© kentoh/Shutterstock

CHAPTER 2

Ethical Decision-Making Guidelines and Tools

Jacqueline J. Glover, PhD

Learning Objectives

After completing this chapter, the reader should be able to:

- Define ethics.
- Identify the importance of studying ethics for the health information management (HIM) professional.
- Identify ethical concepts, including relevant values, principles, virtues, approaches, and theories.
- Apply a process of ethical decision making to HIM scenarios.

Introduction

Ethics is the formal process of intentionally and critically analyzing, with clarity and consistency, the basis for one's moral judgments. It is important for HIM professionals to engage in this process, because they are accountable for their actions as professionals, not just personally as individuals. Ethical reasoning is necessary to resolve the potential tensions between personal values and professional values and among professional values. This chapter presents a model for ethical decision making and outlines ethical theories and approaches that can help HIM professionals identify ethical issues, work with other members of the team to identify and analyze choices, decide on a course of action, and justify that choice.

Scenario 2-A Decision Making for an Adolescent

MT is a 16-year-old young man with terminal brain cancer. At the age of 10 he was diagnosed with acute leukemia. After three years of intense treatment, MT was in remission. After two years of remission, during which he was doing very well in school and loved playing soccer, MT began having severe headaches. Unfortunately, his magnetic resonance imaging (MRI) scan showed a large mass requiring immediate workup. The tissue biopsy of the intracranial mass showed a uniformly fatal tumor, likely related to his previous leukemia treatment. No additional intervention was recommended by the team, and they wanted to refer him to hospice.

MT's parents had heard stories in the media about unprecedented recovery of children with terminal diagnoses. A national search of experimental protocols for brain tumors revealed two centers that were considering starting aggressive surgical approaches to this devastating diagnosis, but no active studies were open at this time. MT's parents were thinking about moving him to a different cancer center for another experimental treatment. A close friend of theirs had been successfully treated there after everyone else said nothing more could be done.

(*continued*)

MT's parents did not want him to know he was dying. They insisted on full code status. They forbid the nurses and resident physicians to tell him anything unless the parents were in the room, and they did not allow any conversation about his terminal condition and their recommendations.

When asked by staff, MT seemed to agree with his parents' decisions in the past. Recently, however, he began to initiate conversations with the night nurse on the rare occasions when his parents were not in his room. One night MT was particularly agitated and asked to speak to a favorite resident physician who happened to be on call and his nurse, and without his parents present. This was a surprising request from MT; his parents were very upset, but they complied and left the room. MT shared with the resident physician and the nurse that he just accessed his health information from the patient portal that he and his parents signed up for a long time ago, and was upset to learn the name of his new diagnosis, glioblastoma multiforme (GBM). Through an online search he discovered the extremely poor prognosis. He asked the resident physician directly, "Am I dying?" The nurse and resident physician had grown close to MT and wondered what they should do.

A completed ethical decision-making matrix for the scenario is provided at the end of the chapter.

What Is an Ethical Issue?

An **ethical issue** is one that involves the core values of practice. The case set forth in **Scenario 2-A** raises ethical issues in that the core values of respect for patient autonomy, truth telling, benefiting, not harming, and integrity are in conflict with the values of respect for family decision making and a different interpretation of what counts as a benefit or a harm. You know you have an ethical issue when such core values are at stake. Often, your emotions are the first to alert you that something may be wrong. Many people become upset when faced with the potential for not disclosing the truth or going against patient or family wishes.

Why Do Ethical Issues Need to Be Addressed?

Many people may want to answer questions of professional ethics according to their own personal morality. They may believe that the issue in Scenario 2-A can be easily resolved according to their own personal upbringing and beliefs. They think, "My parents taught me to always tell the truth," or "My parents taught me that family is important and you should listen to your parents." But is that type of thinking really sufficient? Notice that the two belief systems are in tension. How do you resolve the tension?

Resolving the tensions among values depends on the more formal mechanism of ethics. Personal morality and ethics differ. Most of the time, people do not distinguish between morality and ethics; they just use the words interchangeably. But when a distinction is made, it is often as follows: Morality refers to your own personal moral choices based on your upbringing, faith traditions, and experiences; ethics refers to the formal process of intentionally and critically analyzing the basis for your moral judgments for clarity and consistency. Because of the potential tension between personal values and professional values, and because of the potential for tensions among professional values, we need ethics to help resolve such tensions. Ethics provides a formal way to step back from the tension, search for reasons to support one choice over another, and apply this reasoning in future situations.

This process of stepping back to formally analyze values is important, because you are accountable for your actions as a professional, not just personally. Patients, other professionals, and the general public do not know about your personal moral values. But they do have expectations for your professional conduct. Standards arise from the trust that the public places in you. They expect you to be able to act professionally—even, or perhaps especially, when difficult ethical issues are involved. You have to uphold that trust, and, at the heart of it, that is why you must study ethics.

But You Can't Teach Ethics, Can You?

Two major objections are commonly given to the study of ethics. First, many people claim that their character is already formed, and that the study of ethics is not going to change their behavior if they are inclined not to do the right thing. Second, many people argue that there is no ethical content to teach. There is no knowledge of right and wrong that everyone accepts. Ethics is a matter of opinion, and everyone is entitled to his or her own opinion.

Regarding the first objection, the goal of a course in ethics is not to make you a good person. Rather, it is to enable you to make reliable moral judgments as a professional. Regarding the second argument, as professionals, we expect not just opinions, but judgments backed up by good reasoning. When making clinical judgments, healthcare professionals must offer support for their choices and be able to apply that reasoning in similar situations. The same is true when making moral judgments.

An ethics curriculum has three parts:

1. **Knowledge.** The HIM professional needs to be aware of standards of ethical conduct as expressed in the American Health Information Management Association (AHIMA) Code of Ethics and have knowledge of ethical principles and concepts.
2. **Development.** The moral maturity of the HIM professional needs to be modeled and nurtured. Even if someone's character is formed, it needs reinforcement and application in professional settings. The faculty is responsible for identifying core values and character traits of professionals. This means identifying and reinforcing praiseworthy behavior in practice and applying appropriate sanctions if good character and judgment are not guiding appropriate professional conduct.
3. **Skills.** HIM professionals need practice in identifying ethical issues and applying a process of ethical decision making to ethical issues that arise in the practice of HIM.

The Process of Ethical Decision Making

Various models for ethical decision making are available in the literature, but all share some basic components or steps (Purtilo, 2005; Lo, 2000; Benjamin & Curtis, 2010; Davis, Fowler, & Aroskar, 2010; Jonsen, Siegler, & Winslade, 2006). You should use an ethical decision-making process to ensure that you make reliable moral judgments in your professional practice. We will demonstrate the decision-making process by applying it to Scenario 2-A. See the end of the chapter for the complete matrix.

The first step of the ethical decision-making process is to ask, "What is the ethical question?" In Scenario 2-A, the ethical question is, "Should the nurse and the resident physician disclose MT's prognosis?" There is a second ethical question that will be discussed as Scenario 2-B further in this chapter, "What EMR access should be given to adolescents?" In identifying the ethical questions, the HIM professional needs to look for the "shoulds." These "shoulds" are the normative questions (i.e., what should or ought to happen according to norms or standards), as opposed to descriptive questions (i.e., what actually does happen).

However, the HIM professional needs to be aware of different kinds of "shoulds." For example, there are the clinical "shoulds": in this case, what treatments should be available to MT for his GBM according to evidence-based practice guidelines and the knowledge and judgment of clinicians? In Scenario 2-B, what flexibility should the current EMR platform have for differential access? Should it allow adolescents access to some information and their parents to different information? And at what age?

There also are the legal "shoulds" that help you identify the state and federal laws about what decisions adolescents are allowed to make legally (mature and emancipated minor statutes; decision making for birth control, pregnancy care, and abortion; treatment for sexually transmitted infections; substance use disorders and other mental illnesses) and federal and state rules for the confidentiality of certain information, even from parents (English, Bass, Boyle, Eshragh, 2010). Note that the law and ethics differ. First, ethics is more fundamental. We can always ask, from an ethical standpoint: "Is this a good law, or should I conscientiously disobey it or work to change the law?" Second, even though the law does have some moral content, it is a kind of minimum. Ethics strives to inspire the best professional behavior; the law demands only a decent minimum. Third, the law can be ambiguous. It is not always clear what the law actually says about a certain question, and the law is often not capable of subtle distinctions. Finally, the law does not address many of the issues that are important in ethics. For example, ethics is concerned not only with what you do, but also with the kind of person you are (virtue or character).

With regard to ethical decision making, we are concerned with the ethical "shoulds." These ethical "shoulds" relate to your duties and obligations as a professional. They involve choosing among the core professional values or between your obligations as a professional and your personal obligations, perhaps even to your family. A key distinguishing feature of the ethical "shoulds" is that they are concerned with the well-being of others and are not self-interested or self-directed.

The second step of the ethical decision-making process involves asking about your first reaction to the case: "What is my 'gut' reaction? What is my 'gut' telling me to do on an emotive level?" This step is essential if you are going to be able to identify your own values, assumptions, and biases, and then set them aside to critically analyze the situation. It also helps to notice when others have completely different reactions than you do. You may end up where you began—but not necessarily. The process will help you think more deeply, understand the perspective of others, and justify your final choice. Depending on your background and experiences, you may react by feeling that "of course the nurse and the resident physician need to tell MT the truth." Others may feel quite differently—"of course you would honor the family and their wish to not have MT told certain information." Where are you and why?

The third step is to gather the relevant facts—both the facts already known and the facts that you will need to gather if you are to determine a justified course of action.

In Scenario 2-A, the facts are as follows:

1. Known facts:
   - MT is 16 years old with a terminal brain cancer that was the result of the original treatment for his leukemia at age 10.
   - The team is recommending hospice care.
   - MT's parents do not want him to know about his diagnosis and prognosis and want to explore other experimental treatments. They have asked that the team not talk with MT without their presence.
   - The parents are insisting on full code status—meaning that in the event that he stops breathing or his heart stops beating, they want him to be resuscitated.
   - MT seemed to agree with their decisions in the past, but now he has started to initiate conversations with his night nurse about his condition.
   - MT and his parents signed up for access to a patient portal in the past.
   - MT has recently begun accessing information on his patient portal and has accessed his new diagnosis of GBM. He researched this diagnosis and learned about his poor prognosis.
   - MT has asked his parents to leave and has asked his nurse and resident physician if he is dying.
2. Facts to be gathered:
   - Why is MT asking this question now? What does he really want to know?
   - Why do MT's parents not want to discuss things with MT?
   - Are there other trusted family members who can be of assistance?
   - Is this a family of faith where a chaplain or other clergy could be of assistance?
   - Do the parents realize that MT is accessing information from the patient portal that they signed up for in the past?
   - What information is available on the patient portal?
   - What other experimental treatments are available?

- Is MT stable enough to be transferred?
- Does MT have capacity? Is the brain tumor affecting his capacity?
- What are MT's wishes?
- Would MT be willing to wait and talk with his parents?
- Are there other children in the family?
- What is the law about decision making by minors in your state? (English, Bass, Boyle, Eshragh, 2010)

It is always tempting to avoid a discussion of ethics by claiming that not enough facts are available to make a decision. Although facts are very important—good ethics begins with good facts—the discussion can proceed if you consider why you want to know something and how it will change your analysis. If certain facts are unclear, assume one set of facts for your analysis, and then change the facts to see if your analysis would change.

The fourth step of the ethical decision-making process is to ask, "What are the values at stake in this scenario?" You must consider the values from various perspectives. Who are the stakeholders? What is their perspective? A **stakeholder** is someone who will be affected by the decision to be made. The following stakeholders are relevant to Scenario 2-A:

- **The patient.** MT is 16 years old and seems to want to receive information about his status. Respect for his **autonomy** (self-rule) is a key value. It's his life and body, and decisions made will affect how he lives and how he dies. He may have particular ideas about what he thinks will benefit (**beneficence**) and what will harm him (**nonmaleficence**). He values being told the truth. He trusts his care providers. He seems to want **privacy** (a discussion without his parents) and perhaps **confidentiality** (information not shared with his parents). But he also loves and respects his parents.
- **The nurse and the resident physician.** The nurse and the resident physician have a special relationship with MT, and they value that relationship based on trust. They value benefiting MT and keeping him from harm. The quality of MT's life, not just the quantity of life, is important. They also value telling the truth and respecting MT's autonomy. They want to respect MT's privacy and perhaps his desire for confidentiality. But they also value family relationships, and their obligations to the rest of the healthcare team to provide only beneficial treatments. Their integrity is at stake if MT does not receive appropriate health care according to justifiable clinical judgments. The value of **justice** is also important in that resources could be expended on potentially nonbeneficial treatments that could be better allocated to access more beneficial treatments.
- **The parents.** The parents love MT and want him to live as long as possible. The value of prolonging life seems to be more important than the harms that could be associated with aggressive treatment at the end of life. They seem to want to protect MT from information that could be psychologically harmful. They value their role as decision makers (**family autonomy**) and do not seem to value MT's autonomy.
- **The HIM professional.** HIM professionals shares key professional values with other healthcare professionals. They value *truth telling*, respect for patient autonomy, patient well-being (beneficence), keeping patients from harm (nonmaleficence), and the appropriate allocation of healthcare resources (justice). The HIM professional also has particular values around *accuracy of information*, *transparency*, the *appropriate use* of the electronic medical records, and *appropriate access* through patient portals.
- **Other healthcare professionals.** Although the nurse and the resident physician are most directly affected by the ethical question in this scenario, other healthcare professionals are members of the team and are also involved. They include the attending physician, other consultants, other nurses, the pharmacist, the social worker, and the chaplain. MT is probably well known to this oncology team since his first illness and now this relapse. The whole team will be affected by the decisions made. They all share the values of truth telling, respect for patient autonomy,

patient well-being (beneficence), keeping patients from harm (nonmaleficence), and the appropriate allocation of healthcare resources (justice). They also value working well together as a team to provide the best care for MT and his family.
- **Hospital administrators.** Hospital administrators have an obligation to promote the welfare of patients (beneficence) and keep them from harm (nonmaleficence). As healthcare professionals, they also have an obligation to tell the truth. Administrators value **patient- and family-centered care,** and patient portals are a way to enhance their involvement in their care and respect their autonomy. They also value adolescents as independent decision makers and have granted them access to the patient portal. They value patient privacy and confidentiality, even in the complex situation of adolescents. Just like the patient and family, the hospital administrators also have an interest in controlling healthcare costs and increasing access to health care. The value of *justice as fairness* is also involved.
- **Society.** Society values good care, truth telling, privacy, confidentiality, and patient- and family-centered care that enhances respect for autonomy. Some people would argue that everyone in society who pays for health care also has an interest in seeing that healthcare costs are controlled. Also, everyone is obligated to promote the just or fair allocation of healthcare resources.

The fifth step of the ethical decision-making process is to ask, “What are the options in this case?” Specifically, what could the nurse and resident physician do in this scenario? They could (1) tell MT what they understand about his condition, (2) tell MT to ask his parents, or (3) tell MT that they will discuss this with him with his parents present.

The sixth step of the ethical decision-making process is to ask, “What should I do?” “What do I think is the best option based on the core values of the stakeholders?” Of the three options listed in the fifth step, 1 and 3 are justified (to answer his question), and 2 (not answer his question and tell him to ask his parents) is not justified.

The seventh step of the ethical decision-making process is to ask, “What justifies this choice?” Provide reasons to support your decision based on the values at stake. Anticipate objections and respond to them. The decision to answer MT’s question about whether he is dying—either immediately without his parents or as soon as you can get his parents to join you—is based on the key value of respect for patient autonomy. The nurse and resident have a special relationship with MT, and he trusts them to tell him the truth and to help him. They want to honor his desire for privacy and perhaps for confidentiality as well. Of course, the information should be delivered in a compassionate and skilled way (Kaplan, 2010). Perhaps starting with these types of questions would help to frame your approach. Why do you ask this question now? What do you really want to know? Do you want to talk about it with just us, or do you want us to get your parents? To answer his question is the most respectful and truthful action. MT has been living with cancer for a long time, and he is familiar with the disease and his experience of it. He may be seeking some degree of control over his situation, and contrary to his parents’ belief, the information might help him manage his anxiety and will be helpful, not harmful. At 16, he most likely has the mental capacity to understand his diagnosis and prognosis—depending on his maturity and the possible effects of the brain tumor. The presumption is that adolescents should be involved in their healthcare decision making to the extent that they are capable and desire to be involved (Committee on Bioethics, 1995). Not informing him of what is going on will not change his diagnosis or prognosis. He needs help to prepare for his impending death, and so do his parents. Remember that MT loves his parents and they love him. They will live with his death and dying in a way the healthcare providers will not. Be careful that you do not alienate his family just when MT needs them the most.

But what about the other values, like respect for family decision making and for their interpretation of what is beneficial and harmful for MT? They love him and want to protect him. Why not leave it to the parents to answer MT's questions? They have been the most involved, and they have the most at stake after MT. One response is that to not answer his question would be to deny the unique obligation you have to MT as his healthcare professional. Taking care of the family is important, but MT is your patient and he is asking you a direct question. Leaving it to his family is to risk continued nondisclosure and taking part in this "deception." MT is asking for some privacy and perhaps for confidentiality as well. You can satisfy your obligations to both MT and his parents in carefully planning how to tell. Caring for adolescent patients can be very challenging for healthcare professionals. They have ethical obligations to involve adolescents in decision making in the absence of clear legal support or even contradictory support, especially when it comes to obligations of privacy and confidentiality from parents (Blythe & Del Beccaro, 2012). Institutions share in the obligation to respect adolescents as decision makers and to construct electronic medical records (EMR) systems and patient portals that reflect core healthcare professional values. Institutions should be mindful of legal requirements, but also work to enhance ethical conduct even in the face of tensions. As a professional, you are responsible for your own behavior, and professional standards should be the basis of the values of healthcare institutions, not contrary to them (Griffith, 1993; Worthley, 1997).

The eighth and final step of the ethical decision-making process is to ask, "How could this ethical problem have been prevented?" Are there any systemic changes that could be made to prevent this problem from happening again? If you are thinking that the answer is to make sure that adolescents do not have access to information on a patient portal, read Scenario 2-B and the discussion of the ethical issues involved in the access of adolescents to patient portals and the EMR. Regarding Scenario 2-A, the first suggestion would be to work with this family from the beginning about the role of MT in decisions about his care. For his first cancer treatment he was only 10, and the role of his parents was quite different. Now that he is 16 and desiring more information and more voice, the role of his parents should be different. It should be made clear that the presumption is that adolescents are involved in their decisions to the extent that they have the capacity and the desire to be involved. It should also be made clear that the healthcare team will help the family with difficult disclosures and conversations. Although the team will try to work with the family around the timing and content of information, the family should understand that the healthcare team will not lie to their patient and will answer his questions honestly when asked.

Refer to Appendix 2-A for a blank copy of the ethical decision-making matrix. A completed ethical decision-making matrix for Scenario 2-A and Scenario 2-B are included at the end of this chapter.

Justification in Ethical Reasoning: How Do You Know What Is Best?

The most difficult aspect of ethics is deciding on the best course of action and providing good reasons to support your choice. There is usually not just one right answer; rather, there is a range of morally acceptable options, with some options being better or worse than others. Some answers are even outside the range of moral acceptability; these should not be chosen.

But how do we know which choices are better or worse? How do you justify your actions? Ethical standards depend on the systematic application of key ethical concepts. Judgments of "better" and "worse" are based on a combination of applying key ethical concepts and your past reflection and experience.

This process of ethical reasoning is very complex. We do not just memorize a few ethical theories and then apply them to problems that arise. What is a theory, anyway? Rather than being a kind of special "truth" about the moral life that we can learn and simply apply, ethical theories are organizing structures that help us to identify important language and key concepts and provide for systematic reflection and dialogue (Steinbock, London, & Arras, 2013).

Classic Ethical Theories

Two major types of ethical theories are commonly discussed in the literature: utilitarian and deontological theories (Steinbock, London, & Arras, 2013; Beauchamp, 1982).

Utilitarianism

The philosophers Jeremy Bentham (1748–1832) and John Stuart Mill (1806–1873) are credited with the theory of **utilitarianism**. This theory states that actions are right to the extent that they tend to promote happiness and wrong to the extent that they tend to promote the reverse of happiness (Steinbock, London, & Arras, 2013; Beauchamp, 1982). It is a consequentialist theory in that it judges the rightness and wrongness of an action by its consequences; that is, what will happen if the action is or is not performed. One advantage of this theory is its simplicity. Only one thing needs to be considered—happiness.

Based on this theory, happiness is measurable and comparable. Some objections to this theory are that happiness is not the greatest good, that it is impossible to calculate the probable consequences of every action, and that utilitarianism conflicts with some of our basic moral intuitions (basic ideas that we have been taught). For example, slaves have a claim to be free even if others benefit from continued slavery.

Deontological Theory

Deontological theory is based on the calculation of duties (the Greek word for *duty* is "deon") rather than consequences. Immanuel Kant (1724–1804) is a famous deontological moral theorist (Kant, 1964). If you want to know if a proposed action is morally acceptable, the right question is not "What are the consequences?" but rather "Can I, as a rational person, consistently will that everyone in a similar situation should act the same way?" It is a type of universal golden-rule analysis. However, it is not based on individual idiosyncrasies. Rather than "Do unto others as you would have them do unto you," it is really "Do unto others as you would have anyone do unto anyone/everyone else." Another way to put the question is, "By acting this way, am I treating other people as ends in themselves (as people like me with goals and preferences), and not merely as means to my own ends or goals?"

One advantage of deontological theory is that it supports common moral intuitions about the absolute value of persons and not only the instrumental value. Disadvantages include an inability to decide among duties when they conflict and the inability to take some consideration of consequences when they seem to be particularly important. For example, it seems important to break a promise if it is necessary to save someone from severe harm.

Many people analyze the appropriateness of actions according to theology; that is, their particular beliefs about God (*theos*) and their religious traditions. When asked about a certain course of action, they turn to sacred texts that reveal standards of behavior established by God. In our pluralistic society, in which people have different religious beliefs or none at all, it is difficult to base ethical reasoning on appeals to God's word. However, most major religious traditions support the same kinds of ethical concepts, such as principles, values, and virtues that are involved in philosophical ethical inquiry. Furthermore, the discussion is enhanced by the rich reflection that is a part of most theological ethics.

Applying Multiple Theories

Philosophers develop and stress ethical theories in their search for an ordered set of ethical standards that can be used to assess what is right and wrong in certain circumstances. In recent years, many philosophers have come to doubt that there can be only one correct theory. They believe that it is a mistake to view the various theories as mutually exclusive claims to moral truth. Steinbock, London, and Arras (2013) suggest that "instead, we should view them as important but partial contributions to a comprehensive, although necessarily fragmented, moral vision" (p. 9).

Ethical theories can be useful if we do not ask them to do too much. They cannot provide us with certain truth, but they can guide and direct our moral reasoning as we strive to make reliable moral judgments. For example, in Scenario 2-A, a utilitarian would examine the consequences. What would happen if we answered MT's question honestly? If we brought his parents into the discussion? On the first level, perhaps MT would be relieved to know the truth about what he is facing—or he could be more upset. The information would be out in the open for everyone to deal with. He would be supported in the dying process. His parents could be very upset thinking that now they have to deal with this conversation in a way that they wished to avoid. On a higher level, the consequences of routinely not involving adolescents in decisions when they have capacity and want to be involved could be that they do not trust healthcare professionals and do not seek care when they need it.

A deontological theorist would analyze the duties involved. These would include the duty to tell the truth and to involve patients who have capacity and want to be involved in their decision making. You could not rationally will that all adolescents be excluded from decision making. Adolescents would be treated only as children and not as decision makers who have values and goals that should be respected.

Current Ethical Approaches

Discussions of current healthcare ethics draw not only on the classic ethical theories just discussed, but also on several more current approaches.

Analysis of Principles

Analysis of principles is best exemplified in Beauchamp and Childress's *Principles of Biomedical Ethics* (2012). In this work, the authors identify four core ethical principles: respect for autonomy (self-determination), nonmaleficence (not harming), beneficence (promoting good), and justice (fairness). These principles can be very helpful in understanding ethical issues in professional practice and in drafting policies regarding ethical issues. They are not nearly as helpful in clinical applications, where principles may conflict. This approach has also been criticized for its strong reliance on rules and duties and on dealing with patients and others as strangers. It has been characterized as abstract, impartial, and detached.

A principle-based analysis of Scenario 2-A would include the principles of beneficence (promoting good by helping to relieve his anxiety) and nonmaleficence (avoiding possible harms that follow from hearing the truth). The principle of respect for autonomy would require that we involve MT in decisions. Ultimately, he is the one to determine what would be beneficial and harmful—not his parents and not the healthcare team. The principle of justice supports following the rules that apply equally to all—involve adolescents who have capacity and want to be involved. Or distributive justice would require us to pay attention to whether the resources for potentially nonbeneficial treatment are best allocated for more beneficial treatments. Additionally, some would argue that it is more important to avoid harm than it is to promote good—but that depends on who ultimately determines benefit and harm. Notice that two of the principles (beneficence and nonmaleficence) involve consequences and that the other two (respect for autonomy and justice) involve duties. One medical ethicist argues that duty-based principles always should be respected before consequence-based ones (Veatch, 1981).

Analysis of Rights

Much moral discussion, especially in the United States, uses the language of rights (Dworkin, 1977). A *right* is an especially powerful moral claim that others are obligated to respect. In the United States, we speak of such basic human rights as life, liberty (freedom), and the pursuit of happiness. In healthcare ethics, scholars debate a right to die, a right to life, and a right to health care. One advantage of rights-based approaches is that they are fairly simple to apply. There are few basic rights, and they are particularly important; therefore, they automatically trump other moral considerations. However, one disadvantage is that people disagree as to which claims are basic human rights and on what basis they are determined to be so. Another disadvantage is that rights language tends to polarize debate, with one party asserting a certain right (to choice) and the other party asserting an opposing right (to life). If a right is a justified claim about what one person owes another, it may be more fruitful just to analyze the basis for the obligation in the first place. What does it add to our analysis to claim that MT has a basic human right to decide about his treatment?

Ethics of Care

Proponents of this approach to "doing ethics" emphasize the importance of focusing on the patient and the professional in the context of his or her relationships (Gilligan, 1982; Holmes & Purdy, 1992). An **ethics of care** considers emotional commitment and a willingness of individuals in relationships to act unselfishly for the benefit of others. More than a principle-based approach, an ethics-of-care approach values sympathy, compassion, fidelity, discernment, and love. An ethics of care does not use rights language the way a principle-based approach would. The origins of the ethics-of-care approach are predominantly in theology and in some feminist writings (Larrabee, 1993; Kittay & Meyers, 1987). Although an ethics-of-care approach provides a correction to the too-abstract approach of principle-based ethics, its weaknesses include the lack of a well-developed basis for providing justification for courses of action.

An ethics of care would approach Scenario 2-A by exploring the consequences of the action on the relationships between the parties involved: between the healthcare team and MT; between MT and his parents; between the healthcare team and his parents; and among the healthcare team itself. What action best supports and nurtures these important relationships? Honesty and truth telling are important aspects of any relationship. Compassion in the fact of difficult conversations and choices is also critical. An ethics of care seems well suited to the analysis of not only what you should do, but how you should go about doing it.

Virtue-Based Ethics

Closely associated with an ethics of care is a **virtue-based ethics** that emphasizes the agents who perform actions and make choices (MacIntyre, 1981). A *virtue* is a habit of behaving in a good way. With this approach, one would ask, "What would a good HIM professional do?" This approach examines feelings, motivations, and duties. It examines not only actions, but the individual's character as well. For example, a good HIM professional should have attitudes of respectfulness, honesty, integrity, courage, compassion, and fairness. A virtuous HIM professional's actions flow from his or her character and attitudes. The HIM professional is in the habit of behaving correctly. Critics of the virtue-based approach note that sometimes virtue is not enough. People of good character who act virtuously can sometimes perform wrong actions.

A virtue-based analysis of Scenario 2-A would ask about the character of the healthcare professionals involved. What does it say about the nurse's and the resident physician's character if they are willing to avoid answering a direct question from a patient? It could mean that they have great compassion for the parents and want to preserve this important relationship. But it could also indicate a lack of courage to take on difficult and important issues and advocate for patients.

The Bioethicist's Toolbox

We have reviewed two classic ethical theories and four current approaches to healthcare ethics, outlining the advantages and disadvantages of each and applying them to Scenario 2-A. They also apply to Scenario 2-B. It should be obvious that no one theory or approach is adequate. But do we simply pick and choose which theories and approaches to use depending on the case? How do we build a clearly reasoned argument to justify our actions?

Eric Juengst (1999) has developed a "bioethicist's toolbox," which we describe here. These tools are very useful for illustrating how we "do ethics" in clinical situations—how we analyze a problem and build a moral justification. Rather than choosing just one **ethical theory** or approach, aspects of each can be combined in the following ways:

1. Hammers (most powerful):
    - Appeals to shared moral maxims (rules): "Honesty is the best policy."
    - Appeals to shared moral principles: "We should promote respect for autonomy by including adolescents in decision making when they have capacity and a desire to be involved."

  - Appeals to shared traditions: "HIM professionals have a rich history and tradition of promoting patient autonomy and preserving the accuracy and integrity of the medical record."
  - Appeals to nonmoral goals: "The primary purpose of the medical record (continuity of care for the patient) can be enhanced by accessing patient portals.
2. Clamps:
  - Arguments from precedent: "HIM professionals have promoted appropriate access to patient records by patients themselves."
  - Argument by analogy: "MT could have confidential information about care for a sexually transmitted infection or a substance abuse problem. How is information about the seriousness of his cancer different from this information?"
  - Arguments from paradigm cases: "HIM professionals have been taught about appropriate access to patient portals. Not answering MT's questions is like not granting him access to the patient portal—doing one without the other doesn't make sense."
  - Transcendental arguments: "All reasonable people would agree that we should answer MT's question directly if they had all the facts."
3. Wedges:
  - Exposing consequences: "Not honestly answering MT's question will undermine the trust patients have in their physicians to tell the truth and walk with them through difficult choices."
  - Exposing implications: "A rationale to justify not answering MT's question could justify other deception with direct harm to the patient."
  - Exposing inconsistencies: "Not answering MT's question is inconsistent with his access to information in the patient portal."
  - Exposing biases: "Picking some information that adolescents should have access to over other information could be based on a bias about the capacities of adolescents and a judgment about the morality of some behaviors (i.e., sexually transmitted infections/abortions/substance use disorders)."
4. Duct tape (not very powerful or persuasive):
  - Negotiating compromises: "Only this one time."
  - Appealing to procedure: "How about voting on it?"
  - Passing the buck: "Let the boss decide."
5. Chewing gum (least powerful or persuasive):
  - Moral introspection: "That's just the way I feel about it."
  - Moral hand-wringing: "This is just awful, and it's just not right."

Juengst, E. (1999). The bioethicist's toolbox. Centerviews: The Newsletter of the Center for Bioethics at Case Western Reserve University 10, 5–6.

Two additional comments about justification are necessary. First, what if you have been reading along and you disagree with my analysis of the cases and the development of the arguments supporting the choice to answer MT's question honestly? This disagreement is not a bad thing. It can improve both of our ethical reasoning skills. You must point out exactly where you disagree with me and tell me why. Disagreement is a necessary part of moral analysis. Confronting counterarguments and responding to them makes an argument stronger. As part of your analysis, you should always make the strongest argument possible for the other choice and then show why your original argument is stronger. If it is not, you should change your mind. What makes an argument stronger? A good argument (1) is based on good information; (2) is supported by respect for the most values, duties, or virtues or by the least infringement of key values, duties, or virtues; or (3) is supported by respect for the most important values, duties, or virtues of the HIM profession and other healthcare professionals on the team.

It is important to identify possible sources of disagreement. People can disagree about each of the steps in the ethical decision-making process. They can disagree about the facts, the values involved, or the application of ethical reasoning. The last type of disagreement is the most difficult to resolve. Resolution requires the skills of respectful attention, patience, and open inquiry.

Although a comprehensive and clear process of ethical reasoning usually results in consensus, deep disagreement can still exist. Your responsibility is to be thorough and clear-thinking, challenging assumptions, figuring out where disagreements lie, and striving to resolve them. But disagreement is a part of the moral life. People do hold markedly different values, and conscientious objection (withdrawing from participation in a certain situation because of personal moral beliefs) is an essential ethical concept. We must help build moral consensus when possible and respect moral freedom when it is not.

Moral Distress

Sometimes in professional practice, the ethical issue is not only what the right thing to do is, but also how to do it, given the practice environment. This type of ethical issue has been labeled *moral distress* (Jameton, 1984). For example, consider the following scenario.

Scenario 2-B Access by Adolescents to Patient Portals

Your institution has been working on developing a patient portal for your EMR. You are a member of the task force along with several other HIM professionals. The question of what access adolescents should have comes up for discussion. It is a challenging question ethically and technically. Privacy and confidentiality concerns related to EMRs are already difficult, and "the typical adolescent patient can experience confidentiality issues at virtually every step of the process" (Anoshiravani, Gaskin, Groshek, Kuelbs, & Longhurst, 2012, p. 409). But after careful consideration, your task force recommends a system permitting full access only to the 13- to 17-year-old adolescents, with parents able to receive only nonconfidential information. This approach requires actively blocking access to certain information by parents and requires vigilance and ongoing effort to maintain. Full parental access would be permitted for unusual or complicated situations (e.g., intellectual disability or cancer) ideally customized with input from the adolescent (Society for Adolescent Health and Medicine, 2014). You are working closely with your vendor to make this happen. Partway through the process, word comes down from the administration that work is to stop on this development and no access will be granted to any adolescent patients—only adult patients 18 and over. When asked for a justification, the administration cites legal concerns. They believe that if they cannot guarantee that no breaches in confidentiality will occur with a complex system, then they should not take any chances and therefore deny all access. They announce that this decision is final. You and your colleagues are deeply disturbed by this recent pronouncement. You wonder what you should do.

A completed ethical decision-making matrix for the scenario is provided at the end of the chapter.

In addition to the complex ethical issues involved in determining what access adolescents should have (see Appendix 2-A for an analysis of the ethical issues in Scenario 2-B), (Hollis, 2015, Tegen, 2014) there is an additional moral burden associated with not being able to address the ethical concerns openly and collegially. HIM and other healthcare professionals sometimes believe that by pushing back at what they view as unacceptable practices, they will suffer consequences, such as unsatisfactory reviews, a demotion, or even job loss. This problem is particularly distressing in rural practice, where job opportunities may be severely limited. It takes great moral courage to step up to the challenge of changing institutional culture and practice. Several practical suggestions follow:

- Talk with trusted colleagues and get advice. Be sure to approach problems through the proper channels and document your efforts. Confirm discussions with administration by sending memos or letters summarizing meetings. Frame issues for the institution in terms of shared values, using the professional standards articulated in the AHIMA Code of Ethics (AHIMA, 2011; Griffith, 1993).

- Appeal to professional sources that are locally available. Many healthcare organizations have institutional mechanisms, such as organizational ethics committees or compliance officers.
- Make integrity issues part of your job selection in the first place.

Ethics Resources

HIM professionals facing ethical issues in their practice have three main sources of help. Professionals can look in the literature for information about current ethical problems and their resolution. They can also talk with their professional colleagues about the AHIMA Code of Ethics (2011) and its implications in practice. This dialogue should be both with HIM professionals and with colleagues from other professions. Professional meetings also can be a helpful source of ethical dialogue.

As discussed earlier, ethics resources also are available in individual healthcare organizations, including patient care ethics committees. The Joint Commission (TJC) includes standards that require an "ethics mechanism" to help patients, families, and staff address ethical issues in clinical care. HIM professionals can bring issues to the institutional ethics committees for discussion and resolution. It is also helpful to have HIM professionals on ethics committees. Ethics committees are multidisciplinary committees trained in ethical concepts and analysis that help patients, families, and staff address ethical issues. They also educate the staff about ethical issues and write policies that address institutional practices.

TJC also requires consideration of the ethical issues that arise in the business practices of healthcare organizations. These standards have prompted healthcare organizations to develop organizational ethics committees in addition to patient care ethics committees (Worthley, 1999).

Conclusion

It is important for HIM professionals to be able to identify ethical issues and know how to apply the ethical decision-making process to ethical issues that arise in practice and in the development of healthcare policy. Awareness of ethical theories and approaches can be helpful in understanding why some courses of action are better than others. The goal of the study of ethics is to enable HIM professionals to make reliable moral judgments, and thereby uphold the public's trust in the HIM profession.

KEY TERMS

Analysis of principles
Analysis of rights
Autonomy
Beneficence
Confidentiality
Deontological theories
Ethical issue
Ethical theory
Ethics
Ethics of care
Family Autonomy
Family-centered care
Justice
Nonmaleficence
Patient-centered care
Privacy
Stakeholder
Utilitarianism
Virtue-based ethics

CHAPTER SUMMARY

- Ethics is the formal process of intentionally and critically analyzing, with clarity and consistency, the basis of one's moral judgments. It is important for HIM professionals to engage in this process, because they are accountable for their actions as professionals, not just personally.
- Ethics is necessary to resolve potential tensions between personal values and professional values and among professional values. It provides a formal way to step back from a conflict, search for reasons to support one choice over another, and apply this reasoning in future situations.

- The ethical decision-making process presented in this text has the following steps: (1) identify the ethical question, (2) determine your gut reaction, (3) determine the facts in the case, (4) determine what values are at stake from the perspectives of all stakeholders, (5) identify the available options in the case, (6) determine what you should do, (7) justify your choice, and (8) explore how this ethical problem might have been prevented.
- Two classic theories of ethics are utilitarianism and deontological theory. A utilitarian approach considers the consequences of an action (or failure to take action) in terms of how the action promotes happiness. A deontological approach considers whether it is one's duty to perform or not perform an action. For HIM professionals, such duties would include professional duties, including duties to the public being served and duties to one's employer or client.
- One current approach to ethics is principle-based analysis. Beauchamp and Childress (2012) have identified four core principles of biomedical ethics: respect for autonomy (self-determination), nonmaleficence (not harming), beneficence (promoting good), and justice (fairness).
- Other current approaches are **analysis of rights** based on consideration of whether an action affirms or violates basic human rights, an ethics of care based on what action best supports the relationships of the parties involved, and a virtue-based ethics that emphasizes how the action expresses and shapes the character of the person who performs it.
- The "bioethicist's toolbox" is a collection of ethical approaches that an HIM professional can draw upon to analyze issues with the rest of the healthcare team and determine a justified course of action. According to this classification, the most powerful arguments are appeals to shared moral rules, shared moral principles, shared traditions, and nonmoral goals.
- When confronted with an ethical dilemma, the HIM professional should (1) talk with trusted colleagues and get advice, (2) approach the problem through the proper channels and document his or her efforts, (3) frame issues for the institution in terms of shared values and the AHIMA Code of Ethics, (4) appeal to professional sources as necessary, and (5) address the issue in some way rather than letting it go on unaddressed.

REFERENCES

American Health Information Management Association [AHIMA]. (2011). *AHIMA code of ethics*. Chicago, IL: Author.

Anoshiravani, A., Gaskin, G. L., Groshek, M. R., Kuelbs, C., & Longhurst, C. A. (2012). Special requirements for electronic medical records in adolescent medicine. *Journal of Adolescent Health Care, 51,* 409–414.

Beauchamp, T. (1982). *Philosophical ethics: An introduction to moral philosophy*. New York, NY: McGraw-Hill.

Beauchamp, T., & Childress, J. (2012). *Principles of biomedical ethics* (7th ed.). New York, NY: Oxford University Press.

Benjamin, M., & Curtis, J. (2010). *Ethics in nursing: Cases, principles, and reasoning* (4th ed.). New York, NY: Oxford University Press.

Blythe, M. J., & Del Beccaro, M. A. (2012). Standards for health information technology to ensure adolescent privacy. *Pediatrics, 130,* 987–990.

Committee on Bioethics, American Academy of Pediatrics. (1995). Informed consent, assent and permission in pediatrics. *Pediatrics, 95*(2), 314–317.

Davis, A. J., Fowler, M. D. M., & Aroskar, M. (2010). *Ethical dilemmas and nursing practice.* Boston, MA: Pearson.

Dworkin, R. (1977). *Taking rights seriously.* Cambridge, MA: Harvard University Press.

English, A., Bass, L., Boyle, A. D., Eshragh, F. (2010). *State minor consent laws: A summary* (3rd ed.). Chapel Hill, NC: Center for Adolescent Health and the Law.

Gilligan, C. (1982). *In a different voice: Psychological theory and women's moral development.* Cambridge, MA: Harvard University Press.

Griffith, J. (1993). *The moral challenges of health care management.* Chicago, IL: Health Administration Press.

Hollis, K. (2015). Protecting Adolescent Confidentiality in EHRs, The Journal of AHIMA.

Holmes, H., & Purdy, L. (Eds.). (1992). *Feminist perspectives in medical ethics.* Bloomington, IN: Indiana University Press.

Jameton, A. (1984). *Nursing practice: The ethical issues.* Upper Saddle River, NJ: Prentice Hall.

Jonsen, A. R., Siegler, M., & Winslade, J. (2006). *Clinical ethics: A practical approach to ethical decisions in clinical medicine* (6th ed.). New York, NY: McGraw-Hill.

Juengst, E. (1999). The bioethicist's toolbox. *Centerviews: The Newsletter of the Center for Bioethics at Case Western Reserve University, 10,* 5–6.

Kant, I. (1964). *Groundwork of the metaphysic of morals.* Translated by H. J. Paton. New York, NY: Harper & Row.

Kaplan, M. (2010). SPIKES: A framework for breaking bad news to patients with cancer. *Clinical Journal of Oncology Nursing, 14*(4), 514–516.

Kittay, E., & Meyers, D. (Eds.). (1987). *Women and moral theory.* Savage, MD: Rowman & Littlefield.

Larrabee, M. (Ed.). (1993). *An ethic of care: Feminist and interdisciplinary perspectives.* New York, NY: Routledge.

Lo, B. (2000). *Resolving ethical dilemmas: A guide for clinicians* (2nd ed.). Baltimore, MD: Lippincott, William & Wilkins.

MacIntyre, A. (1981). *After virtue: A study in moral theory.* Notre Dame, IN: University of Notre Dame Press.

Purtilo, R. (2005). *Ethical dimensions in the health professions* (4th ed.). Philadelphia, PA: W. B. Saunders.

Society for Adolescent Health and Medicine. (2014). Recommendations for electronic health record use for delivery of adolescent health care. *Journal of Adolescent Health, 54*, 487–490.

Steinbock, B., London, A., & Arras, J. (2013). *Ethical issues in modern medicine: Contemporary readings in bioethics.* New York, NY: McGraw-Hill.

Tegen, A. (2014), Interview by Mary Butler about protecting adolescents in EHRs. The Journal of AHIMA.

Veatch, R. (1981). *A theory of medical ethics.* New York, NY: Basic Books.

Worthley, J. (1997). *The ethics of the ordinary in healthcare: Concepts and cases.* Chicago, IL: Health Administration Press.

Worthley, J. (1999). *Organizational ethics in the compliance context.* Chicago, IL: Health Administration Press.

Blank Ethical Decision-Making Matrix

Steps	**Information**	
1. What is the question?		
2. What is my "gut" reaction?	What is your first reaction to this case on an emotional level? What assumptions are you making? What biases do you have?	
3. What are the facts?	**KNOWN**	**TO BE GATHERED**
4. What are the values? Examine the shared and competing values, obligations, and interests of the many stakeholders in order to fully understand the complexity of the ethical problem(s). STAKEHOLDERS Patient, family, HIM professional(s), healthcare professional(s), administrators, society, and others appropriate to the issue.	**Patient:** **HIM Professional(s):** **Healthcare professional(s):** **Administrators:** **Society:** **Others as appropriate:**	
5. What are my options?		
6. What should I do?		
7. What justifies my choice?	**JUSTIFIED**	**NOT JUSTIFIED**
8. How can I prevent this problem?		

The ethical decision-making matrix is a tool to help you organize complex ethical problems; however, there is no simple fill-in-the-box approach to ethical decision making. The objective is to follow each step of the process and not move from the question directly to what should be done or how to prevent it next time. If you skip steps, you will not fully understand all of the values and options for action. Also, the matrix provided for each scenario is not the only way to examine the problem. You can make an equally compelling ethical argument for a different decision—just be sure to follow all the steps of the matrix.

Ethical Decision-Making Matrices

SCENARIO 2-A Decision Making for an Adolescent

Steps	**Information**	
1. What is the question?	Should the nurse and the resident physician disclose MT's prognosis?	
2. What is my 'gut' reaction?	What is your first reaction to this case on an emotional level? What assumptions are you making? What biases do you have? I have two reactions that are very different. My parents taught me to always tell the truth and they taught me that family is important and I should listen to my parents. Tell the truth to MT or listen to his parents?	
3. What are the facts?	**KNOWN** ■ MT is 16 years old with a terminal brain cancer that was the result of the original treatment for his leukemia at age 10. ■ The team is recommending hospice care. ■ MT's parents don't want him to know about his diagnosis and prognosis and want to explore other experimental treatments. They have asked that the team not talk with MT without their presence. ■ The parents are insisting on full code status – meaning that in the event that he stops breathing or his heart stops beating, they want him to be resuscitated. ■ MT seemed to agree with their decisions in the past but now he has started to initiate conversations with his night nurse about his condition. ■ MT and his parents signed up for access to a patient portal in the past. ■ MT has recently begun accessing information on his patient portal and has accessed his new diagnosis of GBM. He conducted an Internet search on this diagnosis and learned about his poor prognosis. ■ MT has asked his parents to leave and has asked his nurse and resident physician if he is dying.	**TO BE GATHERED** ■ Why is MT asking this question now? What does he really want to know? ■ Why do MT's parents not want to discuss things with MT? ■ Are there other trusted family members who can be of assistance? ■ Is this a family of faith where a chaplain or other clergy could be of assistance? ■ Do the parents realize that MT is accessing information from the patient portal that they signed up for in the past? ■ What information is available on the patient portal? ■ What other experimental treatments are available? ■ Is MT stable enough to be transferred? ■ Does MT have capacity? Is the brain tumor affecting his capacity? ■ What are MT's wishes? ■ Would MT be willing to wait and talk with his parents? ■ Are there other children in the family?
4. What are the values? Examine the shared and competing values, obligations, and interests of the many stakeholders in order to fully understand the complexity of the ethical problem(s).	**The patient:** MT is 16 years old and seems to want to receive information about his status. Respect for his autonomy (self-rule) is a key value. It's his life and body and decisions made will affect how he lives and how he dies. He may have particular ideas about what he thinks will benefit (beneficence) and what will harm him (nonmaleficence). He values being told the truth. He trusts his care providers. He seems to want privacy (a discussion without his parents) and perhaps confidentiality (information not shared with his parents). But he also loves and respects his parents. **The nurse and the resident physician:** The nurse and the resident physician have a special relationship with MT and they value that relationship based on trust. They value benefitting MT and keeping him from harm. The quality of MTs life, not just the quantity of life is important. They also value telling the truth and respecting MT's autonomy. They want to respect MTs privacy and perhaps his desire for confidentiality.	

(*continued*)

SCENARIO 2-A Decision Making for an Adolescent (*continued*)

STAKEHOLDERS Patient, family, HIM professional(s), healthcare professional(s), administrators, society, and others appropriate to the issue .	But they also value family relationships, and their obligations to the rest of the healthcare team to provide only beneficial treatments. Their integrity is at stake if MT does not receive appropriate healthcare according to justifiable clinical judgments. The value of justice is also important in that resources could be expended on potentially non-beneficial treatments that could be better allocated to access more beneficial treatments. **The parents:**. The parents love MT and want him to live as long as possible. The value of prolonging life seems to be more important than the harms that could be associated with aggressive treatment at the end of life. They seem to want to protect MT from information that could be psychologically harmful. They value their role as decision makers (family autonomy) and do not seem to value MTs autonomy. **The HIM professional(s):** The HIM professional shares key professional values with other healthcare professionals. They value truth telling, respect for patient autonomy, patient well-being (beneficence), keeping patients from harm (nonmaleficence) and the appropriate allocation of healthcare resources (justice). The HIM professional also has particular values around accuracy of information, transparency, the appropriate use of the electronic medical records and appropriate access through patient portals. **Other healthcare professional(s):** Although the nurse and the resident physician are most directly affected by the ethical question in this scenario, other healthcare professionals are members of the team and are also involved. They include the attending physician, other consultants, other nurses, the pharmacist, the social worker, and the chaplain. MT is probably well-known to this oncology team since his first illness and now this relapse. The whole team will be affected by the decisions made. They all share the values of truth telling, respect for patient autonomy, patient well-being (beneficence), keeping patients from harm (nonmaleficence) and the appropriate allocation of healthcare resources (justice). They also value working well together as a team to provide the best care for MT and his family. **Hospital administrato(s):** Hospital administrators have an obligation to promote the welfare of patients (beneficence) and keep them from harm (nonmaleficence). As healthcare professionals, they also have an obligation to tell the truth. Administrators value patient and family-centered care and patient portals are a way to enhance their involvement in their care and respect their autonomy. They also value adolescents as independent decision makers and have granted them access to the patient portal. They value patient privacy and confidentiality, even in the complex situation of adolescents. Just like the patient and family, the hospital administrators also have an interest in controlling healthcare costs and increasing access to healthcare. The value of justice as fairness is also involved. **Society:** Society values good care, truth-telling, privacy, confidentiality, and patient and family centered care that enhances respect for autonomy. Some people would argue that everyone in society who pays for health care has an interest in seeing that healthcare costs are controlled. Also, everyone is obligated to promote the just or fair allocation of healthcare resources.	
5. What are my options?	What could the nurse and resident physician do in this scenario? They could (1) tell MT what they understand about his condition, (2) tell MT to ask his parents, or (3) tell MT that they will discuss this with him with his parents present.	
6. What should I do?	Answer MT's questions	
7. What justifies my choice?	**JUSTIFIED** The decision to answer MTs question about whether he is dying - either immediately without his parents or as soon as you can get his parents to join you - is based on the key value of respect for patient autonomy. The nurse and resident have a special relationship with MT and he trusts them to tell him the truth and to help him.	**NOT JUSTIFIED** Don't answer MT's question and tell him to ask his parents

SCENARIO 2-A Decision Making for an Adolescent (*continued*)

	They want to honor his desire for privacy and perhaps for confidentiality as well. Of course, the information should be delivered in a compassionate and skilled way. To answer his question is the most respectful and truthful action. MT has been living with cancer for a long time and he is familiar with the disease and his experience of it. He may be seeking some degree of control over his situation, and contrary to his parents' belief, the information might help him manage his anxiety and will be helpful, not harmful. At 16, he most likely has the mental capacity to understand his diagnosis and prognosis – depending on his maturity and the possible effects of the brain tumor. The presumption is that adolescents should be involved in their health care decision making to the extent that they are capable and desire to be involved. Not informing him of what is going on will not change his diagnosis or prognosis. He needs help to prepare for his impending death, and so do his parents. Remember that MT loves his parents and they love him. They will live with his death and dying in a way the health care providers will not. Be careful that you do not alienate his family just when MT needs them the most. But what about the other values like respect for family decision making and for their interpretation of what is beneficial and harmful for MT. They love him and want to protect him. Why not leave it to the parents to answer MT's questions? They have been the most involved and they have the most at stake after MT. One response is that to not answer his question would be to deny the unique obligation you have to MT as his health care professional. Taking care of the family is important, but MT is your patient and he is asking you a direct question. Leaving it to his family is to risk continued nondisclosure and your part in this "deception." MT is asking for some privacy and perhaps for confidentiality as well. You can satisfy your obligations to both MT and his parents in carefully planning how to tell.	
8. How can I prevent this problem?	Work with this family from the beginning about the role of MT in decisions about his care. For his first cancer treatment he was only 10 and the role of his parents was quite different. Now that he is 16 and desiring more information and more voice, the role of his parents should be different. It should be made clear that the presumption is that adolescents are involved in their decisions to the extent that they have the capacity and the desire to be involved. It should also be made clear that the healthcare team will help the family with difficult disclosures and conversations. Although the team will try to work with the family around the timing and content of information, the family should understand that the healthcare team will not lie to their patient and will answer his questions honestly when asked.	

The ethical decision-making matrix is a tool to help you organize complex ethical problems; however, there is no simple fill-in-the-box approach to ethical decision making. The objective is to follow each step of the process and not move from the question directly to what should be done or how to prevent it next time. If you skip steps, you will not fully understand all of the values and options for action. Also, the matrix provided for each scenario is not the only way to examine the problem. You can make an equally compelling ethical argument for a different decision—just be sure to follow all the steps of the matrix.

SCENARIO 2-B Access by Adolescents to Patient Portals

Steps	**Information**	
1. What is the question?	Should adolescents have access to patient portals? At what age should adolescents have access? What access should they have and what access should their parents have?	
2. What is my 'gut' reaction?	What is your first reaction to this case on an emotional level? What assumptions are you making? What biases do you have? A gut reaction can be very variable. It could be something like - "of course adolescents should have independent access since the assumption is that they can consent to some procedures without their parents and they deserve the same considerations as other patients. I have experienced disrespect as an adolescent patient and my bias would be to allow access" – to "of course adolescents should not have access with the assumption that their parents are paying and they would find out from the processing of insurance claims anyway. I have experience with adolescents not being as mature as they think they are and my bias is to involve their parents."	
3. What are the facts?	**KNOWN** ▪ Your institution is developing a patient portal for your EMR. ▪ You are a member of the task force with several other HIM professionals. ▪ The question of access for adolescents is raised. ▪ This question is very challenging ethically and technically. ▪ In all 50 U.S. states, testing and treatment for sexually transmitted infections are protected by law as confidential in most situations. (Position paper, The Society for Adolescent Health and Medicine, 2014) ▪ In certain states adolescents can consent to other testing and treatment without their parents, including treatment for alcohol and other drug use disorders and other mental illnesses, and contraception and treatment for pregnancy. Adolescent parents are responsible for treatment decisions regarding their children. (English A, Bass L, Boyle AD et al, 2010) ▪ There are federal requirements for confidentiality tied to certain funding sources. (English A, Bass L, Boyle AD et al, 2010) ▪ There is a growing literature on the potential benefits of EMR use for children and adolescents. (Position paper, The Society for Adolescent Health and Medicine, 2014) ▪ Various HealthCare Policy organizations support the confidential treatment of adolescents and the use of patient portals by	**TO BE GATHERED** ▪ Does your EMR vendor have a product that has robust, flexible, granular privacy settings? ▪ How confident are they that confidentiality/privacy breeches can be avoided? ▪ What was your organization's policy and procedures regarding adolescent consent and treatment *before* you switched to an EMR? ▪ Does your organization have a past history of confidentiality/privacy breeches?

SCENARIO 2-B Access by Adolescents to Patient Portals (*continued*)

	adolescents. (Position paper, The Society for Adolescent Health and Medicine, 2014) ■ EMR vendors are not necessarily prepared with products that meet regulatory requirements (privacy and confidentiality for patients including adolescents) and have robust, flexible, granular privacy settings (Anoshiravani A et al, 2012)	■ What is your organization's policy and procedures regarding patient portals? What is their experience?
4. What are the values? Examine the shared and competing values, obligations, and interests of the many stakeholders in order to fully understand the complexity of the ethical problem(s). STAKEHOLDERS Patient, family, HIM professional(s), healthcare professional(s), administrators, society, and others appropriate to the issue.	**Adolescent patients:** Patients value respect for their autonomous health care decisions; respect for their privacy and confidentiality; getting testing and treatment that will promote their well-being (beneficence); avoiding harms that can follow from not seeking testing and treatment for fear of stigma and negative consequences if people found out (nonmaleficence); being treated fairly (not being discriminated against because of their age and having fair access to health care resources); compassionate treatment; fidelity to promises made to provide respectful treatment with attention to privacy and confidentiality; trust in health care professionals and family members; family relationships **Their parents/guardians:** It can be assumed that most parents love their children and feel deeply responsible for their lives and well-being. They value the well-being of their children and access to healthcare that promotes their children's best interests (beneficence); they want to keep their children from harm whether physical or psychological (nonmaleficence); they value themselves as decision makers for their children; they may or may not value their adolescent children as decision makers for themselves; they may value fair access to information if they are the ones paying for healthcare services (justice); they value gaining and maintaining the trust of their children; and they value keeping their promises to care for their children (fidelity). They also value honesty and truth telling. **Healthcare professional(s) including HIM professional(s):** All health care professionals have a commitment to respect their patients' autonomy to the extent that patients have decision making capacity; this includes adolescent patients, too. They also share a commitment to benefit their patients (beneficence) and keep them from harm (nonmaleficence). They all value honesty and truth telling and treating people fairly (justice as non-discrimination and fair access to health care resources.) Professionals value a trusting relationship with patients and families and also keeping promises (fidelity). They also value respecting privacy and confidentiality. The HIM professional code of ethics is particularly strong on the values of privacy and confidentiality and using the expertise of HIM professionals to make sure systems are developed and utilized that support these values. All health care professionals also value respect for each other and working collaboratively as a team. **The institution:** Health care institutions value providing the highest quality of care for patients and their families (beneficence and nonmaleficence). Most hospitals have policies that support patient-centered care and also family-centered care. They also value respecting patients, whether this is respecting their autonomous decisions, their privacy or their confidentiality. Health care institutions want a trusting relationship with their health care professionals and with patients and their families. They value health care professionals working collaboratively with each other to provide the highest quality, safest and most cost-effective care. Health care institutions value accurate and accessible health information, for the best health care for patients, for accurate quality improvement measures, and for accurate billing. Health care institutions also value their reputation in the community and following state and federal regulations and laws. **Society:** Society values high quality, safe, patient-centered and cost-effective care that is provided by trust-worthy health care professionals and health care institutions. Societal laws and policies support the independent decision making by adolescents in an effort to support public health. If adolescents could not receive confidential testing and treatment for sexually transmitted infections, contraception and pregnancy, drug and alcohol use disorders, and other mental illnesses, not only	

(*continued*)

SCENARIO 2-B Access by Adolescents to Patient Portals (*continued*)

	would their health suffer, but the health of the public could be at risk as well. Society also values the fair treatment of patients, whether in the form of non-discrimination or fair access to affordable health care. **Value Tensions:** All stakeholders share the values of wanting to promote the well-being of adolescents and keep them from harm. The tensions arise in determining who best to define well-being, the adolescent? Family? Healthcare professionals? There is also a tension between respect for the adolescent as a decision maker or the family as a decision maker and between access to health information and helping to insure privacy and confidentiality.	
5. What are my options?	1. Allow only adults (by age – over 18) on the patient portal. 2. Allow adolescents (between ages 13 and 17) on the portal with permission from their parents who have access. 3. Allow adolescents (between ages 13 and 17) on the portal with access given to parents of only non-confidential information or with permission from adolescents.	
6. What should I do?	Option #1 would not afford adolescents the benefit of patient portals, especially in areas in which they are the primary decision makers and not their parents (sexually transmitted infections, contraception, pregnancy, drug and alcohol use, other mental illnesses) and should not be chosen. Option #2 seems to allow adolescents access, but only with the permission of their parents, which also denies the benefits of patient portals and involves considerable breaches of privacy/confidentiality and should not be chosen. Option #3 should be chosen because it affords the most access to adolescent patients and also the most control of what their parents have access to.	
7. What justifies my hoice?	**JUSTIFIED** To deny adolescents access to patient portals is to deny the benefits of them to patients based simply on age, which could be a violation of the principles of respect, beneficence and justice. Our society has determined through laws and public health policies that adolescents should be able to decide about their own healthcare in certain important ways and an EMR could be an important part of improving that care. Key adolescent health care organizations support such access. (Position paper, The Society for Adolescent Health and Medicine, 2014) But all stakeholders are concerned to respect privacy and confidentiality and to minimize the harms that follow from possible breaches (nonmaleficence). It would be important to make sure that the EMR vendor would be able to provide a product with reasonable assurances that breaches could be avoided or at least minimized to an acceptable level. The commitment of the institution should be to grant access, using a vendor that is able to provide this. To go forward knowingly with a product that could not provide the necessary access and protections would be to violate all the associated values of the stakeholders. Another other possible concern is for the families who, in many instances, are paying and who would like to be involved in the decision making. And in so far as the decisions are sensitive, like end of life decisions, one can see the power of their claim to control information.	**NOT JUSTIFIED** Deny adolescent access to patient portal. Go forward with a product that cannot provide access and protections

SCENARIO 2-B Access by Adolescents to Patient Portals (*continued*)

	Adolescents may have some adult capacities, but they are not adults yet. Many would argue that adolescents need the involvement of their families, especially at such critical decision points as pregnancy, parenthood and end of life. But this important claim does not require either extreme – no access for adolescents or no access for families. The values of respect for autonomy, beneficence, nonmaleficence, justice, trusting family and healthcare relationships could be supported by a policy that allowed adolescents to determine through careful dialogue, what access their families should have.	
8. How can I prevent this problem?	The testing, treatment and documentation of care for adolescents waschallenging even before EMR and patient portals. This ethical issue could not have been prevented. It will take the intentional and dedicated efforts of healthcare professionals including HIM professionals working diligently with EMR vendors to create systems that can support the privacy and confidentiality needs of all patients, including particularly adolescents.	

The ethical decision-making matrix is a tool to help you organize complex ethical problems; however, there is no simple fill-in-the-box approach to ethical decision making. The objective is to follow each step of the process and not move from the question directly to what should be done or how to prevent it next time. If you skip steps, you will not fully understand all of the values and options for action. Also, the matrix provided for each scenario is not the only way to examine the problem. You can make an equally compelling ethical argument for a different decision—just be sure to follow all the steps of the matrix.