



CHAPTER 7

Ethics Conflicts in Rural Communities: **Privacy and Confidentiality**

Tom Townsend

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ABSTRACT

This chapter explores the ethical challenges involving privacy and confidentiality in rural health care relationships, due to overlapping relationships and familiarity with patients and communities. In a rural setting, the professional relationship between a health care provider and a patient is frequently a long-term, personal relationship that involves friendship as well as professional responsibilities. In small communities, this is not limited to one-on-one relationship; it involves a family and mutual friends. In contrast, the health care relationships in urban or suburban settings are often like “strangers at the bedside,” facilitated in large institution-style settings with care given by clinicians whom patients seldom know or see outside of the hospital or clinic setting. The intimacy of rural life is a key factor to many aspects of rural health care ethics discussions. An ethical relationship with strangers is different from the ethics of close-knit relationships. The ethics issues within the patient-provider relationship change when strangers, rather than friends, neighbors, or acquaintances, are involved. This distinction is key to many of the differences between urban and rural health care ethics. The reality of rural health care, and the ideals of the health care professional, can be at odds with professional standards of practice, because confidentiality, as a model, simply works differently in rural and urban settings. Trusting relationships in rural health care settings are enhanced by the familiarity common in rural living. In rural communities, residents know many of the details of each other’s lives, which can lead to confidentiality issues.

CASE STUDIES

CASE 7.1 | A patient refusing needed care

Bob Jones is seeing Dr. Sampson for the first time. Dr. Sampson knows Mr. Jones slightly from the local gas station where Mr. Jones works. Mr. Jones' wife is also Dr. Sampson's patient, and the family has an infant son. Mr. Jones tells Dr. Sampson that he has gained approximately 75 pounds in the past year, after quitting smoking. He denies any significant symptoms, but does admit to shortness of breath when walking up an incline. He says he would not be here if it were not for his wife, who "does not like his color." Mr. Jones is 40 years old, weighs 310 pounds, and is slightly pale. He is quiet, intelligent, and friendly. An exam reveals massive edema and anasarca; frothy urine shows 2000 mg protein. Dr. Sampson is quite sure that Mr. Jones has nephrotic syndrome, and may have had it for some time, although a renal biopsy will be required to make a definitive diagnosis. There is an outside concern that an underlying malignancy may exist. Dr. Sampson informs Mr. Jones of his probable diagnosis. The patient tells Dr. Sampson that he does not wish to pursue assessment, and isn't troubled except for the tight clothes. He has no insurance, doesn't think his wife and son should have to shoulder the cost of his illness, and he's "not fixin' to be a charity case." Mr. Jones refuses to let Dr. Sampson talk to his wife, and says that he will tell her, "The doctor said to lose weight and to exercise."

CASE 7.2 | Disclosing health care information to family

Tammy Andrews, age 17, visits Dr. Cohen's office for a viral upper respiratory illness. During the course of the exam, she mentions that she is taking oral contraceptives that she obtained from a distant family planning clinic. Ms. Andrews states that her parents think the pill is being taken to regulate her periods, but she uses it for birth control, and has been sexually active for more than a year. After the exam for her upper respiratory complaint, she asks about painful blisters on her genitalia. A pelvic exam reveals typical genital herpes. After Dr. Cohen explains genital herpes, along with the

risks of other sexually transmitted diseases (STDs), Ms. Andrews cries uncontrollably. She is devastated by the potential chronic infection, along with the guilt of sexual activity and its other risks. She is concerned that her father, a Baptist preacher, respected community leader and friend of Dr. Cohen, will discover her sexual activity and related disease, despite Dr. Cohen's assurance that her health information will not be disclosed. The lesions are less painful and prominent on the teenager's subsequent follow-up visit. Ms. Andrews appears to be depressed, worried about the impact of herpes on her future relationships. She does not want to tell her present partner about her STD. Her parents are concerned about her mood swings and anxiety, and want to know why their daughter seems so upset. The teenager has told them that she is tired due to a viral illness. Rev. Andrews leaves a message at Dr. Cohen's home, seeking information about his daughter. He asserts that he has a right to know and he believes that "a viral illness would not upset her like this." Rev. Andrews is afraid that his daughter is concealing a serious illness.

OVERVIEW OF ETHICS ISSUES

For many, the professional relationship between a rural physician and a patient represents an ideal long-term, close personal relationship that involves friendship as well as professional responsibility. In small rural communities, this relationship is frequently not just a private bond, but also one that involves family and mutual friends. Such a relationship appears quite different from those one might encounter in non-rural settings, where health care professionals are "strangers at the bedside" and health care is provided in large, institution-style settings by professionals that patients seldom know or see outside of the hospital or clinic setting. The relative intimacy of rural life is woven into the clinical and ethical management of health care ethics discussions. An ethical relationship with strangers is different from the ethics of intimate relationships. This distinction is key to many differences between urban and rural health care ethics.

Confidentiality and privacy are essential to all trusting relationships, especially in the professional setting. In various businesses, leaks of

boardroom decisions make periodic headlines that prompt resignations and firings of corporate leaders. In health care, respecting confidentiality and privacy is not only a legal mandate but also a key to the trust that underpins the patient-clinician relationship. Confidentiality is a fundamental component of the American Medical Association's Code of Medical Ethics, "The information disclosed to a physician by a patient should be held in confidence."¹ Like the teen girl in Case Study 2, "The patient should feel free to make a full disclosure of information to the physician in order that the physician may most effectively provide needed services. The patient should be able to make this disclosure with the knowledge that the physician will respect the confidential nature of the communication."¹ Seeking to maintain confidential knowledge also adds to the value and meaning that sustain the long-term trusting relationship between a health care professional and his or her patient.

A foundation of confidentiality dates to the Oath of Hippocrates,² a pledge taken by many physicians to reflect their professional status, to inform society that physicians comprehend and value the importance of their calling, and to publicly promise their competence to the service of the sick. Specifically, the Oath's seventh paragraph is devoted to the special relationship of the healer to the patient when keeping each encounter private, or a shared secret only with the patient; "What I may see or hear in the course of the treatment, or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about."²

The importance of confidentiality to the patient-provider relationship continues to be reinforced in modern codes of ethics and ethical standards of practice adopted by various health care professions. Additionally, the ethical concept of confidentiality as well as the legal obligation to maintain it is typically captured in health care organizations' policies and procedures.

Though health care providers may be dedicated to their various professional roles and diligent about fulfilling their ethical and legal obligations, modern medicine continues to present challenges.³ Despite challenges to confidentiality, it is a fundamental tenet of the patient-clinician relationship.

Individual states have their own laws regarding the confidentiality of medical information. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 addressed a variety of topics, but it is well known among health care professionals for the new federal privacy regulations that resulted, often referred to as a HIPAA Privacy rules. It is important for rural health care providers to be proactive in learning accurate information about what the law requires of them and their staff members with respect to sharing information, as well as what it permits.⁴

In rural communities, maintaining confidentiality is challenging, simply because residents are privy to each other's activities and lives. There continue to be some communities where local radio stations update listeners about current hospitalizations, and clergy offer public prayers to help guide a named physician in the diagnosis of a certain patient. This may seem quaint to an urban audience, but it is part of normal networking in some small communities. Imposition of outside standards on such practices often does not sit well with rural populations that practice a culturally important expectation of information sharing between neighbors, regardless of possible deleterious outcomes. Similarly, legislation or regulation may be viewed as an intrusive invasion of urban standards on the traditional way things are done—an officious imposition from the powerful “outsiders” who make most of the laws.

The dominant characteristic of familiarity in rural life and small communities creates clinical and ethical benefits for patients and health care professionals. For example, Mrs. Jones, in transit to a small hospital, is rarely described by age, symptoms, and vital signs by the volunteer rescue squads because the squads communicate with ER nurses who know people by their first names. The staff in the ER may know a lot about the incoming patient's disease and health care goals, if they know her personally. Care might be tailored for her even before the ambulance arrives if the hospital staff is familiar with her values, family, and outlook on life, as well as her preferences about health care. The depth of the staff's knowledge of “Mrs. Jones” as a patient can foster adherence to shared decision-making regarding the patient's choice of treatment. The example suggests that respecting confidentiality and privacy standards as well as the awareness and sharing of health care information can be beneficial to patient care.

CASE DISCUSSIONS

The previously presented cases are interpreted using the analysis method presented in Chapter 4 of this *Handbook*.

Both cases raise ethics issues related to sharing patient information with families in a rural community. Such challenges impact not only the patient and his or her family, but also the broader community.

CASE 7.1 | A patient refusing needed care

In this case, Dr. Sampson is faced with an ethics conflict involving his patient's confidentiality and autonomy. He is obviously concerned about Bob Jones' likely diagnosis of severe and chronically progressive kidney disease (nephrotic syndrome) as well as the need for further assessment and treatment. Mr. Jones tells Dr. Sampson that he does not want to pursue further evaluation or undergo any potentially helpful treatment. He tells Dr. Sampson that he has limited resources and lacks insurance, a common concern in rural communities. Mr. Jones emphasizes that he does not want to be a financial burden to his wife and son.

Dr. Sampson can understand Mr. Jones' desire not to create a financial burden for his family. However, the doctor strongly believes that his patient needs to better understand his illness and the possibility of treatment. All treatments seem difficult, time-consuming, and expensive to Mr. Jones. He appears to have little insight into the treatments' benefits, including the fact that treating his potential condition would likely allow him to enjoy a longer life with his family. Despite the clinical certainty of a serious renal disease, there are several potential related disease states. Even if a nonreversible disease process were to be found, renal dialysis or a transplant might be viable options offering Mr. Jones a longer life.

Complicating the health-related problems is Mr. Jones' apparent refusal to discuss the situation honestly with his wife. Dr. Sampson can respect Mr. Jones' autonomy and accept his decision not to pursue further work-up. As an alternative, the doctor could try to maintain regular medical contact, including screening for depression, to see how Mr. Jones' situation evolves. However, Dr. Sampson is clinically and ethically

disturbed, because he believes this plan would postpone or eliminate the potential benefits of needed care. Dr. Sampson feels that sharing this health care information with Mr. Jones' wife is an important means to foster a more appropriate care plan.

Dr. Sampson discusses with Mr. Jones the nature of the syndrome, the need for further assessment, and the importance of sharing such information with his wife to gain her support, but Bob Jones continues to be adamant that he will have no treatment. However, Mr. Jones is willing to discuss the matter further in a follow-up appointment.

Dr. Sampson believes that Mr. Jones and his wife have a good relationship, but he is concerned that withholding the knowledge could help undermine the stability of that relationship. It is also hard to imagine how maintaining confidentiality could truly support a person's autonomy when that person doesn't have family and social support. A person with a new, serious diagnosis is not the same person emotionally as the person who did not have that diagnosis. Dr. Sampson believes that family and friends can actually help foster Mr. Jones' autonomy through communication and support.

CASE 7.2 | Disclosing health care information to family

In this case, Dr. Cohen struggles with several ethics issues, including patient autonomy, confidentiality, and privacy. Tammy Andrews' newly diagnosed genital herpes has created a problem that is not merely clinical—the guilt, anxiety, and chronic nature of a newly diagnosed sexual disease is psychologically distressing. The teen girl is overwhelmed, despite Dr. Cohen's reassurance that the illness can be monitored and controlled with medication. Tammy Andrews' health issue has also created a crisis within her family. Ms. Andrews has refused to let Dr. Cohen discuss the situation with her family. She has suggested that she is not planning on telling anyone, not even her sexual partner.

Dr. Cohen is placed in a difficult ethical position, because he is unable to reassure Ms. Andrews' father, Rev. Andrews, that her health problem is not life-threatening, without breaching confidentiality. Dr. Cohen realizes that Rev. Andrews' suspicions are understandable and may escalate. The situ-

ation also creates a broader challenge, because Rev. Andrews will potentially solicit the clinic's office staff for information regarding his daughter's illness. Such a situation raises concerns about maintaining patient privacy and confidentiality within the clinic as well as within the community.

Though Dr. Cohen believes it would serve the best interests of both his patient and her family if Ms. Andrews were to inform them of her situation, she refuses. Though he is committed to Ms. Andrews' right to confidentiality and privacy, Dr. Cohen is concerned that he and his staff will be not be able to pacify Rev. Andrews without her cooperation.

RESPONDING TO PRIVACY AND CONFIDENTIALITY CONFLICTS

Such scenarios are common for rural health care teams, because of the overlapping relationships found in small communities. Urban residents may dismiss these cases as simple issues settled long ago in ethics discussions and case analysis. However, when occurring in rural areas, these situations are never reducible to something occurring "anywhere," because the rural context is so unique.

CASE 7.1 | A patient refusing needed care

Dr. Sampson recognizes Bob Jones' need for further assessment to clarify the diagnosis and to determine any appropriate treatments. A traditional health care setting would likely respect Mr. Jones' autonomous decision to postpone treatment, after clinicians had undertaken a certain level of discussion to encourage him to pursue further testing at this time. But in this situation, Dr. Sampson knows the patient and his wife on many levels. He delivered their baby, and is aware of their desire to have a larger family. Knowing Mr. Jones' family, his values, and his medical and community contacts, Dr. Sampson believes that Mr. Jones' reasoning doesn't reflect his actual personal goals. Mr. Jones' reasoning may have been diminished in the face of the physical threat of serious illness. It is very difficult for Dr. Sampson to argue with Bob Jones about his decisions after such bad news, because Mr. Jones is not thinking about his life in the same manner as before.

Mr. Jones' desire for Dr. Sampson to maintain confidentiality by remaining mute, deflective, or maybe even lying in communication with Mr.

Jones' wife, is ethically unacceptable to Dr. Sampson. Dr. Sampson also doubts that he could even "carry off" such deception in response to questions from Mr. Jones' wife. Questions will inevitably come from this patient's family and friends, because of the extent and obvious nature of Mr. Jones' symptoms. The doctor is not ethically allowed to lie or mislead his patient's wife, but he also may not breach his patient's confidentiality.

Dr. Sampson should emphasize to Mr. Jones the importance of seeking further assessment to better understand his illness and treatment options, including the benefits of treatments. Mr. Jones needs to be reminded of his stable, committed marriage, the importance of his wife's support, and the emotional weight for both of them in failing to communicate and share openly. The lack of communication with his family and friends will only foster more concerns, questions, and problems. Dr. Sampson should also explain the awkwardness he will feel when encountering Mr. Jones' wife, in both his office and in the community, if she remains uninformed.

Dr. Sampson's discussions with Mr. Jones will likely require multiple clinic visits and telephone contacts. In the meantime, the doctor needs to maintain confidentiality while actively encouraging Mr. Jones to honestly and openly disclose his condition to his wife.

CASE 7.2 | Disclosing health care information to family

Cases like the situation involving Tammy Andrews, the teen girl, do not only happen in rural areas; however, living in the rural setting does create a unique dynamic among Dr. Cohen, Ms. Andrews, and her parents. Despite rural-urban contextual differences in such cases, the appropriate response is similar.

As noted, there are many layers of concern for Dr. Cohen in the care of Tammy Andrews, which include clinical management of the disease, emotional support, and her family's needs. Despite Dr. Cohen's reassurance that the illness can be monitored and controlled with medication, his teen patient is overwhelmed and unwilling to share her troubles with anyone besides him, her doctor, at least at the present time. Dr. Cohen should strongly emphasize to Ms. Andrews the importance and value of

sharing her health situation with her family, despite the disappointment they will likely demonstrate and the shame she already feels.

Tammy Andrews is very concerned that her family, especially her father, will not be able or willing to accept and support her in this situation. She thinks that her father will not be able to contain his anger regarding her sexual activity and resulting venereal disease. Dr. Cohen should offer to help her to share the health information as part of a family meeting. Ms. Andrews needs to understand that being deceptive with her family will foster further problems. Any deception will be difficult to maintain because of the need for regular medication for herpes. Dr. Cohen should reinforce the fact that if she refuses to share the health information and refuses to allow him to share the information, he will respect her decision. However, he will not suggest to the family that she has some other health problem. He will refer the family to speak with their daughter directly.

There are also concerns that Dr. Cohen's staff, who may also be members of the Reverend's congregation, will be pressured to reveal the clinical situation as they understand it, regardless of the accuracy. It is unlikely that personal contact between the involved parties will not eventually occur. If it is somehow avoided in the clinic, it will occur later in the community. The intimacy of rural life does not allow providers, including Dr. Cohen or his staff, to live in a reclusive bubble of isolation. However, while the office staff can appreciate Rev. Andrew's desire to obtain the medical information, they need to understand the circumstances in which the law shields a minor's medical information from parents and when it does not.

As is the case in many states, Rev. Andrews has no right to see his daughter's medical information in this situation. Ethically, Dr. Cohen must protect her privacy. However, Dr. Cohen should strongly reinforce to Tammy Andrews how important it is for her to share her health information, despite her perception that it will create conflict within the family. He needs to inform Ms. Andrews about the disease, its management, and the precautions she will need to take regarding contact with any current or future sexual partners. Dr. Cohen will also need to reinforce to the clinic staff that privacy and confidentiality are both an ethical and legal obligation—essential to a trusting relationship between patients and provid-

ers. If Dr. Cohen shares the health information it must be done with Ms. Andrews' concurrence. If she refuses to disclose, or allow Dr. Cohen to disclose, her health information, Dr. Cohen will need to emphasize to Rev. Andrews when they meet that, like clergy, he is ethically required to maintain confidentiality about information shared in a professional relationship.

ANTICIPATING PRIVACY AND CONFIDENTIALITY CONCERNS

Patients trust health care professionals to foster and maintain privacy and confidentiality. When providers breach this professional and legal mandate, they jeopardize not only their personal integrity but also the moral status of their profession within the community.

Because people in rural settings may be relatives, friends or have frequent contact, health care professionals need to be particularly diligent in maintaining confidentiality. It is simplistic to think that breaches in confidentiality would not occur. Similarly, it would be wrong to think of rural health care providers as infallible, or above the law, or to exclude them from taking careful, rigorous steps to protect health information and from monitoring for breaches of confidentiality.

There are several practical ways that rural providers can seek to address and potentially diminish ethics conflicts regarding privacy and confidentiality. Some of these are required by law, as noted in Box 7.1.

BOX 7.1

ADDRESSING CONFIDENTIALITY AND PRIVACY ETHICS CONFLICTS

- Clarify confidentiality and privacy policy with patients
- Conduct informative discussions about confidentiality and privacy with the community in general
- Review medical record management for potential privacy breaches

Health care professionals should ensure that they are following the legal requirements for providing notice of their privacy practices and that the written information available for all patients about their policy regarding confidentiality is clear. Providers should discuss their position regarding

confidentiality with all new patients. Health care professionals should proactively participate in discussions and education programs in the community regarding these topics. Community programs can include various providers who have similar professional rules of conduct and confidentiality, as in the case involving Dr. Cohen and Rev. Andrews. Members of the community would have an opportunity to express their concerns, thus fostering an increased community-wide understanding of privacy and confidentiality issues.

Health care professionals should also have regular training and ongoing discussions with staff about their legal obligations and the importance of confidentiality for maintaining trust and professionalism. Hospitals, clinics and provider offices should regularly review patient record maintenance protocols to prevent any breaches in personal health information. As in Dr. Cohen's case, when staff members understand the ethical foundations for such policies and know how to best manage records, they are more equipped to maintain ethics goals.

Despite the ethical mandate to adhere to patient confidentiality that is the foundation for a good provider-patient relationship, there are several morally justified exceptions to preserving confidentiality that may be permitted by law, depending on the particular jurisdiction. Some possible exceptions are noted in Box 7.2.

BOX 7.2

EXAMPLES OF POSSIBLE EXCEPTIONS TO MAINTAINING CONFIDENTIALITY

- Testifying in court
- Reporting communicable disease (and notifying partners)
- Reporting gunshot or other suspicious wounds if criminality is questioned
- Reporting potentially impaired drivers
- Warnings by physicians to persons at risk, when there is a legally recognized duty to warn
- Reporting in workers' compensation cases
- Reporting of child abuse, domestic violence, or elder abuse

These limited exceptions are intended to protect the public and, in some cases, the patients themselves. Unless there is a clear and unambiguous legal exception obligating the clinician to disclose information, health care providers should dedicate themselves to maintaining patient confidentiality and privacy.

CONCLUSION

The discussions of ethics issues that occur in rural settings resonate differently than they would in non-rural settings. Rural culture is embedded in both cases discussed in this chapter. In rural towns, health care professionals and other members of the community frequently encounter one another. Regular contacts within the community may lead people to ask providers for information about patients more often than would occur in non-rural settings. While providers might try to avoid the questions, the very intimacy of rural life does not allow them to live in a reclusive bubble of isolation. Such overlapping relationships can create ethics conflicts. For example, if a doctor were to consistently refuse to answer questions that involve disclosing protected health information about mutual neighbors, this might cause another neighbor, or even the entire community, to question a provider's broader responsibility to the community and its values.

Because many rural patients frequently receive their personal caregiving from family and friends, or people whom they know at some level outside of a health facility, community members sometimes feel they need to know about health issues in order to provide assistance. Sensitivity to these values in rural settings is important for any health care provider, but also fosters ethics challenges. Though it may be difficult at times, providers need to maintain confidentiality. However, awareness of, and sensitivity to, community values and culture should be a part of the patient-provider discussion to make a shared decision regarding how a patient's private, protected health care information may or may not be communicated.

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