogate is using the term in a manner similar to the provider.¹³

Health care providers must be sensitive to, and respectful of, the diversity of moral beliefs surrounding end-of-life care, and must clearly understand the moral justifications for actions that may be perceived as hastening death. For example, the “principle of double effect” is often invoked to justify the use of high doses of narcotics to effectively treat pain in terminal illness (although hospice advocates would argue that it is irrelevant here) and the use of sedation to treat intractable symptoms.⁴ Most doctors and nurses who work in end-of-life care know that, although the narcotic is given to treat increasingly unbearable pain, drugs like morphine given in increasingly high amounts that produce unconsciousness can also hasten death.

The principle of double effect (see Box 11.5) allows one to perform such actions if the action has two effects—one that is good and desired and one that is bad and foreseen but not desired. Additional requirements are that the bad effect is not the means to the good effect and that the good effect outweighs the bad.⁵

BOX 11.5

PRINCIPLE OF DOUBLE EFFECT

- Planned action must have good as well as bad effect
- Only the good effect is desired
- The bad effect cannot be the means to the good effect
- The good effect must outweigh the bad effect

Health care providers must also be aware that while legally and ethically, there is no difference between withholding therapy in the first place and withdrawing therapy once it has been started, family members

may feel differently. While a clinician's moral obligation is to his or her patient during end-of-life care, the patient-family unit is more often the object of care, even when other family members are not actually patients. Clinicians may have moral duties to the family unit as well as to the patient, especially when end-of-life-care choices run counter to prevailing community sentiments.

Do Not Resuscitate/Do Not Attempt Resuscitation Orders (DNR/DNAR)

Choosing to forgo resuscitation is the most common end-of-life care decision. This decision, based on patient or surrogate consent, is enacted when a clinician issues a Do Not Attempt Resuscitation (DNAR) order, which instructs medical personnel not to begin cardiopulmonary resuscitation (CPR) when a patient suffers a cardiac or respiratory arrest.¹⁴ At one time CPR was seen as a medical obligation, rather than a therapy that could be withheld at a patient or surrogate's request. As statistics of survival to hospital discharge after CPR have accrued, it has become apparent that survival rates after CPR are dismal for most people with end-stage diseases, and that resuscitation offers little or no benefit to the terminally ill; in many cases it simply prolongs their suffering. This dilemma has sparked discussions among ethicists about futility and CPR;¹⁵ specifically about whether there is a need for informed consent before initiating a DNAR order in certain terminally ill patients.^{5, 6}

Currently, patient or surrogate consent is generally required before a DNAR is issued. The issue of how to handle a situation in which the patient or surrogate insists on CPR despite the fact that it would be medically futile is an area of intense debate.¹³ At least two states have enacted statutes that address this situation.¹⁵

While withholding resuscitation for the dying makes clinical sense to those in the medical profession, patients and family members may see these decisions as an attempt to limit other therapies or restrict care. DNAR discussions between provider and patient are, in fact, often the logical starting point for broader discussions about therapy limitation(s); since a DNAR order, by itself, only limits one specific therapy, cardiopulmonary resuscitation. It is important that patients,

their surrogates and hospital staff all understand the limited nature of a DNAR order and appreciate that it is consistent with both aggressive disease-fighting care as well as comfort measures only. By emphasizing the limited nature of DNAR and sensitively exploring patient goals for care, clinicians can help their patients understand and navigate other potential treatment decisions that might arise. Providers can also uncover and address any inconsistencies in choices; for example, patients who request resuscitation, but simultaneously refuse treatment for the underlying condition that will likely result in cardiopulmonary arrest.^{13, 15-18} Even after a decision is made, the clinician and patient can discuss the issue of resuscitation again when a related therapy decision needs to be made.⁷

DNAR discussions with patients and families should always involve honest and sympathetic dialogue, with the health care provider trying to determine as clearly as possible what are the patient's or surrogate's wishes. To further emphasize the value of such discussions, one study noted that in almost one in three cases, the patient's preferences not to use CPR were different than the physician's perception of what the patient wanted.¹⁹ The study reinforces the importance of DNAR discussions and other end-of-life issues with patients or surrogates.

End-of-Life Care and the Rural Setting

The ethical principles underlying end-of-life care are the same, regardless of whether that care is given in rural or urban settings.²⁰ Certain characteristics of rural life and society, however, may pose unique ethics conflicts to rural-based clinicians doing end-of-life or palliative care. The close-knit relationships among people in small and rural communities, while a source of support in times of crisis, are often a threat to medical privacy and confidentiality. When patients and surrogates make end-of-life choices that stray from the moral values of the community majority, it is important to safeguard their privacy in ways that may not be necessary in larger, more anonymous settings. These same close-knit relationships often make it likely that the same physician will care for multiple family members. Balancing the desires of the dying with the needs of the living and the available choices of care can be difficult. Compromises and accommodations are often necessary, but the clinician should never permit pain and suffering for the dying.^{17, 18}

Rural practitioners also need to honestly evaluate the type of palliative care they can provide in their community. Ideally, a patient's death will occur in a local setting, surrounded by family and friends, and attended by the patient's trusted family physician. There are circumstances, however, where the burden of disease and suffering requires expertise in pain and symptom management, as well as supportive staff who are comfortable administering large doses of opiates and sedatives for refractory symptoms. Such circumstances require clinicians to have not only a commitment to symptom relief, but also an understanding that such activity is not intended to be euthanasia, but is a morally acceptable treatment for intractable symptoms.²¹ Without both medical and ethical competence, rural providers must question whether they should provide end-of-life care for some highly complex patient situations.

CASE DISCUSSION

Each of the cases in this chapter involves ethics conflicts centered on advance directives. Each also attempts to illustrate the emotional turmoil that families experience when they are faced with the impending death of a loved one, and are asked to make decisions that will impact that outcome. Even when such situations have been discussed in advance and family values are congruent, grief and loss can cause families to question their previous choices. Clinicians who are sensitive to the needs of family members will realize that what the medical team sees as ethically and medically appropriate is not necessarily seen the same way by the family.

The interpretation for the following cases is based on the analysis method discussed in Chapter 4.

CASE 11.1 | Surrogate wishes run counter to advance directives

Dr. Townes is obligated to both Frank and Brenda Foote as their primary care provider. He has obligations to respect Mr. Foote's autonomy by carrying out his wishes for end-of-life care, and to help Mrs. Foote by minimizing the psychological and emotional trauma of her impending loss. Dr. Townes wonders to what extent the need to avoid or minimize harm to Mrs. Foote trumps Mr. Foote's autonomy?

Dr. Townes' discussions with Mr. Foote constitute an oral advance directive, but there is no existing written document, other than chart notes, which substantiates Mr. Foote's wishes. A problem may arise if Mrs. Foote insists, in the future, that her discussions with Mr. Foote on end-of-life care differ from Dr. Townes' recollection of the oral discussions. A copy of the document Mr. Foote wrote, though not witnessed, might further clarify his wishes and form the basis for a discussion with Mrs. Foote about substituted judgment.

A further and independent dilemma exists for Dr. Townes, regarding the appropriate location for terminal weaning, since this is an anticipated outcome of the decision-making process. He should evaluate whether he, or someone in the hospital or clinic, is competent in providing pain and symptom relief as the ventilator is withdrawn. How does the nursing and respiratory therapy staff feel about removing a ventilator from someone who is not ready to be extubated, not permanently unconscious, and who will need pain and anxiety medications during the process? If potential participants say, "This is euthanasia, but I am willing to participate because it is the right thing to do," is it the right thing to do?

Dr. Townes knows that his first duty is to his patient, Mr. Foote, and he must discuss options with Mrs. Foote. But he is unsure how exactly to proceed, given his relationship with Mrs. Foote and the capabilities of the rural hospital.

CASE 11.2 | Colleagues disagree with end-of-life decisions

Dr. Dennis is faced with a dilemma: a colleague has a disagreement with her about whether to withhold artificial nutrition and hydration (ANH) from a patient with advancing Alzheimer's disease who is unable to maintain adequate hydration through oral intake. The colleague's disagreement has challenged the decision of the patient's family. The family members are now confused and question the decision they previously made. The patient's advance directive was executed years before, and does not contain specific mention of ANH, further complicating the situation. Fortunately, the state the Coulters live in does not require a specific directive regarding ANH before nutrition and hydration can be withheld.

Dr. Dennis is unsure about the extent of her colleague's ethics disagreement—or its implication for Mr. Coulter's future care, if he should return to the facility. Does the facility require a feeding tube in all circumstances similar to Mr. Coulter's? If not, under what conditions do they allow withholding or withdrawing? Does her colleague believe that nutrition and hydration must never be withheld, in any circumstance or by any means? If so, will that become an institutional policy?

While Dr. Dennis feels that she had come to a clear understanding with the family before transfer to the nursing home, she is now unsure whether they fully understood Mr. Coulter's condition, and what could happen if the feeding tube were withheld. Why are they changing their decision? Were they unprepared for such rapid deterioration? Are they ethically challenged by the consequences of their decision, reframed as starvation? How can Dr. Dennis rectify the situation to Mr. Coulter's greatest benefit?

RESPONDING TO RURAL END-OF-LIFE ETHICS CONFLICTS

End-of-life conflicts are fueled by the emotional intensity of the dying experience. Family members want to believe that they are doing the right thing, and that medical providers are treating their loved ones with professional competence, compassion, and respect.

CASE 11.1 | Surrogate wishes run counter to advance directives

First, Dr. Townes must examine the implications and implementation of various options, including where withdrawal of ventilator support in a terminal weaning situation should occur. If Mrs. Foote decides to support Mr. Foote's wishes, and if she allows ventilator withdrawal, it is important that it be done in a clinically and ethically competent way. If withdrawal cannot be done locally, Dr. Townes should consult the palliative care service at the referral center about arrangements to transfer Mr. Foote.

Family members sometimes need time before they can abandon their own wishes and accept the clinical reality and the previously expressed wishes of a loved one. If Dr. Townes begins slowly, addressing the seriousness of Mr. Foote's condition and the generally poor outcome of resuscitation, he may negotiate a DNAR order, opening further

discussions of limiting therapy with the patient's wife. Given time and support, Mrs. Foote may accept Mr. Foote's impending death, and honor his wishes for how his death with dignity should occur. Mrs. Foote has a right to expect that Dr. Townes will be honest with her, and will not knowingly deceive or coerce her into conforming to Mr. Foote's wishes. If a transfer is arranged to the tertiary center, Mrs. Foote should be aware of the intent, whether that is aggressive or palliative therapy.

If Mr. Foote will be transferred regardless of the type of care he will receive, Dr. Townes should not leave the discussions of end-of-life care to the clinicians at the tertiary center. He has had long-standing relationships with Mr. and Mrs. Foote. He should advocate for Mr. Foote's choices, both in discussions with Mrs. Foote about the transfer, and in talks with the tertiary center about Mr. Foote's wishes. He should also prepare Mrs. Foote for the possible discussions and decisions she may face at the tertiary center, and inform her of the helpful services available there, such as social workers and ethics committees. Mr. Foote may not return as Dr. Townes' patient after the transfer to the tertiary center, but Mrs. Foote will still be his patient. Dr. Townes' future relationship with her will be shaped by the compassion, honesty, and integrity of their conversations now.

Dr. Townes has an overriding obligation to treat Mr. Foote's pain and dyspnea before he attempts to honor his commitments to both Mr. Foote and Mrs. Foote. When Dr. Townes is assured that Mr. Foote is comfortable, he can begin to negotiate goals of therapy and a plan of care with Mrs. Foote. Dr. Townes may find it helpful to address Mrs. Foote's difficulty by reframing her reluctance as love rather than denial. He also must read the written document from Mr. Foote, even if it's not witnessed. If this document echoes the wishes Mr. Foote expressed to him, it can help him to gently lead Mrs. Foote in the direction of substituted judgment. If it is vague, or allows for decisions at Mrs. Foote's discretion, Dr. Townes may need to modify his own thoughts of what should be done.

CASE 11.2 | Colleagues disagree with end-of-life decisions

For Dr. Dennis, whose patient and family have been caught in the crossfire of a disagreement between health care providers, it is important to understand the nature of that disagreement before renegotiating

the plan of care. If the nursing home's new medical director has no problems with the ethics of withholding the therapy, but is concerned about legal issues or safeguards, returning Mr. Coulter to the nursing home without a feeding tube can resolve the situation. If there are ethics issues related to feeding tubes, Dr. Dennis should determine if these are universal, regarding allowing a patient to die; or specific to her patient, who is not yet in the very end stages of Alzheimer's. Depending upon her colleague's responses, Dr. Dennis can ascertain the circumstances under which Mr. Coulter may return to the facility without a feeding tube, or the circumstances under which the tube may be removed once he is a patient in that facility. Such discussion may warrant the assistance of a health care ethicist and/or legal counsel. Such a discussion will help shape her discussions with the Coulter family.

For the Coulter family, it is important to know that their initial decision was "right," loving, and consistent with Mr. Coulter's wishes as they interpreted them. Dr. Dennis should explain to the family the disagreement about morality regarding the withholding of intravenous or tube feeding. The remarks about starvation should be explained, though not excused, as the interpretation of those who are morally opposed to withholding artificial nutrition and hydration (ANH) under any circumstances.

Dr. Dennis should offer the Coulters an opportunity to review all options, including hospice referral. She may consider starting the discussion with a review of Mr. Coulter's life—his attitudes, the things he enjoyed, and his beliefs. What he said about his future at the time of his diagnosis and at the time he executed his advance directive may also help the family understand what he would want them to do now. Whatever decision the Coulters make should be supported. Decisions about withholding artificial nutrition and hydration are difficult, even when there is a clear written directive. Support for a decision to initiate tube feeding should not imply that the original decision was wrong or uncaring.

ANTICIPATING RURAL END-OF-LIFE CARE CONFLICTS

Death brings an end to relationships and, in turn, brings loss and grief to those left behind. The moral diversity inherent in these relationships can play out in end-of-life decision-making in ways that may or may not present true ethics conflicts. Families who participate as surrogates are

sometimes unable or unwilling to participate as agents of substituted judgment. Rural hospital and nursing facilities may lack policies on important and sometimes controversial end-of-life decision-making, as well as aspects of palliative care. Rural clinicians might be unaware of regulations governing aspects of withdrawal of therapy, especially when these regulations change. These factors combine to create difficult conditions under which patients, health care providers, and families must make choices.

Advance directives are a useful tool, but are only as good as the communication and clarity that goes into their execution. Individuals who know that their spouses will not make the decisions they request, in the event of their becoming incapacitated in the future, should be strongly advised to name another surrogate. Patients should not rely on other family members or the family's PCP to push reluctant agents to agree to the patient's point of view.^{22, 23}

Because of the importance of advance directives, some individuals should be encouraged to complete advanced directives more urgently than others. These categories are noted in Box 11.6.

BOX 11.6

PATIENTS WHO SHOULD BE STRONGLY ENCOURAGED TO HAVE ADVANCE DIRECTIVES

- Patients with a life-limiting illness
- Patients who are estranged from their families
- Patients who belong to faith communities with specific limitations of therapy
- Patients who are involved in committed same-sex relationships that are neither sanctioned nor protected by their state's laws
- Patients who are involved in dangerous occupations or recreational activities
- Patients whose values or desires regarding end-of-life care are not shared by family or community members
- Patients who have no family
- Patients of advanced age, even if they do not yet have a life-limiting illness

People who are estranged from their families, or the values of the community, or who are members of faith communities with limitations on health services (such as Jehovah's Witnesses), or who are involved in committed same-sex relationships, in states which don't recognize these, should be strongly encouraged to execute advance directives so that their values and surrogate choice will be respected in end-of-life care. Young people who engage in dangerous occupations (law enforcement, firefighting, the military) or enjoy dangerous recreational activities (extreme sports, rock climbing, professional mountaineers) should likewise be encouraged to initiate discussion and document their desires regarding treatment of a catastrophic injury that results in permanent impairment of decision-making capacity. In states where there are specific requirements regarding withholding of artificial nutrition and hydration, providers should encourage patients to complete specific documentation related to this decision. Providers should also prompt patients to make these documents available to clinicians, the named surrogate, and local health care institution. Patients should also update their documents regularly, particularly with changes in their health and marital status, as well as changes in the law related to end-of-life decision-making.

Rural institutions that provide care for patients at the end of life should develop adequate resources to address potential ethics conflicts that may arise in the provision of this care. Some important resources are listed in Box 11.7.

BOX 11.7

INSTITUTIONAL RESOURCES NEEDED TO ADDRESS END-OF-LIFE CARE ETHICS CONFLICTS

- Clear-cut policies and procedures related to DNAR, palliative care and symptom control, and limitation of therapy including artificial nutrition and hydration
- Relevant education for employees regarding end-of-life issues
- Readily available information about legal aspects of end-of-life care
- Mechanism for conflict resolution

Rural hospitals should have policies and procedures related to end-of-life care, especially in the areas of surrogate decision-making, DNR orders, limitation of treatment and palliative care, and withdrawal and withholding of certain therapies, especially artificial hydration and nutrition. Such policies should reflect current state law(s) and should be periodically reviewed and updated. These institutions should also have an easily accessible source for information related to the legal aspects of end-of-life care that is available to all practitioners. When legal counsel is not readily available through a hospital or medical society to discuss specific situations, health care professionals can review up-to-date and accurate Web sites. Rural institutions should also identify and meet the educational needs of their staff regarding end-of-life practices, particularly those that have some degree of moral ambiguity. Staff members must understand institutional policies. Institutions and staff must commit to privacy and confidentiality regarding end-of-life decisions for individual patients. A family's decision to withhold artificial nutrition and hydration is not a matter for discussion by hospital members outside of the treatment setting. The institution should also have a mechanism for arbitrating conflict about end-of-life care, especially if this involves disagreement between members of the treatment team. Such a mechanism might include an ethics committee, a mediation group, or a referral to an outside ethics resource.²⁴⁻²⁶

Because of the close ties between rural hospitals and the communities they serve, hospitals should consider extending their educational efforts around end-of-life care into the community. This can be done by developing educational materials, such as pamphlets and brochures about end-of-life care choices; by sponsoring community forums about advance care planning; and by promoting advance directive use through partnering with local faith communities. Such activities foster an understanding of end-of-life decision-making and treatment options that patients and families might need to consider. These activities encourage communication within families, and between patients and their health care providers, and may lessen the difficulty for surrogate decision-makers as they grapple with hard choices.^{25, 27}

CONCLUSION

Caring for patients and guiding families through the dying process are a natural conclusion of the patient-clinician relationship for rural physicians. Once, unfettered by technology and the choices it engenders, this was a simpler, if not necessarily gentler, scenario. Pain and dyspnea were still there, and families still grieved and wrestled with unresolved guilt and conflict, but treatment options were fewer, and family values were more congruent. As life and technology have changed, the experience of death has undergone the same medicalization in rural and urban settings. People are living longer, and families are more fragmented than they were in the past. The additional burden of making decisions about modern medical advances including resuscitation, food and fluid administered through tubes rather than being swallowed, and breathing machines are add to the stress of end-of-life decision-making.

As patients and families have struggled with the new options available to them, questions and conflicts have arisen about the limits of intervention and choice. “Can life-sustaining care, once started, be stopped?” “If I say it is okay to turn off his respirator, am I killing him?” Patients and family members see these issues from one perspective, while practicing clinicians may view them from another. The challenge for rural clinicians in guiding their patients and families through the dying process is to anticipate conflict and reframe options and choices in ways that resonate. To be done well, end-of-life care calls for both clinical and ethical competence. With foresight and planning, rural physicians can meet the challenge.

REFERENCES

1. Field MJ, Cassel CK, eds. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997.
2. Lynn J. Why I don't have a living will. *Law Med Health Care*. Spring-Summer 1991;19(1-2):101-104.
3. Doukas DJ, McCullough LB. The values history. The evaluation of the patient's values and advance directives. *J Fam Pract*. Feb 1991;32(2):145-153.
4. Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room". *JAMA*. Nov 15 2000;284(19):2502-2507.
5. Lynn J. Perspectives on care at the close of life. Serving patients who may die soon and their families: the role of hospice and other services. *JAMA*. Feb 21 2001;285(7):925-932.
6. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA*. Jan 13 1999;281(2):163-168.
7. Ethics manual. Fourth edition. American College of Physicians. *Ann Intern Med*. Apr 1 1998;128(7):576-594.
8. Patrick DL, Curtis JR, Engelberg RA, Nielsen E, McCown E. Measuring and improving the quality of dying and death. *Ann Intern Med*. Sep 2 2003;139(5 Pt 2):410-415.
9. Meisel A, Snyder L, Quill T, American College of Physicians--American Society of Internal Medicine End-of-Life Care Consensus P. Seven legal barriers to end-of-life care: myths, realities, and grains of truth. *JAMA*. Nov 15 2000;284(19):2495-2501.
10. Lo B. *Resolving Ethical Dilemmas: A Guide for Clinicians*. 2nd ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2000.
11. Lo B. The persistent vegetative state. In: *Resolving Ethical Dilemmas: A Guide for Clinicians*. 2 ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2000:162-165.
12. Lorenz KA, Lynn J, Dy SM, et al. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med*. Jan 15 2008;148(2):147-159.
13. Lo B. Confusing ethical distinctions. In: *Resolving Ethical Dilemmas: A Guide for Clinicians*. Philadelphia, PA: Lippincott Williams & Wilkins; 2000:119-128.
14. Lo B. Tube and intravenous feedings. In: *Resolving Ethical Dilemmas: A Guide for Clinicians*. Philadelphia, PA: Lippincott Williams & Wilkins; 2000:145-150.
15. Cantor MD, Braddock CH, 3rd, Derse AR, et al. Do-not-resuscitate orders and medical futility. *Arch Intern Med*. Dec 8-22 2003;163(22):2689-2694.

16. Gazelle G. The slow code--should anyone rush to its defense? *N Engl J Med*. Feb 12 1998;338(7):467-469.
17. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA*. Dec 21 1994;272(23):1839-1844.
18. Halevy A, Brody BA. A multi-institution collaborative policy on medical futility. *JAMA*. Aug 21 1996;276(7):571-574.
19. Teno JM, Hakim RB, Knaus WA, et al. Preferences for cardiopulmonary resuscitation: physician-patient agreement and hospital resource use. The SUPPORT Investigators. *J Gen Intern Med*. Apr 1995;10(4):179-186.
20. Summaries for patients. Treatment of seriously ill patients who are near the end of life: recommendations from the American College of Physicians. *Ann Intern Med*. Jan 15 2008;148(2):142.
21. Van Vorst RF, Crane LA, Barton PL, Kutner JS, Kallail KJ, Westfall JM. Barriers to quality care for dying patients in rural communities. *J Rural Health*. Summer 2006;22(3):248-253.
22. Planning ahead. National Hospice and Palliative Care Organization. <http://www.caringinfo.org/PlanningAhead>. Accessed May 10, 2008.
23. National Rural Health Association. *Providing Hospice and Palliative Care in Rural and Frontier Areas*. Kansas City: National Rural Health Association; 2005. Available from: <http://www.capc.org/palliative-care-across-the-continuum/hospital-hospice/Rural-Toolkit-READER.pdf/view?searchterm=Providing%20hospice%20and%20palliative%20care%20in%20rural%20and%20frontier%20areas>. Accessed Dec. 13, 2008.
24. Jennings B, Kaebnick GE, Murray TH. *Improving end of life care: why has it been so difficult?*. . Garrison, NY: Hastings Center; 2005. http://www.thehastingscenter.org/pdf/improving_eol_care_why_has_it_been_so_difficult.pdf. Accessed Dec. 13, 2008.
25. Tulsky JA. Beyond advance directives: importance of communication skills at the end of life. *JAMA*. Jul 20 2005;294(3):359-365.
26. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. Nov 15 2000;284(19):2476-2482.
27. Perkins HS. Controlling death: the false promise of advance directives. *Ann Intern Med*. Jul 3 2007;147(1):51-57.