



CHAPTER 8

# Ethics Conflicts in Rural Communities: **Shared Decision- Making**

Denise Niemira

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

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# Ethics Conflicts in Rural Communities: Shared Decision-Making

Denise Niemira

## ABSTRACT

Shared decision-making is a collaborative interaction between the provider and patient in making treatment decisions in the informed consent process. Shared decision-making is based on trust, truthfulness, and respect for the patient's choice. Good communication is the vehicle that fosters this process within the patient-clinician relationship. A pivotal aspect of the shared decision-making process is a dialogue in which both parties share information, leading to a decision regarding the patient's health care. For the patient the subjects of discussion may include his or her life goals, values, religious and cultural beliefs, and finances. For the clinician, the discussion should include the risks and benefits of possible treatments as well as the likely outcome of no treatment. How information is shared, and what information is shared may influence the patient's choice. Clinicians may find themselves challenged by patient choices that, medically, do not seem in the patient's own best interest. At an ethical level, there is a tension between patient autonomy and beneficence that may not be easily resolved. For rural clinicians, the process may be challenging when the patient is a friend, and boundary issues are intensified; when multiple members of the same family are patients, and wish to participate in decisions of other family members; or when conflicts of loyalty seem to pit the interests of the patient against those of a struggling local medical community. Shared decision-making in the rural setting should be facilitated by open, honest communication between provider and patient, and includes the treatment expectations and boundary issues of each party. Ethics conflicts, especially involving family members, should be anticipated in shared decision-making. When possible, such conflicts should be addressed proactively rather than in a crisis setting.

## CASE STUDIES

### **CASE 8.1** | The extent of information provided in the consent process

Dr. Jonah Smith, a primary-care provider, is discussing with a patient, Sam Tanaka, the need for a referral for major surgery for a condition that is potentially life-threatening. The surgical procedure could be done at the small, rural hospital; however, the general surgeon has limited experience with the needed procedure. The surgery is one whose outcome is statistically volume-sensitive, i.e., the more procedures the surgeon and institution perform, the better the outcome. Mr. Tanaka does not ask where the best location for performing the procedure is, but says, “Just tell me what to do, doctor.” The local community hospital is struggling financially. Contributing to the problem is the number of referrals to large facilities away from the rural community. The surgeon’s experience with the particular surgery remains limited because of the frequency of referrals to large, distant hospitals. Dr. Smith is uncertain about how to respond to Mr. Tanaka. How do the economic needs of the rural facility influence Dr. Smith’s discussion with the patient about the options and alternatives? Does the discussion change if Mr. Tanaka specifically asks, “Where would you have the surgery done?”

### **CASE 8.2** | A patient’s refusal of needed diagnostic evaluation

Dr. Joan McDougall, a primary-care provider, has recommended additional diagnostic testing for an 80-year-old patient, Ursula Mueller, who may have a malignancy related to a long-standing blood abnormality. Mrs. Mueller has recently been treated for anemia, and she accepted blood transfusions when she becomes symptomatic. Dr. McDougall explicitly states her concerns about cancer with Mrs. Mueller. Though the patient fully understands Dr. McDougall’s concerns, she declines further assessment for financial reasons. Ursula Mueller and her husband, who live on the income made from the sale of their farm, are still paying off the hospital bills from her previous testing and treatment. She wishes

not to incur further debt at this time. Dr. McDougall treats other members of Mrs. Mueller's family and suspects that they would want their mother evaluated and would help with financial issues. Mrs. Mueller refuses to give Dr. McDougall permission to discuss this matter with her family.

## OVERVIEW OF ETHICS ISSUES

Shared decision-making is a collaborative interaction between the provider and patient in making treatment decisions in the informed consent process. Communication is the heart of a good patient-clinician relationship and of shared decision-making. In the shared decision-making model of the doctor-patient relationship, the goal of communication is to enable patients to make informed, autonomous choices regarding their medical care. These choices are made within a dialogue in which the health care professional's clinical experience and fiduciary responsibility are used to inform and guide the patient's choice among the various options for treatment according to the patient's personal preferences and goals. The importance of this process is captured in the American College of Physicians Ethics Manual.<sup>1</sup>

The shared decision-making process attempts to balance the often-conflicting demands of patient autonomy (self-determination) and beneficence (promoting patient well-being and preventing harm), as discussed in Chapter 3 of this *Handbook*. A patient who voluntarily agrees to the treatment recommended by the clinician in the course of this dialogue has given informed consent. A patient who refuses the recommended treatment has given informed refusal.

### Elements of Informed Consent<sup>2</sup>

There are several criteria for informed consent. These include:

- **Full Disclosure of Adequate Information:** Communicating all information necessary to understand the medical condition, treatment options, and the risks and benefits of reasonable treatment(s) and non-treatment
- **Voluntariness:** The ability to make treatment decisions free of coercion or undue influence

- **Decision-Making Capacity:** The ability to understand and process information and arrive at a preference-for-treatment decision

**Full Disclosure of Adequate Information:** Informed choice entails a dialogue in which clinicians provide patients with relevant, understandable information about their medical condition, the types of treatments available for the condition, and the risks and benefits of the treatment(s) or non-treatment for the condition. While there may be an ethics debate about the extent of specific information that must be provided, there are a few generally accepted norms guiding disclosure. The disclosure may be tailored to the patient's desire for information, but the information provided should be truthful. All relevant information that could significantly impact a patient's choice should be disclosed. The standard for disclosed information is shifting from a professional-centered one (what a reasonable practitioner would reveal), to a patient-centered one (what a reasonable person would want to know).<sup>3</sup> Patients may choose to forgo discussions regarding risks and benefits of treatment, or may defer the discussion and/or decision to family members (a process that is common in certain cultural and ethnic traditions). In these settings, clinicians should clarify the patient's desires regarding disclosure and how voluntary is the patient's decision to forgo or defer discussion.

Clinicians exercising beneficence may guide, but not coerce patients in their choices. They can help patients translate personal needs, values, and lifestyle goals into concrete medical choices that will best support these needs and goals. Clinicians may make recommendations in favor of a treatment option based on their clinical judgment of what is best for the patient.

**Voluntariness:** Patients have the right to accept or refuse any procedure or treatment offered to them. The patient should make a decision based on his or her goals and disease, without having to experience undue force or pressure from clinicians that would erode their voluntary decision. Patients may not always agree with the recommendations of their health care providers. They might reject the recommended treatment. Clinicians faced with this situation often question the patient's choice. Did the patient hear the information that

was presented? Did the patient understand the information? Is the patient capable of processing the information to make an informed, voluntary choice? When it is clear that patients understand their disease and the consequences of their choice(s), their decisions should be respected. It is appropriate for clinicians to challenge a patient's ability to make informed decisions when it is unclear whether the patient has a capacity to understand and process information about his or her medical condition. This challenge should be based not on the decision the patient has made, but on how they have come to make it—did the patient have reasonable reasons for their decisions?<sup>4</sup>

***Decision-Making Capacity and Competency:*** When patients lack the ability to understand their disease state and appreciate the consequences of the decision they are being asked to make, they are said to lack decision-making capacity.<sup>5</sup> While decision-making capacity is sometimes equated with competency, competency is a legal determination that a person lacks the cognitive capacity to make reasoned decisions. When a court determines that a person is incompetent to make medical decisions, that person is unable to consent for treatment, even if he may understand his medical condition and the options and outcomes of treatment. The status of incompetent adults is similar to that of minors, particularly older minors who, regardless of understanding and decision-making capacity, are legally unable to consent to treatment. Clinicians in these situations often try to reconcile legal and ethical responsibilities to their patients by fostering their participation in the treatment discussion as much as possible and by obtaining their assent to the treatment.

Lack of decision-making capacity is a clinical determination.<sup>6</sup> It may be obvious, as in patients who are unconscious, floridly delirious or severely demented. In other cases, lack of decision-making capacity may be considerably less obvious—even questionable. There is no single test or standard for determining decision-making capacity. Clinicians must rely on clinical interviews and findings, responses to neurological and psychological testing, and reports from family and significant others. In difficult cases, professionals may need to consult with colleagues, specialists such as psychologists or psychiatrists, hospital counsel, or a risk-management or ethics committee. Since

the lack of decision-making capacity may be a temporary condition, clinicians should treat any reversible causes.

When a provider determines that a patient lacks decision-making capacity, an alternative decision-maker, or surrogate, must make treatment decisions. Depending upon the medical circumstances, geographic location, hospital policies, local customs and relevant legal statutes, family members or appointed surrogates may become involved.

### **Surrogate Decision-Makers**

Surrogate decision-makers are individuals who are duly authorized to make decisions for patients who lack decision-making capacity. There are three basic types of recognized surrogates which are defined in Box 8.1.

#### **BOX 8.1**

##### **BASIC TYPES OF RECOGNIZED SURROGATES**

- Court-appointed guardian for health care decisions
- Advance-directive documented surrogate or Durable Power of Attorney agent (proxy)
- Next of kin

These three types of surrogates are appointed or selected in several ways. The court, through a guardianship procedure, can appoint the surrogate. Surrogates can be named in a legal document or advance-directive document to assume decision-making when the person naming them is no longer able to make decisions. A frequently used document is the Durable Power of Attorney to make such a designation. Surrogates may also be based on the next-of-kin status. The order of kinship with responsibility to make decisions is generally spouse, adult child and parent. Most states have statutes regarding how to designate surrogate decision-makers, including the order of kinship. The Department of Veterans Affairs has a specific order of surrogates in their national Informed Consent Policy. Surrogates may also be determined by local custom in the absence of specific legislation or regulation to make decisions for relatives or significant

others who have lost decision-making capacity. Clinicians should consult with legal counsel to be familiar with the laws and appropriate forms and customs in their state.

The authority of surrogate decision-makers varies with the circumstances of their appointment and relevant legislation. Surrogates are to provide “substituted judgments” based on clear and specific directives from the patient who once had the capacity to decide for himself or herself, or to provide what the surrogate believes is in the “best interest” of the patient lacking capacity, if the patient never specifically clarified his or her desires. More about the surrogate’s role, including advance directives, can be found in Chapter 11.

### **Clinicians as Moral Agents and Informed Consent**

In the informed-consent process, clinicians have a moral as well as a professional responsibility to act for the benefit of their patients. Their disclosure and advice should be based on what will best serve their patients’ needs, and should not be compromised by self-interest, employers, colleagues or community institutions.<sup>7</sup> When these conflicts are present and cannot be avoided, clinicians must ensure that they do not influence the extent of disclosure to patients, or manipulate the presentation of treatment choices. In general, disclosure of non-patient loyalty conflicts is ethically required.

Clinicians must respect the autonomy and right to privacy of their patients who have decisional capacity. When clinicians question a patient’s decision-making capacity, they may query family members about the patient’s mental status without specific consent, but should not pursue such an option solely due to disagreement with the patient’s choice.

When patients request or even demand a treatment that will cause harm, or have no promise of benefit based on empirical assessments, clinicians may refuse to order or provide such treatment. Clinicians should consider the request, but are not morally required to provide any treatment that they believe lacks scientific validity. Clinicians may also refuse to participate in any treatment(s) to which they are morally opposed. Clinicians have an obligation to inform patients of their moral opposition and to make referrals to other providers when possible.

## CASE DISCUSSION

The discussion of the following cases is based on the analysis method presented in Chapter 4.

### CASE 8.1 | The extent of information provided in the consent process

Dr. Smith must discuss a surgical referral with a patient, Mr. Tanaka, who needs major surgery for a condition that is potentially life-threatening but not an emergency. This is an illustration of the informed-consent discussion, focusing on the elements of full disclosure and voluntariness. At issue in the informed-consent process is not only the decision to seek surgical treatment but also the location of that treatment. Specialist surgeons who practice at larger community hospitals and medical centers usually do the surgery in question. The outcome of this procedure is statistically better when the hospital and surgeon perform greater numbers of the surgery. This volume might not be achieved in a small rural hospital, even if most patients from the community chose to have it performed there. While the issue is framed in the context of a surgical referral, it applies to other complex care provided in the rural setting, including diagnostic modalities and intensive care.

Dr. Smith realizes that his surgeon colleague and their community hospital are caught in a challenging situation regarding this surgery and other volume-sensitive procedures. If patients like Mr. Tanaka are routinely sent out of the community to larger referral centers with more experience, the community hospital will not improve its outcomes.<sup>8</sup> Dr. Smith realizes that when the medical community loses the experience to manage such cases, fewer talented surgeons and other specialists will choose to practice in the community, and will instead go where their skills can be utilized in a more challenging way. The loss of revenue is detrimental to the small facility, and may threaten its long-term viability. There is an issue of divided loyalties, the extent of which may vary depending upon the practitioner's relationship to the local surgical colleague and hospital, as well as the institution's response to referrals outside the area. Is the practitioner in partnership with the surgeon, or employed by the hospital? Is there an overt pressure to refer within the institution?

The patient in this case, Mr. Tanaka, appears to be short-circuiting the disclosure process by deferring the decision to the clinician's recommendation. This might be a measure of respect for, and trust in, the physician, or of deference to the role of the practitioner in a rural community. It could suggest a paternalistic model of the patient-clinician relationship. It may be an expected social convention. While patients have the right to waive informed consent, health care professionals should accept the role only with the utmost caution; they should ensure that it is truly what the patient wants and is a voluntary request. If the clinician accepts this role, he or she should openly and clearly review his or her thinking with the patient. This is especially important in circumstances where there are conflicts of loyalty.

The primary care practitioner has an ethical duty to be truthful in his or her disclosures and to offer recommendations that will benefit the patient. The clinician also bears a responsibility to the community to maintain and foster the availability of health care treatment. Regardless of the community need, however, the primary-care provider must first act for the benefit of the patient.

### **CASE 8.2** | A patient's refusal of needed diagnostic evaluation

Dr. McDougall faces an elderly patient, Ursula Mueller, who is refusing recommended diagnostic evaluation for a potentially serious illness. The focus of the ethics issues is on the validity of an informed refusal, including the elements of decision-making capacity and voluntariness of the patient. The clinician's recommendation is based on Mrs. Mueller's abnormal blood test and the knowledge that the patient's condition could transform into a cancer. Mrs. Mueller's refusal to undergo further evaluation at this point will impact future treatment decisions and outcomes. She is able to articulate an understanding of her condition and the clinician's concerns about cancer, but is unwilling to proceed with the recommended testing. Mrs. Mueller appears to have decision-making capacity, but the reasons for her decision—her current financial indebtedness to the hospital and a desire not to incur further debt—seem short-sighted. The clinician wonders if this choice is truly voluntary. Does the patient feel pressured by demands to make payments for past care? Are there social services agencies that can assist or guide

the family in addressing the financial issues? Does Mrs. Mueller feel the need to sacrifice for other family members? Are the risks of forgoing evaluation enough to challenge the decision? And how much challenge constitutes coercion on the part of the clinician?

Dr. McDougall faces additional ethics challenges in accepting Mrs. Mueller's refusal of further evaluation. She also treats two of the patient's children, who are mindful of the doctor's confidentiality policy and respectful of their mother's independence, but have expressed concern about their parents' aging and unwillingness to seek health services for financial reasons. The children have stated their willingness to become involved and to help financially when needed. Dr. McDougall has responded to these conversations with a suggestion that a family discussion be held to discuss these issues. However, the patient refuses to participate in such a discussion with other family members. The prior conversations raised by the patient's children led Dr. McDougall to believe that they would want their mother to have the diagnostic work-up and that they would address their mother's financial concerns. She also feels that they would most likely exert pressure on their mother to have the testing done, but would likely accept her refusal if cancer were diagnosed and she did not want treatment. Dr. McDougall believes that the children expect Mrs. Mueller to involve them in this situation. Should the doctor override her patient's refusal to discuss the matter with them?

## **RESPONDING TO THE SHARED DECISION-MAKING CONFLICTS**

### **CASE 8.1** | The extent of information provided in the consent process

In Dr. Smith's case, Mr. Tanaka's casual remark, "tell me what to do, doctor," should not be taken as an invitation to make a recommendation about the risks and benefits of the surgery, as well as where it should be done, without further discussion. Dr. Smith should explore what the patient knows about the planned surgery, and review any concerns Mr. Tanaka might have, what his support network would be after surgery, and what his preference is regarding the location of the surgery. Mr. Tanaka may have reasons for choosing a location for surgery independent of any statistics, such as having family members in that

area. Dr. Smith should ask about Mr. Tanaka's preferences because the patient may need specific information that will shape the discussion. Dr. Smith should be aware of what Mr. Tanaka considers important in arriving at his decision, and of the influence that he, as the doctor, may have exerted on that decision.

The issues involving the community hospital and local surgeon in this case are not without moral relevance, but they do not supersede the need for the provider to disclose to the patient any information that is important when making medical decisions. Practitioners can shape and frame their disclosure of information with patients, including how they present the statistical data or offer recommendations, in ways that will impact the patient's ultimate choice. For example, if the patient is inclined to have the procedure done locally, the primary care practitioner should acknowledge that the medical center hospital has more experience with the procedure, and that statistically this means that results are potentially better. The practitioner may then discuss the local surgeon's experience and offer the patient a choice between the local setting, with its perceived benefits to the patient, and the tertiary setting, with its greater expertise, without favoring one place of surgery or the other.<sup>9</sup>

If the patient asks the clinician whether the procedure should be done elsewhere, the clinician should answer honestly. If the clinician suspects that the patient should not have the procedure in the community, for any reason, this must be disclosed. If the clinician lies, fails to disclose information a patient considers important, or persuades a patient who was inclined to go to the tertiary center to instead remain in the community for a high-risk procedure, the harm of a poor outcome is far worse for the community and the clinician than the loss of the local procedure. And naturally the outcome is far worse for the patient – resulting in a lose-lose situation all around. It is the betrayal of a patient-clinician relationship grounded in trust.

### **CASE 8.2** | A patient's refusal of needed diagnostic evaluation

The purpose of informed consent is to enhance the patient's autonomy. This means that the professional must respect choices with which he or she disagrees. It does not mean that the provider must accept

such choices without question, nor does it preclude him or her from attempting to persuade the patient otherwise, as long as such attempts are not coercive or manipulative. Respect for autonomy also includes the provider's respecting the confidentiality of patients who are competent to make decisions, in spite of pressure from concerned third parties, such as family members. In cases when family members are likely to be involved as future caretakers and/or surrogate decision-makers, it is important that patients be encouraged to involve them earlier in the decision process, so that such conflicts may be discussed and hopefully avoided.

Dr. McDougall should enhance Mrs. Mueller's autonomy in shared decision-making. The doctor's concerns about the voluntariness of Mrs. Mueller's refusing a diagnostic work-up should be discussed— independently of the doctor's knowledge of and relationship to other family members.<sup>10</sup> Dr. McDougall should not override Mrs. Mueller's objections by involving the family, unless she believes that Mrs. Mueller's choice is not autonomous, and the situation warrants that the doctor involve family members regardless of her relationship with them. Mrs. Mueller is not in imminent danger from a life-threatening condition, and has accepted symptomatic treatment. Her refusal to undergo further testing may be a form of denial or an unwillingness to confront a diagnosis of cancer. Her concern about finances might not only involve the proposed diagnostic work-up, but the treatment that could ensue. Mrs. Mueller may simply need more time to process the news. Giving the patient the time and opportunity to revisit the issue, either alone or with her family, allows her to process the information and then have the choice to either change her mind, or to further articulate her goals. It also allows her to remain autonomous and independent, and involve to her family as she chooses.

Since Mrs. Mueller's illness is unlikely to be hidden from her family, Dr. McDougall should encourage her to discuss her plans with them, particularly if Mrs. Mueller continues to deny evaluation and/or treatment. Dr. McDougall should remind Mrs. Mueller that if she becomes incapable of making decisions in the future, her family might need to become involved as surrogate decision-makers. If Mrs. Mueller does not discuss her goals with her family now, they may try

to intervene in her future treatment in a way that is inconsistent with Mrs. Mueller's wishes. Suggesting a group meeting to include the doctor, patient and patient's family to review and discuss the issues would serve several purposes: it would involve the family, it would allow Mrs. Mueller to clarify her values in a comfortable setting, and it would allow Dr. McDougall to articulate all the potential risks and benefits of further evaluation to all family members. Dr. McDougall should avoid the temptation to use the family meeting as a forum to coerce or manipulate Mrs. Mueller or her family.

Clinicians faced with patients refusing care should ask themselves what values are at stake from the patient's perspective: how great is the therapeutic benefit and what is the projected loss? Knowledge of the therapeutic benefit may be of little comfort to a patient who has limited savings; and if she were to pursue treatment, she might not be able to afford a final vacation, or might leave a surviving spouse destitute. Death or significant morbidity from an illness that is easily, though perhaps not inexpensively, treated is difficult to explain to family members and patients. The degree to which a clinician persuades or considers coercion should parallel the overall therapeutic benefit to the patient, as well as the immediacy of the situation. Often this is a matter of clinician judgment, based on best guesses or population-based benefits.

When a patient with decision-making capacity persists in refusing a treatment or evaluation, despite multiple attempts at persuasion, the clinician should generally respect the decision. In such situations, the clinician might consider consulting with a colleague or an ethics committee to review alternatives. The clinician should not use the threat of termination of care as a method of coercion to force an unwanted treatment. Even after accepting the patient's refusal of further evaluation, the clinician should continue to see the patient for follow-up visits regarding symptomatic support, and to be a resource in the event that the patient later changes his or her mind and does decide to pursue treatment.

### **ANTICIPATING SHARED DECISION-MAKING ETHICS CONFLICTS**

The patient-clinician relationship does not exist in isolation from its rural context. The social contexts of the community in which both the physician and patient reside exert an influence on their interaction in

shared decision-making. This can create conflicts and potentially disrupt the bonds of trust and respect on which the patient-clinician relationship is based. It is important that such conflicts be anticipated and recognized, so that the integrity of shared decision-making is maintained.

### **Conflicts Arising Within the Health Care Institution**

Rural primary-care practitioners and their local hospital(s) share a mutual commitment to the health of the community served. Rural hospitals and clinicians are dependent upon each other to provide quality care to meet their community health needs and expectations. They are also dependent on factors that ultimately affect the direction and shape of their activities, including financial pressures, population base, provider expertise, hospital technology, and geographical location. These factors often determine limits to the possible services offered, and force painful choices about what kind of care the local hospital should provide. For example, as a result of community demands, financial need, or efforts to recruit talented clinicians, rural hospitals may attempt to expand services in areas for which they do not have the population base or clinical services to adequately sustain. The rural hospital might then expect local providers to support such new services through referrals without reservation, and without adequate disclosure to patients, as noted in the first case.

Rural clinicians should work with their medical colleagues, professional associations, hospital boards, administrators, and ethics committees to ensure that local hospitals provide quality care, emphasize shared decision-making, and conduct ongoing efforts to upgrade and maintain clinical competency. Hospitals should solicit and address concerns from practitioners regarding the quality of services provided. Hospitals and physicians should work toward an understanding that supports and encourages local care without limiting or manipulating a patient's right to know or choose.

Both clinicians and institutions should develop policies and procedures that address issues involving potential informed consent, conflicts of interest, confidentiality and privacy. The basic components of policies regarding informed consent and conflicts of interest may be found in Box 8.2 and Box 8.3 respectively.

**BOX 8.2****COMPONENTS OF AN INFORMED-CONSENT POLICY**

- Define informed consent and the need for shared decision-making
- List and describe the elements of valid consent and refusal
- Delineate what procedures and treatments require a signed informed consent
- Clarify the requirements for documenting informed consent
- Identify the resources for clarifying the informed-consent policy, such as an ethics committee

**BOX 8.3****COMPONENTS OF A CONFLICT-OF-INTEREST POLICY<sup>2</sup>**

- Define conflict of interest
- Affirm that the patient's interests are primary for the organization
- Delineate how, when, and to whom conflicts of interest (or potential conflicts) are to be disclosed
- Indicate the implications of violating the conflict-of-interest policy
- Identify a facility resource to clarify questions regarding the policy

**When Conflicts Arise with Family Members**

Primary care providers practicing in rural areas should anticipate conflicts around shared decision-making because of overlapping relationships with multiple members of the same family. The provider's establishment of ethics-grounded practice guidelines is essential in order for him or her to define the boundaries for what patient information is shared with whom. The provider's articulating and sharing a policy with patients, as part of the office routine, will emphasize that the guidelines are an expectation. Such information-sharing can be easily and efficiently implemented as part of a patient handout or handbook that the provider gives to all patients. The language does not have to be complicated; however, the guidelines and their reasons should be clear. Such a document is often better when it is short and somewhat lighthearted—something that can be referred to when ethical challenges occur. A sample is provided in Example 8.1

**EXAMPLE 8.1****AUTHOR'S CLINIC CONFIDENTIALITY STATEMENT**

**Confidentiality:** The information in your records is confidential. It will not be shared without your permission unless there is a legal requirement to do so. You sign a release when you join the practice to release information for billing purposes and for government review. If you wish to share information about your visit with your family, it is your prerogative to do so. Doctors, nurses or other medical staff cannot share your medical information without your permission. If you wish that your provider may speak to your family members, please let him or her know. (This applies to hospitalizations as well.) Please respect your family members' and friends' right to confidentiality and do not ask medical providers about their health or whether and when they have been to the clinic.

Having articulated the ground rules for shared decision-making, it is important for the clinician to follow through in action, and for him or her to deflect requests that would be contrary to the stated practice guidelines. Patients and family members will learn quickly how serious a practitioner is about protecting information.

**Use of Advance Directives**

Staff of rural health facilities and clinics should actively encourage the use of advance directives to decrease the potential for ethics conflicts, and to improve the quality of end-of-life decision-making. Clinicians should routinely raise the topic of advance directives, especially with any patient in a potentially life-threatening or terminal situation. Clinicians can encourage patients to discuss the issue with their family members, and can offer to include family members in discussing future health care decisions. Clinics and hospitals should also obtain, and make available to patients, written material that describes the purpose and process for making advance-directive decisions. The elements of advance health care planning are listed in Box 8.4.

**BOX 8.4****ELEMENTS OF ADVANCE HEALTH CARE PLANNING**

- Anticipate potential conflicts in shared decision-making involving family members
- Initiate conversations about advance health care planning
- Make use of state-based advance care planning material
- Involve the patient's family when this would be acceptable to the patient
- Share the clinic and/or hospital's policy regarding sharing advance health care planning information
- Document advance health care planning in the patient's chart
- Adhere to the policy described to protect patient confidentiality
- Advocate for patient autonomy through the implementation of the advance care planning

Family involvement in discussions about advance health care planning should be encouraged without endangering patient autonomy. Such discussions would also allow patients to share fundamental personal values that influence health care decisions, and to identify a family member or members who can speak for these values when patients are unable to speak for themselves.

**CONCLUSION**

Shared decision-making is a joint effort between the clinician and patient to promote the patient's goals and preferences in health care decisions. It is more than a recitation of risks and benefits followed by a recommendation. Shared decision-making is a conversation that explores the patient's desires and values. It recognizes and respects the rights of patients with decision-making capacity to pursue their particular visions of health care. Shared decision-making reflects the professional's duty to inform and clarify the choices, and to ensure as much as possible that decisions are voluntary, and reflect the patient's stated health goals. Shared decision-making occurs in a larger social matrix and is subject to influences from that sphere. Shared decision-making may be enhanced through several practical approaches as noted in Box 8.5.

**BOX 8.5****PRACTICAL WAYS TO ENHANCE SHARED DECISION-MAKING**

- Develop policies and procedures about informed consent, conflict of interest, confidentiality and privacy
- Share with patients the expectations and boundaries regarding these issues
- Recognize and protect patients' interests if conflicts of interest occur
- Maintain good communications skills, especially listening
- Identify and develop methods to anticipate and possibly avoid complex problems before they develop
- Promote the use of advance care discussions and decision-making through an open discussion of potential future health issues
- Practice truthfulness and embrace choice

Shared decision-making can be flawed when patients do not fully understand the future implications of their choices, or when professionals are too quick to accept patients' abrogation of choice. "Do whatever you think is best, doc" is the beginning and not the end of a conversation. It should evoke a response, such as, "Tell me what is important to you with this particular health issue and I will help you figure out what is best."

Shared decision-making can be compromised when patients do not have the ability to understand and make choices. It can also be compromised when outside parties attempt to coerce patients in their decisions, or to influence clinicians in their disclosure or recommendations.

Issues and problems arising with shared decision-making vary in the ease with which they can be recognized and rectified. Sometimes clarity can be achieved through salient questions: Would I question decision-making capacity if this patient were agreeing with my recommendation? Would I let my spouse have this procedure done here? Would I be thinking about talking to this patient's family without her consent if they were not also my patients? If I were 80 years old might, I feel differently

about pursuing aggressive therapy than if I were 40? Questions regarding how competent a patient is, i.e., what their decision-making capacity is, can be thorny, and may require a psychiatric or neurological consult to help resolve. At times, the issues have legal implications. Identifying experts who can provide help in these types of situations is important, particularly if such expertise is not available locally.

To enhance the shared decision-making process in practice settings, clinicians should develop policies and procedures around informed consent, confidentiality and privacy. Clinicians should communicate with patients about their ethical thinking regarding boundary issues, recognizing and protecting patients' interests, and maintaining communication. Clinicians should identify and develop clinical, ethical, and legal resources to address problems when they arise. And, most importantly, providers must practice truthfulness and embrace choice.

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