



CHAPTER 14

# Ethics Conflicts in Rural Communities: Health Information Technology

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

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# Ethics Conflicts in Rural Communities: Health Information Technology

David A. Fleming

## ABSTRACT

The use of health information technology (HIT) is becoming increasingly important in medical providers' efforts to support decision-making and to promote quality health care delivery and equitable access to services in rural areas. However, technological interventions in remote settings have attracted ethics concern and conflict. Complex patient information processes, service shortages, high demand, and a widening array of medical interventions and treatments constantly challenge health care providers as they struggle to maintain standards of care. For patients in rural areas, barriers to reasonable access for even basic health care services, such as primary care, screenings, and prevention, are also common. Numerous technologies have been introduced in recent years to remote sites, with the intention of enhancing quality and improving access. However, as with any well-meaning and innovative medical advance, these technologies bring both intended and unintended consequences to the lives and welfare of patients. This chapter will address four domains of health information technology: telehealth, electronic medical records, electronic clinical support, and online prescribing services. These technologies bear careful scrutiny when deployed in rural settings, due to both the nature of the setting and the complexity of the technology. When deploying HIT in any setting, rural or urban, health care providers must place patient welfare above all other considerations, protect confidentiality, ensure privacy, promote trust in the healing relationship, and ensure fair and equitable access to quality services.

## CASE STUDIES

### **CASE 14.1** | Privacy and consent issues when using telehealth in rural areas

Gina Conti is 75 years old, with multiple chronic medical conditions including severe rheumatoid arthritis. She lives in a rural chronic-care nursing facility, and requires a wheelchair to get around. Mrs. Conti was recently seen by her family physician for a persistent rash. Following several failed diagnoses and treatments, her physician recommended referral to a dermatologist at a university hospital 60 miles away. Neither Mrs. Conti nor her physician feels that she can make a trip of this kind due to her fragile condition, but since the local hospital is part of the university's telehealth network, Mrs. Conti agrees to have the dermatology consultation done remotely. Mrs. Conti is not sure what to expect, and has only been informed that she will, "... be seeing a skin doctor on the TV screen." Upon arrival at the local hospital, Mrs. Conti is taken to a room near the emergency room waiting area where the dermatologist appears on a videoconferencing screen. Mrs. Conti feels a little uneasy while talking to the dermatologist on the screen, especially when the dermatologist asks the nurse to disrobe Mrs. Conti so her rash can be examined. The nurse is instructed to use a special camera for a closer examination of the rash on Mrs. Conti's buttocks, and scrapings are taken and sent to the lab. Mrs. Conti notices that the dermatologist seems to be talking to someone else, but it isn't until the session is almost over that she realizes that a student and resident have been present off-camera, without her knowledge or permission having been requested. When Mrs. Conti is wheeled out of the telehealth room, she feels as though people in the ER waiting room are staring. She is grateful to have seen a skin specialist without having to travel far, but wonders why her physician didn't give her more advance warning about what to expect in the video consultation.

**CASE 14.2** | Availability of, and access to, electronic medical records (EMR)

Dr. Adams, a rural general internist, is on call for his three-person group. He is in the ER seeing a patient who normally sees one of Dr. Adams' partners. Lars Danielson is a 57-year-old male, who was referred to an out-of-town cardiologist last week for evaluation of recurrent chest pain. Mr. Danielson is concerned because he is still having chest pain, and wants to know more about the previous tests, and why he is on so many new medications. He feels dizzy and nauseated and thinks it might be due to one of the new drugs, so he has stopped taking them all. Dr. Adams has Mr. Danielson's medical record, and there is no information from the cardiologist, other than a brief discharge summary stating, "inoperable coronary artery disease," and a list of several new medicines. The letter indicates that the patient's electronic medical record (EMR) provides a full account of his hospital stay. Dr. Adams' group uses a paper record system, and the clinic has only one computer, used only for billing and appointments. Although it would be useful, Dr. Adams' group can't afford an EMR system. If they had the system, however, he still wouldn't be able to access the patient's hospital record because his clinic is not in the same networked health care system as the cardiologist's hospital. Dr. Adams will have to call the referral hospital to get a faxed copy of the patient's record. Meanwhile, Mr. Danielson is complaining of chest pain and becomes short of breath.

**CASE 14.3** | Using electronic clinical decision support systems

Robert Taft is a 65-year-old general contractor in a small rural community. He has been unusually tired for several days, and while at a construction site, he becomes very nauseated and fatigued. When symptoms persist for 20 minutes, he agrees to be driven to the emergency department of his 20-bed community hospital. When the physician, Dr. Kimberly Russell, arrives 15 minutes later, Mr. Taft feels much better except for mild fatigue. Dr. Russell examines Mr. Taft and finds no abnormalities other than mild blood pressure elevation and a slightly rapid pulse. Lab work is normal, and an ECG is electronically interpreted as having "nonspecific ST

abnormalities.” Still concerned, Dr. Russell performs a second ECG using new software that electronically interprets and predicts the probability of cardiac ischemia. The second ECG report estimates an “80% probability of cardiac ischemia.” With this information, Mr. Taft agrees to be transferred to a university hospital. There, a cardiac catheterization finds a 95% blockage in one of his coronary arteries, which is then dilated and stented. No cardiac damage is found, and Mr. Taft returns to work the following week.

**CASE 14.4** | Addressing patient use of online treatment and prescribing services

Gwen Thompson lives alone in a remote rural area. She frequently goes online to get information, and to obtain goods and services that are not easily accessible due to her isolation. She has recently been diagnosed with hypertension, but finds it difficult to keep appointments at the clinic 20 miles away. Ms. Thompson ran out of one blood pressure medicine several weeks ago and has been feeling light-headed. She also noticed that her blood pressure has been running high. It is winter, the roads are bad, and she fears going out, so she begins taking double the prescribed daily dose of the other blood pressure medication that she has not run out of. While surfing the net, she finds *CyberDocs.com* and discovers that a “virtual house call” can be obtained for a modest fee, so she requests a “house call....” That same day a physician (in a different state) responds online and Ms. Thompson describes her symptoms, gives her recent blood pressure readings, and mentions that she has run out of medication. The physician offers to provide a one-month prescription, and even arranges for quick mail delivery of the medication. One week later, Ms. Thompson is found unconscious by a neighbor. At the hospital, she is diagnosed with acute kidney failure, possibly a result of taking two different prescribed diuretics, one from her regular physician and the other from *CyberDocs*. She ultimately recovers, but the kidney damage is irreversible, and sadly, she will require chronic dialysis. Ms. Thompson’s attorney contacts *CyberDocs.com*, but the prescribing physician no longer contracts with them. *CyberDocs* claims that since no face-to-face contact occurred, no patient-clinician relationship existed and,

therefore, there was no professional duty to “do no harm.” *CyberDocs* also argues that printed warnings of risk came with the prescription when it was delivered. Arguing that this was a contracted service with full disclosure of potential risk, *CyberDocs* is unwilling to accept any obligation or responsibility for Ms. Thompson’s situation.

## OVERVIEW OF ETHICS ISSUES

More than ever, health care is being driven by the need to access and use health information technology (HIT), regardless of where services are delivered. Modern technological innovations increasingly influence standards of care, by allowing patients and providers to be better informed. This enables more effective diagnosis and treatment of illness, and improves the relief of suffering. Patients are also uniquely empowered, because they are now able to access health information directly, without depending on physicians, clinics, and hospitals to select what they read and hear about health and health care. Although the quality of Web-based health information may be questionable (particularly with regard to meeting standards of evidence-based medical care), and subject to commercial influence, health information is readily available and easily accessible by almost everyone. This means that many patients are better informed, and feel more empowered to participate as partners in the decision-making. Ethically, this is beneficial as long as the information the patient receives is accurate, appropriate, and does not result in greater harm than if the patient had had no information at all. For providers, the day-to-day use of electronic sources of information is unavoidable. In fact, there are few health care interventions today that do not directly or indirectly incorporate health information technology in some fashion. These basic health information technologies (HIT) are summarized below.

- **Telehealth:** Delivery of health-related services and information via telecommunications technologies, including both health care and education
- **Electronic Medical Records:** Computer-based patient records
- **Electronic Clinical Support Systems:** Computer-based knowledge management technologies that support the clinical decision-making process from diagnosis and investigation through treatment and recovery



- **Online Health Care Resources:** Web-based resources that market to health care consumers, as well as providers, linking to information and education about products, medical and dental services, alternative health care, hospitals, providers, employment, publications, and mental health

Traditionally, health care technologies have been developed and introduced predominantly by scientists and physicians for the good of patients. When needed, patients are informed about the technologies or interventions that their clinicians recommend to further their health, and together, patients and physicians decide on a course of treatment. Interventions, such as radiology, surgery, and intravenous therapy, are utilized in the doctor's office or hospital, and are available to patients only through the guiding hand and advice of their provider. Hopefully, patients benefit from the use of these technologies.

In the modern paradigm, however, patients and providers seek health information technology both independently and in partnership. This new paradigm may require adjustment, as multiple individuals and organizations relinquish control over information at some level when it is freely accessible. Even in rural areas where access to technology is often difficult, patients are becoming increasingly empowered and many seek to be partners in the pursuit and use of HIT. The traditional moral precepts, including autonomy, beneficence, nonmaleficence, justice, and confidentiality, that shape our professional behavior while caring for patients, remain the same.<sup>1</sup> However, we must never lose sight of them. These principles are discussed in more detail in Chapter 3 of this *Handbook*.

As information technologies evolve and become available, the skills necessary to access and employ them likewise become increasingly sophisticated. As availability grows, so will the risk that misinformation, missed information, and misused information will potentially lead to poor quality and dissatisfied users. Multiple forms of informational technology, including cell phones, personal digital assistants (PDAs), and laptop computers are now commonplace even in rural settings. The ethical concern for information integrity brings a parallel concern regarding privacy and confidentiality, when electronic devices are used outside the relatively secure confines of homes, cars, and offices. Health information



technology may also dramatically impact the relationships between providers and patients, the quality of care, and the clinical outcomes. In response to these external forces, health care providers must remain focused on their primary goal of providing high-quality care. Therefore, a prudent and balanced approach is needed when introducing new health information technologies.

### **Balancing Ethical Obligations to Patients with Technology Usage**

When using health information technology, unintended harms must be considered in pursuit of the intended good.<sup>2</sup> Of utmost concern are patient confidentiality and autonomy. Respecting patient autonomy requires that clinicians do everything in their power to ensure privacy, and to respect the patient's right to make informed decisions.<sup>1</sup> The ethical obligations pertain to actions taken on patients' behalf, to improve their health status and protect their personal information. For example, meeting this obligation may be achieved by clinicians' providing local access to specialty care using telehealth systems, as in the dermatology case, and improving standards of care in the use of electronic decision support. Respect for autonomy, however, requires that information regarding patient encounters be kept private, whether obtained in person or via electronic (virtual) means, unless the patient requests or gives permission to have personal information shared.<sup>3</sup> This task can be especially difficult when the clinical encounter is "broadcast" beyond the privacy of an exam room. When using e-mail, telephone, videoconferencing, or other electronic means, one can never be completely sure who is gleaning information on the other end of the line, or even tapping into such information as it is being sent across the network.

A broader ethics concern is that confidentiality may become less important, or more difficult to enforce, as health information technologies become more universally available and applied, particularly as human curiosity continues to promote behavior that derails even the most secure system.<sup>4</sup> Breaches in confidentiality can be both visual and auditory. Such breaches may be quite innocent, such as when a passer-by inadvertently views or hears a provider's videoconference interactions with patients. Other concerns include unauthorized viewing of patient images or clinic notes in an electronic database that is shared

by providers, and/or unauthorized retrieval of patient information from a protected database by staff members for purposes other than billing or quality assurance. Unauthorized viewing of patient information of any kind—intentional or unintentional, whether written, electronic, or auditory—is unethical and, typically, not in compliance with the law or regulatory policies regarding privacy.<sup>5</sup>

Improving access has also become an ethical imperative for HIT. The use of electronic medical records (EMR) and electronic decision support in emergency rooms and other clinical settings is increasingly commonplace. In fact, they are becoming the standard of care in many clinical domains. But significant economic and logistical barriers impede widespread adoption of these tools.<sup>6</sup> Finding cost-effective ways to implement technology where it is most needed may help solve one of the most challenging problems confronting health care today—the uneven distribution and relative shortage of specialty providers in rural areas. Despite concerted efforts by federal and state governments over the past 30 years to address this problem, mal-distribution of skills and provider shortages in rural areas persist.<sup>7</sup> In dermatology, for instance, although the workforce has risen in recent years (presently 3.4 per 100,000 population, compared to 1.8 in 1965 and 2.8 in 1985), there continues to be a major migration of newly trained dermatologists to metropolitan areas. Dermatologists tend to move away from underserved areas (poor urban and rural locations), where they are increasingly needed.<sup>8</sup> Therefore, many patients in remote areas who need treatment don't get it at all, or often delay care until it is too late because they find it difficult or impossible to travel long distances for clinic appointments. This is particularly true for those individuals at greatest risk, including the elderly and chronically ill. These patients are particularly vulnerable to geographic, physical, cognitive, or economic barriers to health care services. Telehealth and other forms of health information technology are important resources in making the lives of these and other rural patients safer, healthier, and more comfortable.

**Telehealth:** Telehealth is one means by which rural patients can gain access to health care when needed services are a prohibitive distance away. However, the location and accessibility of telehealth may still be a problem for those who find traveling even short distances a challenge,

such as debilitated patients and those in nursing homes. Telehealth technology is typically nonportable, and some patients will still have to travel some distance to gain access. Providing telehealth services is primarily an organizational concern with significant fiscal up-front costs, although over time the service pays for itself in savings on travel and in-person visits at the tertiary center. There can be a high cost also in installation and maintenance of the equipment. Rural telehealth units are typically in hospitals or clinics, and may be located hundreds of miles from the tertiary care centers and specialty providers who offer the telehealth services. How these services are financially supported, and subsequently reimbursed, is a fiduciary concern that must be addressed—since both the initiating site and the specialty provider must pay up front for the equipment, and then must dedicate ongoing resources during telehealth “visits.” Deploying telehealth requires an additional financial investment that rural hospitals may not have.

**Electronic Medical Record:** Between 30 and 40% of rural hospitals report using computers to collect basic clinical information that could potentially be used in an electronic medical record (EMR) or computerized provider order entry (CPOE) system.<sup>9</sup> Even though hospitals and clinics have been under great pressure to incorporate HIT for purposes of quality improvement and patient safety, many have been slow to comply, because to do so requires a significant investment of money, time, and human resources. Most clinic and hospital administrators simply feel that they don’t have the resources to afford EMR systems. Even if EMR systems were deployed in today’s networked health care system, the chance of interoperability among EMR systems is essentially nil for the time being. Electronic records are individually contracted and “firewalled,” so outside persons or systems cannot be allowed in. The emerging national and international privacy standards that have created this morass of impenetrability are in response to both legal and ethical requirements that health systems and individual providers must maintain the confidentiality of patient information.<sup>10</sup>

**Electronic Clinical Decision Support Systems:** Several preliminary studies are encouraging in this arena. One recent study found that physicians using a cardiac ischemia predictive instrument provided an accurate diagnosis to triage patients with chest pain.<sup>11</sup> In another study,

an Internet-based antimicrobial prescribing support system improved prescribing behavior in rural Idaho physicians, although organizational and cultural barriers to behavioral change were still evident.<sup>12</sup> These are compelling data, but many physicians still resist the use of electronic triage systems because they feel that experience, knowledge, wisdom, and skill are still the gold standard—as well they should be. Physicians have a professional obligation to hone their skills and utilize knowledge to provide optimal care for their patients. Wisdom, though variably defined, comes with years of experience, instinct, and knowledge of patients with whom physicians have developed long and trusting relationships. Physicians who first rely on their mind, instinct, and senses, and then use technology to confirm their clinical suspicions may be wary lest technology and “informatics” become the driving force in health care, thereby supplanting the “art” of diagnostic and therapeutic excellence. Paradoxically, if electronically derived information about patients becomes the prime focus of attention, the welfare of those same patients may actually become subsidiary to the welfare and integrity of the information itself—even though it is the patient’s information to begin with. Decision support and informatics will be an increasingly important means to good health care in the future, but their use and integrity should never be considered the goal of health care.

***Use of Online Health Resources:*** Rural areas have historically trailed urban regions in the use of computers and the Internet; however, this trend is changing. Malecki informs us that Internet access rates for rural households now approximate those of urban areas.<sup>13</sup> There is an expanding and seemingly limitless wealth of information now available to health care consumers everywhere, even in remote areas. However, individuals seeking online information are also often seeking advice, which makes patients vulnerable to misinformation in times of need. As a free society, anyone can publish and offer opinions on the Web, so judging the reliability of scientific and health-related Web sites becomes the responsibility of each individual user. Thus, online research becomes a very challenging—if not precarious—enterprise for those seeking health care. As health information becomes increasingly marketed, commercial influence will be unavoidable in determining what and how information is conveyed. Information may also express unilateral—and therefore biased—opinions of a particular group or organization. Online information of this

pedigree is potentially misleading, erroneous, or misinterpreted, and may lead to inappropriate and even harmful decision support for patients.<sup>14</sup>

The laudable incentive for online health information is to provide timely and easily accessible opportunities for patient education and decision support. In *Crossing the Quality Chasm*, the Institute of Medicine (IOM) proposed guidelines for developing an improved health care system.<sup>15</sup> The IOM recommended that health care systems and society improve patients' access to personal medical information and to clinical knowledge. This system they envision would be one in which patients would have unprecedented control of personal health information, and broad access to knowledge. Patients who are better informed will hopefully be encouraged by, and have improved communication with, their physicians and other providers. Evidence-based and reliable online resources, such as those offered by the National Library of Medicine through *MedLine Plus*, offer a tremendous boost to patient understanding. Resources like *MedLine Plus* are particularly effective when used in partnership with, and guided by, health care providers with whom the patient has a close, trusting relationship.

## CASE DISCUSSION

The following case analyses were interpreted using a method similar to that presented in Chapter 4.

### **CASE 14.1** | Privacy and consent issues when using telehealth in rural areas

It would be difficult and perhaps dangerous for Gina Conti to travel a long distance to see a dermatologist. She is thankful that specialty consultation and care can be obtained locally through telehealth. The process is a bit unnerving and uncomfortable for her, though, especially when she is instructed to disrobe on camera. Mrs. Conti also feels exposed due to the proximity of the telehealth room to the emergency waiting room. Most egregiously, Mrs. Conti is disturbed after discovering that other trainees were present with the dermatologist during the telehealth “virtual visit” and examination, about which she was neither notified nor asked to give permission. The ethics concerns involving telehealth are described in brief in Box 14.1.

**BOX 14.1****ETHICS CONCERNS IN THE USE OF TELEHEALTH**

- Lack of maintaining privacy and confidentiality
- Lack of adequate patient informed consent
- Inadequate disclosure of the possible presence of other clinicians or trainees
- Lack of informed consent for the presence of others, photos being taken and stored, biopsy, or scrapings, or telehealth intervention
- Potential loss of trust between patient and provider

Overall, Mrs. Conti is pleased to be able to see a dermatologist without having to travel a long distance, although she would have appreciated being fully informed about what to expect, including being asked for permission to have others present during the interview and examination. Mrs. Conti was also not told what would become of the photos taken of her skin lesion.

Unquestionably, Mrs. Conti has benefited medically by seeing a specialist via telehealth. But her primary care physician and the dermatologist conducting the telehealth visit should have been more forthcoming about how the visit would be conducted and who, given the patient's permission, would be present. The physical disconnect that occurs with telehealth visits also threatens to undermine clinical relationships and trust, if special attention is not given to the emotional, as well as physical, distance.

**CASE 14.2 | Availability of, and access to, electronic medical records (EMR)**

The irony in the scenario of the Electronic Medical Record is that one ethical requirement (confidentiality and respect for patient autonomy) impedes the ability to effectively respond to other ethical requirements in the care and safety of patients. In Case 2, it is very difficult for Dr. Adams to effectively treat the patient, Lars Danielson, because the doctor does not have access to important patient information from another

hospital. This case exemplifies the frustration that many rural physicians feel when decision-making for a returning patient is hampered by the inability to obtain records from a hospital or provider to which the patient had been referred. Patient harm could be avoided if contingencies were put in place to ensure that critical information is shared, especially when critically needed, such as in this case during an ER visit. Hospital systems and physicians have an obligation to ensure that mutual patient information is shared in a timely fashion—whether or not mutually compatible EMRs exist. Most rural hospitals and physicians don't have electronic systems; therefore, traditional means of communication will need to be used until compatible electronic records allow immediate access to medical information. It is difficult for physicians like Dr. Adams to prevent harm and promote patient autonomy and equitable treatment when information is restricted in this fashion.

This case scenario demonstrates an ethics problem that extends beyond the individual professional concern of two physicians to encompass a greater organizational issue. If health care systems are going to implement information systems like EMRs, and require physicians and staff to use them, as well as firewall them to ensure protection, then parallel mechanisms must be implemented to ensure that important information is made available in a timely fashion. Organizations should ensure that mechanisms are put in place that allow electronic information to be transmitted to referring physicians quickly and effectively. The *prima facie* nature of autonomy dictates that we do everything we can to prevent harm; in this case, by using a “firewall” system to ensure patient privacy and confidentiality. However, autonomy does not dictate that we demand privacy at all costs, if in doing so we compromise patient welfare and the physician's ability to do his or her job. Dr. Adams, the cardiologist, and their respective hospitals should establish policies and practices that communicate patient information in a way that is both secure and efficient, so that patients can receive the best possible care available from both facilities.



**CASE 14.3** | Using electronic clinical decision support systems

Rural citizens have a right to expect that their health care needs will be met with certain basic standards of care. Case 3 has a positive outcome on many levels<sup>16</sup> and reflects the potential for moral distress that remote health care providers often feel when trying to ensure access to equitable standards of care. Mr. Taft does well because Dr. Russell is able to meet his acuity needs using decision support technology, thus providing him with a higher standard of care than might normally have been available. More importantly, perhaps, are the warm feelings and renewed trust that Mr. Taft, and perhaps others in the community, now have for Dr. Russell, and the local hospital that employs her. The fact that Mr. Taft returns “well” to his job and community is due, in large part, to the superlative care that she has given him, which is reinforced by the decision support technology deployed by the hospital. Similar stories are playing throughout the world, where access to quality educational and clinical support is being provided electronically in rural and remote regions.<sup>17</sup>

**CASE 14.4** | Addressing patient use of online treatment and prescribing services

In Case 4, Gwen Thompson seeks online information, “cyber” advice, and treatment from a doctor she has never met, with whom she has no prior relationship, and who is later unavailable. This “*Cyberdoc*” has only a cursory working knowledge of her situation and, therefore, is unaware of potentially serious complications. Though prescribing guidelines for *CyberDocs.com* only permit giving a one-month prescription, this is enough to result in irreversible harm for Ms. Thompson. No face-to-face contact occurs between this doctor and patient; thus, *Cyberdoc* argues that no “duty” exists beyond a contractual relationship based solely on the buying and selling of goods (in this case, information and a prescription for medication). However, the unique nature of patient-clinician relationships requires accountability through shared trust, an awareness of vulnerability, and a fiduciary response to the patient’s needs—regardless of how or where the interaction occurred.<sup>18</sup> Therefore, the *Cyberdoc* is ethically responsible for Ms. Thompson’s treatment and the unfortunate resulting complications.

## RESPONDING TO HEALTH INFORMATION TECHNOLOGY ETHICS CONFLICTS

### CASE 14.1 | Privacy and consent issues when using telehealth in rural areas

Beware of the burden of technology. For patients who suffer from chronic conditions and those who reside in long-term care facilities, the perceived benefit of telehealth may be overshadowed by the foreign experience of videoconferencing. To speak to a doctor via video may be unpleasant or strange for older and chronically ill patients, further adding to their burden of illness. Patients may feel overwhelmed by the technology itself, or by the geographic and emotional distance that they sense between them and their provider when technology is used.<sup>19</sup> Medical staff members may pick up on the patient's discomfort, creating their own internal struggle. Gina Conti is uncomfortable with the situation she finds herself in and, though it isn't discussed directly in the case example, the nurse provider may also feel moral discomfort after witnessing Mrs. Conti's distress. Facilitating a discussion about these issues could provide guidance in resolving this case and similar cases in the future. Preparation for telehealth experiences might include some of the suggested tasks listed in Box 14.2.

### BOX 14.2

#### PREPARING FOR TELEHEALTH EXPERIENCES

- Educate nurses and physicians involved in telehealth and related activities about the importance of full disclosure and transparency, as well as what the clinicians may expect of the patient
- When patients become distressed, it is important to provide reassurance, and to further inform the patient and his or her family about the nature, benefits, and risks of the telehealth service being offered
- Patients have the right to refuse, and should be given the information necessary for informed decision-making, including any potential negative aspects of the telehealth experience

Many patients embrace new technologies, once they have become accustomed to them and encouraged by their use. Sometimes patients actually feel more satisfied and closer to their provider(s), knowing that they have more immediate access as a result of telehealth and other forms of HIT.<sup>20</sup> Therefore, at the first sign of discomfort or conflict, it is important for the provider to optimize communication, clarify the issues, and resolve misunderstandings. This requires time and availability. Often, a meeting of all stakeholders can be very helpful, including the patient, family, and care team members. A clinical ethics consultant may also be helpful to facilitate a discussion, including understanding the ethics questions related to HIT, what ethics concepts relate to those questions, what are the value perceptions from all stakeholders, and what possible means exist for conflict resolution.

In the case of Gina Conti, the discomfort and sense of exposure she feels during her tele-dermatology visit would likely be averted if the care team were to ensure a private environment, and effectively communicate with Mrs. Conti about what to expect during the telehealth visit. Improved communication would allow this patient to make a truly informed decision regarding whether or not to be seen via telehealth. The team also should be transparent about who, besides the dermatologist, would be participating. This could be accomplished by panning the consultant's room with the camera at the beginning of the video visit, and introducing all participants to the patient, while also asking permission for other trainees or clinicians to be there. Virtual visits can be as comfortable and satisfying as face-to-face visits, for all patients, including children, when special attention is given to issues of patient privacy, camera comfort, and specialist comfort.

#### **CASE 14.2** | Availability of, and access to, electronic medical records (EMR)

Case 2 presents a challenging situation because relatively few rural practices, only about one in five, have access to electronic medical record systems.<sup>21</sup> From both an ethical and professional standpoint, this case underscores the obligation of individual physicians and organizations to meet reasonable standards of care, by utilizing available technologies to ensure safe and equitable health care for all patients.

The operative word in this claim, however, is “available.” In this case Dr. Adams will likely be forced to be much more aggressive in the use of medical resources in treating Lars Danielson, unless outside hospital records are readily available at the time they are needed. Without the information from the cardiologist, Dr. Adams will no doubt treat Mr. Danielson aggressively, as if the other recent hospitalization had not occurred. Dr. Adams is obligated to provide optimal care in response to the information and technologies available. In the interest of good patient care, there is also an obligation to communicate with the referral hospital and to garner as much information as possible, but this will take time. In the meantime, Mr. Danielson must be treated.

The ethics challenge to meet modern standards of care in the use and transmission of health information should be addressed at the organizational level. Modern health care is informatics-driven, and electronic health records have been available in recent years to securely transmit patient data, both between physicians, and among different health care systems. These systems help to coordinate the care of patients with both acute and chronic conditions. Accurate, timely and secure information sharing is critically important for providers when the care of patients is shared between clinicians on different systems. In Box 14.3, three recommendations are offered regarding the implementation of electronic records to enhance care coordination.

### **BOX 14.3**

#### **ENHANCING CARE USING ELECTRONIC MEDICAL RECORDS (EMR)**

- Create a common health record to facilitate the exchange of clinical information among health providers
- Create regional governance structures to encourage the exchange of clinical data
- Initiate payment by purchasers of care, both public and private, to physicians for using electronic health records

To meet the electronic record challenge in future cases like that of Dr. Adams’ patient, Mr. Danielson, the medical staff and hospital leadership

in both the rural clinic and tertiary hospital should jointly advocate at the organizational and societal level to develop systems that will communicate information, both internally and between systems, when the care and treatment of patients is shared among institutions.<sup>22</sup> Individual physicians, systems, and society must work together to negotiate to make information accessible when and where it is needed. The logistical and ethical challenge of achieving standardization, so that electronic systems will talk to each other, is a major challenge. However, optimal communication and information sharing between providers for the welfare of patients is an ultimate and worthy goal if universal access to quality health care—and sustainability of that care—is to be attained.

### **CASE 14.3** | Using electronic clinical decision support systems

Case 3 demonstrates both clinical and organizational ethics concerns that relate to meeting new and evolving standards of care resulting from the availability of new technologies. Robert Taft experiences a good outcome, at least in part, because the remote clinic has access to computer-based decision support software that helps providers to make complex clinical decisions where specialty expertise is not available. The ethics challenge is one of ensuring equitable and safe health care that meets modern standards. It has been demonstrated that decision support systems can improve the quality of clinical decisions in the primary care setting.<sup>23</sup> However, the study's authors caution that considerable work is needed to ensure that the introduction of this technology is not detrimental to the quality of the relationship between the doctor and patient. They also advise that providers ensure that systems are adaptable to local needs and practices, and are acceptable to both physicians and patients. A careful analysis is needed in each health care system before introducing new technologies, to ensure that they are a good fit for all parties, including staff and patients who jointly will use them. New technologies should be introduced in a manner that ensures patient safety, through effective training and other quality assurance measures.

Happily, Case 3 has a good outcome, which results from the effective use of decision support technology. The physician makes the correct diagnosis, Mr. Taft does well and is happy with the outcome, and

thus no ethics conflict arises. This might not have been the result, however, had the technology not been available when it was needed and wanted, if it had failed to perform as designed, or if the physician had been ill-prepared or unwilling to use it. In each case the patient might have had a bad outcome, due to a delay in appropriate diagnosis and treatment. An ethical analysis of the case again demonstrates that a patient-centered approach, equitable access, and quality health care are necessary precursors for a successful implementation of this technology by providers and systems investing in it. Providers and health care organizations must advocate together to ensure that reasonable and equitable access to evidence-based technologies is made available to patients when need is demonstrated, patients are accepting, and providers are willing and able to use such technologies. Access, quality, and benefit are the defining variables, and should never be subjugated to the economic gain of the physician or the system in which the physician practices.

#### **CASE 14.4** | Addressing patient use of online treatment and prescribing services

The ethics concerns in Case 4 are clear. Gwen Thompson was harmed following inappropriate pharmaceutical treatment by a physician who did not know or examine her, but still responded by prescribing a medication. Because no face-to-face contact between the doctor and patient occurred, it could be argued that no professional duty exists. However, the professional relationship is implied by the fact that medical advice and treatment was requested, and the *Cyberdoc* agreed to provide it; thus the patient-physician relationship was formed. By responding to the call for help, a professional promise was made confluent with the professional oath that defines the practice of medicine. A similar argument of fiduciary responsibility can be made for on-call physicians who prescribe medications sight-unseen for patients of whom they know little; the professional responsibility for safety and quality does not abate after hours or on weekends. Overall, there was a failure in the fiduciary responsibility that physicians, by the nature of their healing profession, traditionally have for patients, by the nature of their vulnerability and need.

Physicians and health care systems play an important role in forewarning and educating patients about dangerous practices, and encouraging state law enforcement and regulatory officials to take action against physicians who engage in illegal and unethical online practices. The FDA also encourages physicians and patients to report potentially illegal Web sites to the FDA or to the National Association of Boards of Pharmacy.<sup>24</sup> Although patients and their families clearly have the right to seek other opinions, and pursue other treatment options beyond what is recommended, physicians still have an indirect responsibility to do all they can to protect their patients from undue harm. In Gwen Thompson's case, her primary physician would probably not be held culpable, from a legal or regulatory perspective, for the harm inflicted by the other doctor's cyber-prescribing. That said, the professional promise to "keep from harm" will always remind the physician to do all he or she can in the future to protect the patient and guide his or her care appropriately.

## **ANTICIPATING HEALTH INFORMATION TECHNOLOGY ETHICS CONCERNS**

Telehealth and other information technologies are still evolving; these technologies promise access and decision support in remote areas for primary care providers as well as specialists. Though health information technologies present unique and ethically challenging opportunities for both patients and clinicians, they tend to be expensive, and should be implemented in direct response to clear and appropriate needs. Health care systems and providers must be cautious against developing excessive reliance on information technologies, such that the traditional patient-clinician relationship is inadvertently weakened.<sup>25</sup> Providers and administrators must also guard against complacency regarding the risks and distractions that accompany the use of such technology. Entrepreneurism and technology-focused programs that grow within health care systems tend to distract from the primary goal of medicine, and may ultimately lead to cost-prohibitive health care for many patients, especially in rural areas.

When using health information technologies, we as providers must never sway from the moral precepts that underscore our obligations as health care professionals: to serve the patient's needs first (beneficence); prevent harm if at all possible (nonmaleficence); provide fair access



to reasonable forms of treatment and care (justice); and above all, to respect the patient’s right to make informed decisions about his or her health care—including the right to refuse or accept what is offered. Keeping these precepts in mind with each patient will help maintain a balanced and satisfying experience, although conflict is often unavoidable. Suggestions on some ways in which providers may prevent ethics conflicts related to health information technology are given in Box 14.4.

### **BOX 14.4**

#### **PREVENTING ETHICS CONFLICTS IN HEALTH INFORMATION TECHNOLOGY**

##### **Telehealth**

- | Respect privacy and confidentiality; ensure adequate informed consent

##### **Electronic Medical Records**

- | Ensure accuracy, accessibility and accountability by providers; seek information transferability between systems

##### **Electronic Clinical Support Systems**

- | Ensure access and reliability of decision support systems for local sites, with support from tertiary care sites when needed

##### **Online Health Care Resources**

- | Ensure accuracy and reliability of information being accessed; encourage careful scrutiny by those accessing such information

##### **Additional Protections**

- | Establish policies and procedures to ensure consistency, generalization, and quality; develop informational material for providers and patients; provide community-wide education on health information technology

### **Telehealth**

Telehealth will be a unique first-time experience for many patients. Therefore, it is important for clinicians to prepare patients in advance for the “talking head” interaction of videoconferencing. Ensuring

that providers who interact with the patient will respect privacy and confidentiality is also very important to the success of a telehealth experience, as shown in Gina Conti's case. Telehealth is a clinical intervention and, therefore, requires verbal or written informed consent from the patient, or his or her representative. There should also be an established hospital policy and procedure regarding the use of telehealth, including patient education materials that clearly describe what one should expect during a telehealth visit.

### **Electronic Medical Records**

Unfortunately, barriers to effectively using electronic medical records in rural areas will not be brought down soon. Individual health care systems will continue to deploy complex and separate firewalls for EMR systems that are inaccessible to outside providers who refer and share patients. Most rural physicians, and many rural hospitals, will not have electronic systems in the foreseeable future, unless such systems become more affordable, and also become standardized to allow critical information to be accessed when needed. Until such time, physicians like Dr. Adams and the cardiologist will need to take responsibility for communicating with each other directly and effectively, sharing important information, and ensuring that redundancy is minimized and safety optimized for their patient(s).

### **Electronic Decision Support**

Electronic decision support for rural physicians is of burgeoning importance and is increasingly available. By enhancing standards of care and implementing improved quality and patient-safety standards, providers and administrators will improve care and promote equitable outcomes everywhere, including in remote and rural outposts. The cautionary plea is for the provider not to rely too heavily on technology, or to allow a false sense of security to extend one's self beyond one's own abilities. Decision support interventions are designed to be just that—supportive. Knowledge, skill, experience, and wisdom are still the mainstay of clinical decision-making, but these important human tools can be enhanced by the amazing technologies now available. When electronic decision support tools are used wisely, as in the case of Mr. Taft, patients, clinicians, and the hospital all benefit.

## Online Health Information

Patients will continue to become increasingly computer-savvy and informed about health matters. They will continue to bring their physicians stacks of printouts and questions about information just pulled from the Internet regarding their health concerns. This behavior empowers patients to take personal responsibility, and physicians should support the process as an important component of their decision-making. But, in supporting patients, we must also partner with them by assessing what information is relevant and accurate, and by helping them use all forms of information technology wisely. Given the proper direction, patients might avoid the serious health complications that resulted in the case of Gwen Thompson. It is also very helpful to develop and distribute patient-education materials that enlighten patients about the use of online health care resources, distinguishing fact from fiction.

When advising patients about online health-information sources, consider the questions listed in Box 14.5 as a starting point for evaluating medical Web sites. These questions are found on the U.S. Department of Energy Human Genome Project's information Web site and are adapted from the U.S. Food and Drug Administration.

### BOX 14.5

#### QUESTIONS PATIENTS SHOULD ASK WHEN USING MEDICAL WEB SITES

- Who maintains the site?
- Is there an editorial board or listing of names and credentials of those responsible for preparing and reviewing the site's content?
- Does the site link to other reliable sources of medical information?
- Does the site provide references to reliable sources?
- When was the site last updated?
- Has the site been reviewed for mistakes in grammar or spelling?
- Are informative graphics and multimedia files such as video or audio clips available?

As consumers increasingly use the Internet to obtain information about health, it must be the responsibility of each individual user—whether professional, public or private—to check the accuracy, reliability, and overall trustworthiness of information given on health-related Web sites. The questions offered above provide a good starting point for evaluating medical Web sites, and their use should be encouraged, especially for patients who are inquisitive and computer-savvy.

## **CONCLUSION**

Access to health care in rural areas is a burgeoning concern, especially for the elderly.<sup>26</sup> Our society is responding to this intense need with telehealth and other technological means of decision support. The Federal Communications Commission (FCC) Chair announced a comprehensive proposal that would expand access to health care to rural and underserved communities through the creation of broadband telehealth networks in 42 states and three U.S. Territories.<sup>27</sup> This is a welcome initiative that, if successful, will provide relief to rural areas. More is needed at the state and local levels to ensure that reasonable health information technology interventions are deployed equitably and effectively to meet the health care needs of underserved areas.

In light of this evolution, health care providers and systems must never lose touch with their central purpose, which is driven not by information, science, or technology, but by the clinician's primary responsibility to protect the welfare of individual patients. The need for innovative technologies that can promote access to specialized health care services and enhance decision-making for the growing number of underserved in this country should and will continue to be of paramount concern in years to come. In particular, health care systems and providers who are committed to serving the needs of geographically isolated and otherwise disenfranchised persons in rural America should continue to seek innovative means to support rural health care.

When used ethically in the appropriate setting, health information technology can have a tremendously positive impact on the lives and welfare of patients. But it must be emphasized that information technologies, like any innovation, must be developed and implemented under the rubric of strict clinical and ethical standards to ensure safety

and quality. Therefore, the goal of health information technology should be to optimize the balance of risks and benefits to the patient, and to augment, but never replace, the skills, shared trust, comfort, and compassion manifested by the healing presence of physicians, nurses, and other health care providers.

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