



Autonomy

He alone is free who lives with free consent under the guidance of reason.

—Spinoza

Points to Ponder

1. What are the key issues for the healthcare administrator (HCA) with respect to informed consent?
2. How does HIPAA change the way you view confidentiality?
3. Is it ever appropriate to withhold the truth from a patient?
4. What is the significance of fidelity to the success of HCAs?

Words to Remember

The following is a list of key words for this chapter. You will find them in bold in the text. Stop and check your understanding of them.

authorization

disclosure

informed consent

veracity

competence

fidelity

reasonable person standard

voluntariness

■ INTRODUCTION AND DEFINITIONS

Autonomy is one of the four major principles of healthcare ethics that are derived from the theories you studied in Chapter 1. In this chapter, you will explore the meaning of this principle and its application to healthcare practice. Current concepts of autonomy stem from its Greek definition as self-rule and self-determination (Beauchamp &

Childress, 2008). The healthcare system's position on this principle is supported by Kant, Frankl, and others who believe that because people have unconditional worth and should be given respect, they also deserve self-determination.

To be applied, the principle of autonomy must assume that you are free from the control of others and have the capacity to make your own life choices. You also must have the right to hold views that are incongruent with those of the healthcare establishment. For example, if you are a Jehovah's Witness and do not believe in blood transfusions, you have the right to refuse such treatment even when your physician recommends it. The word "choice" is a key element in this principle. How does this relate to your position in health care? As an administrator, you must understand that people should be free to choose whether to be compliant with their physician's instructions or not. They must also be able to make informed decisions about signing consent forms for surgery or other procedures without undue influence or punitive repercussions from medical staff. You will learn more about the complexities of autonomy as informed consent later in the chapter.

Autonomy is more than just making informed choices. It is also concerned with how individuals are viewed and treated within the healthcare system. If autonomy is an ethical principle for your organization, then certain standards should prevail. In this chapter, you will explore some of these standards including autonomy as confidentiality. You will also examine how the Health Insurance Portability and Accountability Act of 1996 (Title II) (HIPAA) rules have increased the awareness of the need to protect this area. Autonomy as truth-telling is also included in this chapter; you will learn what telling the truth means in healthcare situations. Finally, you will explore autonomy as expressed as fidelity and learn what it means to keep your word to patients and employees. A summary will be included to reinforce the key concepts of the chapter. You will then be able to apply your knowledge of this principle to two cases that are based on real-world healthcare incidents.

■ AUTONOMY AS INFORMED CONSENT

Legal and ethical considerations come together when applied in the area of **informed consent** for treatment. Through case law and legislation, informed consent has come to be seen as the duty of physicians or their designees to obtain the patient's permission for treatment. This permission should be given only after the patient understands the treatment and supports its implementation. Failure to obtain permission can constitute negligence or even lead to medical malpractice actions. From a larger view, informed consent is an ethical issue because it requires

respect for the autonomy of individuals and their right to choose what is done to their bodies.

Autonomous consent is implied through a person's actions. For example, if you make an appointment with your dentist and keep that appointment, it is implied that you consent to treatment. However, if a procedure must be used that is not routine, then there is an ethical (and often legal) duty to obtain specific written consent.

What is meant by informed consent? Beauchamp and Childress (2008) present a model that clarifies this term and serves as a basis for discussion. This type of permission to treat contains the preconditions of **competence** on the part of the patient to understand the treatment, and **voluntariness** in his or her decision-making. It also requires disclosure on the part of the physician of material information including the recommended treatment plan. Finally, consent means that the patient is in favor of the plan and gives his or her **authorization** to proceed.

The idea of competence is not a simple one in health care. In general, it is assumed that adults are competent to make decisions about their health but that children are not. However, adults can be in situations where they are not deemed competent. This includes incidents when they are unconscious, mentally ill, or under the influence of drugs. There are exceptions to the child rule, too. Children can be deemed competent when they are legally emancipated from their parents. In these nonroutine circumstances, healthcare professionals can need additional guidance about informed consent, and the physician's responsibilities through policies, procedures, and training programs that are provided by the institution in which they practice.

Voluntariness means that the person is not under the influence or control of another person when making a decision. This means that he or she is not threatened or forced into treatment. While this sounds bizarre, there are occasions when patients can think they are being forced into treatment by healthcare professionals or other parties. In even more rare occurrences, the patients are actually threatened to undergo treatment by physicians presenting dire consequences if they do not. Whether the situation is actual or perceived, these patients do not freely choose to participate in the treatment. The use of threats or the perception of a threat means that an autonomous decision by the patient is not possible.

Similarly, if a healthcare professional tries to manipulate a person into consenting to treatment, this negates autonomy. For example, suppose a researcher needs a certain number of subjects in order to maintain funding for his study. This researcher finds a suitable subject and promises him or her that there are benefits for participation in the study. The subject then signs a consent form, without knowledge of the researcher's true agenda. This manipulation of study information is unethical and removes the voluntary element from the process of informed decision-making.

Disclosure is a major element in both legal and ethical aspects of informed consent. It can appear to be a very simple thing to disclose information about a patient's condition, the methods of treatment, and alternatives for that treatment. However, this does not always happen. Many states now require what is called a **reasonable person standard** with respect to what should be disclosed in order to obtain consent. This means that there is an obligation to present enough information so that a "reasonable person" would be able to make an informed decision about the procedure. Adhering to this guideline poses some ethical issues, particularly in sophisticated and often expensive research studies. If a researcher is too zealous in making statements about the anticipated benefits versus the risks of the study, the subjects might choose not to participate. This could lead to expensive searches for subjects or even a loss of funding for the research.

In order for patients to make an informed decision about their healthcare options, a recommendation must be made by the health professional. Recommendations must include all of the options available for the patient and the practitioner's best assessment of the best choice. Even this part of informed consent is not without difficulty. For example, there are alternative treatments, such as the use of herbs or holistic medicine, that have proven to be effective but are not approved by the Food and Drug Administration or fully recognized by the medical community. If the physician does not support the use of such forms of treatment, he or she might not present these options to the patient. Another complexity of disclosure occurs in the case of managed care. The physician's recommendation cannot be based solely on the covered treatments in the plan. The patient should be informed of the costs of other existing treatments so he or she can decide if he or she is able to pay for them if the treatments are not covered by his or her health maintenance organization.

Making efforts to ensure the patient understands the disclosures and the treatment plan is an ethics obligation if you are seeking informed consent. News about a medical condition and required treatment can evoke an emotional response on the part of the patient that affects his or her ability to make sound decisions. Therefore, requiring a signed consent too soon after such news might not be appropriate action. Ignoring the patient's human reaction to his or her state has the risk of obtaining uninformed consent. However, delaying consent too long can impede treatment and potentially cause a negative outcome.

Achieving understanding also requires comprehension of what is being presented. This is a challenge because consent forms are often full of legal and medical jargon and are written at a college reading level. Because the average reading level of Americans is between sixth and eighth grade, a true understanding of such forms might not be possible. Again, HCAs have the responsibility to put policies, procedures, and

forms in place that encourage understanding as a way to meet the competence aspect of autonomous consent. Checking the readability of such forms and having qualified personnel available to answer any questions is both good business and good ethics.

Finally, you must consider the patient's decision to implement the plan and the appropriate authorization. This final step can require the use of additional personnel to verify that the patient fully understands the form and the procedures described therein when he or she gives consent to proceed. Even though nonphysician personnel are used during the process of obtaining informed consent, ultimately, the responsibility for this consent lies with the physician. Therefore, he or she must be willing to verify informed consent with the patient.

As you can see from the discussion, the issue of autonomy as informed consent is a complex one for the healthcare system. It is important for you, as an administrator, to know your level of responsibility for ensuring that forms used to gain consent are understood, questions are addressed, and procedures are followed during this process. You also might be required to maintain proof of consent in various formats and to ensure that this proof is kept confidential and secure. You must also keep up to date on any changes in the HIPAA laws and maintain compliance with these changes.

■ AUTONOMY AS CONFIDENTIALITY

Autonomy is also practiced when information about a person's identity, family, health status, and treatment procedures is kept private. This aspect of autonomy also extends to information that you know about employees and their families. As an HCA, you have many duties when it comes to confidentiality, some of which extend into the legal realm because of the HIPAA laws.

When patients enter the healthcare system, what is their expectation of confidentiality? Most believe that they have a right to privacy or to have control over access to their physical bodies, their health information, and their decisions. When patients choose to surrender some of their privacy, they expect that what they say or what is done to them will be kept confidential (Beauchamp & Childress, 2008). This expectation goes all the way back to the time of Hippocrates when physicians were cautioned not to disclose what was said to them in confidence.

Is there absolute confidentiality in health care settings? The truth is that it can often be necessary to share private information about patients to treat their conditions. Nurses, physical therapists, radiation technicians, and many others might need access to a patient's information in order to treat him or her appropriately. HIPAA allows types of communication with those involved in the patient's care and even family and

friends under certain conditions. However, patient consent or agreement is required and professional judgment is required in specific cases (Office for Civil Rights, 2008). Only those who have a legitimate need to know the information should have access to the patient's medical record. Safeguards need to be in place to ensure that medical information is protected from access by those who do not have a need to know.

On the surface, this sounds straightforward, but safeguarding confidentiality in today's healthcare system is not as simple as a locked file cabinet. With the advent of the electronic record, the risk of inappropriate access to confidential information has greatly increased. This is part of the reason for the enactment of certain provisions of HIPAA. These provisions standardize the electronic record and provide safeguards for confidentiality. While none of these policies is foolproof, they demonstrate that efforts are being made to protect confidentiality.

There are additional problems involved in safeguarding confidentiality beyond those surrounding electronic records. Within the structural procedures at a hospital or clinic, there are practices that can automatically threaten the patient's confidentiality. For example, before HIPAA, it was customary to post patients' names and procedures on a white board outside of outpatient surgery. While this might have been standard procedure and convenient for the staff, it could be devastating for patients when they realized that anyone who saw that board knew their impending procedures. If this action were to occur today, it would be a violation of HIPAA. What about discussing the patient's medical condition when he or she is in a semiprivate room? Only a curtain separates the patient from the other occupant of the room, so confidentiality is not protected. Every effort needs to be made to ensure that confidentiality is respected, but it can be difficult to accomplish.

Actions in the informal organization that can threaten confidentiality can be even more subtle. If your staff is not trained on how to manage patient information effectively, discussions about interesting cases can occur in the hallways, elevators, break room, or the cafeteria. Such conversations, while not intended to do harm, can be overheard by anyone, including the patient's family. It is your responsibility as an administrator to reduce the likelihood of such staff actions through appropriate policies, procedures, and training. In addition, you can conduct informal observations to evaluate how such training is being utilized; this has often been called "management by walking around."

Patient confidentiality is not an absolute even with appropriate practices and procedures in place. There are occasions when the law or ethical practice makes such action necessary. Legally mandated exceptions to confidentiality include such things as reporting certain diseases, traumatic events such as gunshot wounds, and incidents of child abuse. In the case of mental health providers, there is a duty to warn others if a client threatens to be violent. This position is supported by

the utilitarian theory that you have studied; it is based on the consequences of keeping that confidence versus the benefits of breaching it.

Other issues of confidentiality pose even more complex ethical challenges. For example, should employers have a right to your medical records? If so, can they use what they find in them to avoid hiring you if you have an expensive pre-existing condition that will drive up their insurance costs? What if you are diagnosed with a genetic condition that could affect the health of your family members? Should the physician tell your relatives even if you do not want it discussed with them? These questions are just a few examples of how complicated confidentiality can be when considered in its full ethical context. The decision of a patient to withhold information from his or her family can create some true dilemmas for the practitioner and the organization. As an administrator, you have to understand that such decisions are not always black and white. An ethics committee (to be discussed in Chapter 10) can assist you with determining appropriate action in these cases.

There is another area to consider with respect to confidentiality. This concept goes beyond the realm of patient care. Depending on your position in the health facility, perhaps you have access to very private information about your employees and their families. It is imperative that you recognize the need to maintain confidentiality with this information and not to share it with those who have no need to know. Because you are in a position of authority, violation of employee confidentiality might not only be a breach of trust, but might also cause you to lose your job. Therefore, it is vital for you to be aware of the need to keep private information private.

■ AUTONOMY AS TRUTH-TELLING

Should you always tell the truth? Kant includes truth-telling as meeting the categorical imperative. The truth should be given to everyone. Beauchamp and Childress (2008) consider it one of the obligations of health care. “Society cherishes truth telling because it is the glue of human community. . . .” (Boyle, Dubose, Ellingson, Guinn, & McCurdy, 2001, p. 14). Can you imagine trying work as an HCA if you could not assume that people were telling the truth? You would drown in “proof paperwork.” Contracts and verbal agreements would be all but impossible to negotiate.

Therefore, truth-telling or **veracity** is a key part of the business of health care. When patients interact with a person in the healthcare system, they have an assumption that they are being told the truth. Likewise, the practitioners must assume that truthful information is being given to them by their patients. Confidence in truthfulness is the basis of trust that underlies decisions for effective treatment.

Given this patient right to truthfulness, you could assume that it is always ethically correct to tell the truth. However, health care presents situations where an absolute position on truth-telling might not be the best position. The utilitarian position on truth-telling is that you should always weigh the benefit against harm before disclosing the truth. Once this assessment is done, it might be more ethical to be cautious about disclosure or to tell the truth in pieces over time. What exactly does this mean?

Professionals in health care often have to give bad news and even news of impending fatality to patients. The full information about this news and the timing of full, truthful disclosure can be influenced by the age and emotional state of the patient and the family's desires for such disclosure. For example, if a 90-year-old patient has been diagnosed with end-stage cancer, the family might not want her to know the full truth. They might feel that it is more ethical to deceive this patient and have her enjoy what time she has left. If the physician is aware of the family's request, it can pose an ethical dilemma. Does the physician tell the family and not the patient? What does this mean to the patient's right to know and to choose what she wants to do with her remaining time? Will the family feel that their trust has been violated if the physician tells the patient the truth?

There can be different standards about the scope of truth-telling when dealing with the diagnosis and the subsequent prognosis of a condition. Perhaps a patient can be given the full truth about his or her condition and treatment options. However, when it comes to what happens under treatment, practitioners can choose to give information in pieces over time to avoid overwhelming the patient (Beauchamp & Childress, 2008). This decision is justified as ethical because no one ultimately knows how well a person can do under treatment. Treatment results may deal with statistical data and not human determination. In dealing with the truth in stages, providers do not erode the patient's hope—which in and of itself can be a great motivator for treatment compliance and even healing. This type of truth-telling has the potential to challenge the trust between practitioner and patient, but compassion is the motivation behind it.

Truth-telling is not limited to the clinical aspects of health care. As an HCA, you are in a position of power. Your power can affect those with whom you work, the patients whom you serve, and the larger community in which you live. Power carries with it the ethical responsibilities of truth-telling. In fact, the American College of Healthcare Executives Code of Ethics (Hoffman & Nelson, 2001) specifically addresses this issue and makes it part of your responsibility to your organization. This code is described in detail in chapter 14.

On the surface, this seems like an easy thing to do. However, there can be times when it is extremely difficult. For example, when there is a

possible need to downsize the staff at your organization, do you tell the whole truth? If you do, there is a possibility that your best staff will seek employment elsewhere rather than go through the stress of this process. It is also possible that senior executives do not want anything disclosed to protect their fiscal interests. Therefore, you might also find yourself engaged in stages of truth-telling, just like the clinical staff.

Even in daily interaction with staff, you must remember how powerful your words are and be careful in how you use them. Truth can destroy or enhance performance depending on how it is delivered. Consider your words carefully. This applies to both spoken and written communication. Words can have great emotional impact on others, but written words can come back to haunt you. Be sure to consider the text of your e-mails when considering truthful communication. In the business world, e-mail is not just a friendly exchange; it can be evidence of your truthfulness on any given issue.

Your silence can also provide a certain truth because it implies your consent. You must have the courage to speak your thoughts about an action or a decision, even when it might challenge your career status. Finally, you must be aware that lying, while expeditious now, might cause the end of your career. You have to keep track of lies and tell others the same lies to cover them up. Eventually, a lie can lead to a loss of integrity and even to the loss of your position (Dosick, 2000).

While truth-telling seems, on the surface, to be a straightforward aspect of autonomy, you can see that, with regard to health care, it is much more complex. There is power in the truth and you will be tempted to use that power in both positive and negative ways. It is wise to remember that the way in which truth is delivered (the message) is often as important as the facts (the content). Think carefully about the methods of telling the truth before you deliver the truth.

■ AUTONOMY AS FIDELITY

Fidelity means keeping your word to others, or promise-keeping. In ethics, it fits the Kantian view of the categorical imperative because it is universal. People want to have their promises kept by others, so they should, likewise, keep their promises to others. Buber agrees with promise-keeping as part of autonomy because it respects the I-You relationship. Because you respect the individuality of people, it is ethical to honor them by keeping your promises. Even the utilitarians agree with this aspect of ethics because it can provide the greatest good for the greatest number or avoid the greatest harm.

In business, the idea of fidelity has long been an ethics standard. It used to be said that a man was as good as his word. Business deals could be accomplished with a handshake and only scoundrels failed to

uphold them. Even in today's business settings, fidelity is important because there is an assumption that contracts, both oral and written, will be honored. This assumption permits services to be rendered and payment to be made without undue concern about fraud and abuse. The vendors with whom you do business count on your fidelity as part of their business.

You are acting in a trust-based business. This means that fidelity is expected by the community as well as your business contacts. The community considers it a norm that you will keep your word to treat patients with dignity and fairness, and provide care that is appropriate and effective. The *Patient Care Partnership* documents created by the American Hospital Association (2003) reflect the promises expected by patients. They assert that fidelity is not only an ethics duty, but it is also a right for all patients and that you will honor this right.

This ethical imperative is also part of your mission statement that can be used by the community as an indicator of your business position. For example, if you use your mission to advertise your services, you have an obligation to honor those promises. For example, suppose a hospital uses the mission statement "Grant Hospital: Demand Excellence" in its television, print, and radio campaign. The employees at Grant Hospital might well be inundated with patients "demanding" all kinds of services and special treatment based on these advertisements. Perceived promises would not be kept and employees and patients would feel deceived.

This obligation of fidelity means that you must create a mission statement that is specific enough that you can actually meet it but not so crass as to offend your community. Therefore, you would not want to have a mission statement that says "Profit Is Number One" because the community thinks that they, the patients, should be your number one concern. Likewise, your mission statement should not be something vague like, "Optimum Health for All People" because it is a promise that cannot be met. Remember to review your mission statement frequently so that it truly reflects your commitment to service and ethical behavior. In addition, you are obligated to make sure all employees understand what fidelity toward this mission means in their daily work behaviors.

Fidelity is also an ethics obligation to your employees. If you make promises about any aspect of the employment relationship, you must honor those promises. Be careful about perceptions versus actualities. Your words are powerful and can easily be viewed as a promise by employees. This is why you need to be aware of what you say and when you say it. For example, if you are discussing benefit changes with employees, you must have correct information on what those benefits will be, what they will cost, and when they will be in effect. Misinformation can lead to situations where trust can be broken. This

is especially true when major changes are occurring, such as during a merger or buyout. You must be able to act on any promise that is made, so use your words appropriately.

As you have seen in earlier sections, maintaining autonomy through fidelity is not a simple matter in health care. Violations of promise keeping occur for many reasons. Perhaps the most obvious is the potential conflict of keeping your word to the patient while also being loyal to third-party payers' demands. Are you loyal to those you serve or to those who pay for services? In health care, these are often two different groups. Payers might require gate-keeping and other functions to provide appropriate levels of care at the least amount of expense. However, when managed care organizations pay bonuses to physicians for controlling this access, an ethical problem can occur. Would the physician be tempted to cut corners on treatment when 10% to 20% of his or her salary is at stake? Should the physician disclose the bonus arrangement to the patient? Gate-keeping and other fiscal arrangements are appropriate for the bottom line but could present real ethics problems for patient fidelity.

There are other incidents where fidelity to patients can be challenged. For example, when a healthcare professional works in a prison setting, there can be conflict of fidelity between the interests of the patient and those of the institution. Certainly, when the legal system is involved, there might be a need to violate patient fidelity because of a subpoena or other action. In areas of public health, such as in the prevention of epidemics, fidelity to the overall community can take precedent over fidelity to the individual. This is also true in the military where different rules exist for physicians and other healthcare professionals. Using knowledge and skills to keep soldiers "combat ready" and regarding them as "government property" can appear to be an issue of fidelity to the organization over that of the individual.

What is your responsibility for fidelity as an administrator? Certainly, you need to be aware of the impact of mission on fidelity and do what you can to see that the promises of your mission are fulfilled. This can entail periodic reviews of the mission statement, training efforts, and observation to see if the mission is being met. You also have an obligation for fidelity where any contract is concerned. This means that you should understand the word and the intent of the contract before you sign it. You must also be able to communicate the features of the contract to those that the contract will affect. In the case of third-party payers, this communication effort includes patients as well as employees. Finally, using the Kantian question of, "If I were the patient or the employee, would I want this promise kept to me?" can guide you in making appropriate decisions about the fidelity aspect of autonomy.

Summary

Autonomy as a principle of ethics assumes a certain level of respect for persons and their ability to take actions that affect their health. It includes issues of informed consent, confidentiality of information, truth telling, and promise keeping. On the surface, autonomy seems to be a basic principle that should remain inviolate; however, in health care it is never this easy. There are situations and relationships that challenge the principle of autonomy and make it difficult to follow on a consistent basis. Your responsibility is to be aware of these challenges within your organization and to do whatever you can to maintain the right of autonomy. The community and your employees expect this of you.

Cases for Your Consideration

The Case of the Misguided Relative

As you read this case, consider the following questions. Responses and commentary will follow the case.

1. What aspects of autonomy were violated in this case?
2. Why did Ms. Jamie Jenson make the telephone call?
3. What was the impact of this action on the family?
4. What action could the family take?
5. If you were the administrator of this clinic, what action would you take?

Case Information

The Scene: The office of Dr. Randy Williams, internist, in Smalltown, USA.

The Situation: Mr. Basil Carpenter was suffering from problems with urinary insufficiency and frequent urination so he went to his physician, Dr. Williams, for evaluation. Dr. Williams performed an ultrasound in the office and saw a shadow in the kidney area. He explained to Mr. Carpenter that this might be a tumor and that he needed a consultation with an urologist. An appointment with Dr. Samuels would be made as soon as possible.

While Mr. Carpenter was not thrilled to hear this news, he knew that further tests were needed before he should be worried about his situation. He accompanied Dr. Williams to the front office where instructions were given to Ms. Jamie Jenson, the receptionist. She was to make an appointment with Dr. Samuels so that he could evaluate Mr. Carpenter. She also needed to make a follow-up appointment for Mr. Carpenter. After reviewing the chart, she made the call to Dr. Samuels, scheduled the follow-up, and gave Mr. Carpenter his appointment card.

However, Ms. Jenson was the cousin of Mr. Carpenter's ex-wife and this news was just too good to keep. As soon as Mr. Carpenter left the office, she called her cousin and told her that Basil had a kidney tumor and it might be cancerous. On hearing this news, Basil's ex-wife called their son, Hamilton, and told him that there was a problem with his father; he had cancer of the kidney and might not live.

Hamilton decided to get further information about his father's status and called Basil's current wife, Sandra. His first question to her was, "Does Dad have his will and finances in order?" Sandra responded, "Why are you asking this?" Hamilton told her that that Ms. Jenson from Dr. Williams' office said that Basil had kidney cancer and was terminal. Sobbing, Sandra hung up the phone just as Basil walked in the door. Only 30 minutes from the time he left Dr. Williams' office, he walked into hysteria of unknown origin.

Responses and Commentary on Questions

1. What aspects of autonomy were violated in this case?

It should be noted that this case occurred before the HIPAA rules were in effect. However, it clearly is a case of breach of confidentiality by a nonmedical staff member. Because Ms. Jenson needed to provide referral information, she had the right to access the chart. However, information that she found, no matter what the relationship with the patient, should have been kept confidential.

Kant would be very upset by this situation because it violated the categorical imperative for confidentiality. Imagine if this same incident happened to Ms. Jenson instead of Mr. Carpenter. How would she feel? Yet, she did not even consider this question before she called her cousin. The utilitarians would also find this action inappropriate because it had the potential to cause the greatest harm to the greatest number if it were to become a routine in this practice.

Comment: The self-profit motive enhances the temptation to violate confidentiality when there is access to confidential records. Suppose the patient was a major celebrity and the condition was erectile dysfunction. The temptation to leak this information to the press for profit might sway a person's sense of ethical obligation. This might sound like an exaggeration, but similar incidents frequently occur.

2. Why did Ms. Jenson make the telephone call?

Several things could have motivated Ms. Jenson in this case. Perhaps she saw herself as altruistic by giving the family important information that might not be shared by the new wife. Perhaps, she saw it as an issue of family loyalty and a duty to honor the family's

right to know. She might not have even realized that she was violating Basil's right to confidentiality because no one ever told her not to do this. Of course, the motive could have been more purulent and she could have succumbed to the need to share gossip that was truly juicy.

Comment: It is important, as an administrator, to consider that everyone who has access to the medical record is important to the chain of confidentiality protection. Often persons who are not on the clinical side of patient treatment are forgotten in this important area. Receptionists, office managers, and even custodians might have more access to sensitive materials than you realize. Training and monitoring of policies and procedures is necessary.

3. What was the impact of this action on the family?

In this case, the family includes an extended network of individuals. First, you need to consider Ms. Jenson—who just put her job in jeopardy to inform her cousin of some family news. We will deal with her consequences in later responses. You must also consider Basil's ex-wife, who was upset enough to contact their son, Hamilton. How do you think she was feeling? Basil is her son's father and his loss could be very painful. Of course, you might also wonder why she called Hamilton when she did not have the whole story about Basil. Perhaps less than altruistic motives were in place.

How about Hamilton's role? He received this shocking news from his mother. Perhaps he was upset and concerned about his financial future. Of course, he too had the option of waiting for the full story before he called Sandra. You might wonder about his motivation and his response to the news, but you cannot deny that he was affected by this misinformation and added to the chain of grief that it caused.

Poor Sandra. She waited for Basil's return from Dr. Williams' office and was worried about his health. Then she got that telephone call from Hamilton. The news shocked her but also made her furious. How did Basil's ex-wife know about his condition before she did? What right did Ms. Jenson have to share this information with Basil's ex-wife before she even knew it? Just how bad is the situation? Will she lose her husband and the father of her children? It is no wonder she is crying.

What do you think about Basil? Can you imagine walking into this situation? He had been given potentially frightening news but decided to put it in its proper perspective until more information was known. He knew that he would have to tell his family but did not want to upset them too soon. Despite his sensible nature, he must have had some fears in the back of his mind. He wondered,

“What will happen to my family if I am not around?” He walked in the door to chaos. Sandra was crying and he did not have a clue why. Imagine how angry and upset he was.

Comment: Sometimes it is difficult for healthcare personnel to understand how much of an impact their actions have on others. This case is an example where an entire family was affected by the actions of one healthcare team member, but there are many incidences where whole communities can be affected. Healthcare professionals must always be aware of their power and use it ethically.

4. What action could the family take in this situation?

Minimally, Basil should contact Dr. Williams personally and inform him of what took place. This would allow the physician to take appropriate action in his practice and deal with Ms. Jenson. Dr. Williams could also apologize to Basil for what happened and assure him that it would never happen again. If Basil was so inclined, he could contact his attorney to see if there were grounds for suit.

What actually occurred in this case was very interesting. Sandra accompanied Basil to his appointment with the urologist. She told the specialist that she did not want the records released back to Dr. Williams. She also asked that they be stamped as confidential. When she was asked the reason for her request, she informed the urologist of the events. He was upset for the family and promised to honor Sandra's request. He also spoke to Dr. Williams about the situation. Shortly after this, Basil received a telephone call of apology and numerous statements in the mail about new protection of confidentiality policies in Dr. Williams' office.

5. If you were the administrator of this clinic, what action would you take?

First, the minute you received the information about what transpired, you would have the obligation to investigate. You would document what the family told you about the situation. It would be important to remain calm, listen attentively, and provide assurance that action would be taken. Next, you would need to speak with Ms. Jenson privately to hear her account of what happened. You might also want to contact your legal counsel to get his or her advice on the best course of action. Once all of the information has been obtained, you would have to confer with Dr. Williams about the situation. He could decide on immediate termination or some other form of action with regard to Ms. Jenson.

This action would deal only with the immediate situation, however. To prevent future incidents of this nature, you would have to review your current policies and procedures to make sure they are clear about confidentiality. You would also need to review all

HIPAA rules and regulations to be sure that you comply with those standards. New policies or clarifications would have to be written if they are needed.

In addition, you would have to determine that the current staff understands the policies and how their implementation. You might want to have an in-service education meeting to review confidentiality procedures with staff. In addition, you might consider doing some nonintrusive observations to see if procedures are being implemented. These actions would help you to prevent any future legal actions regarding the violations of confidentiality.

The Case of the Valiant Skateboarder

As you read this case, consider the following questions. Responses and commentary will follow the case.

1. How does this case illustrate the concept of patient autonomy?
2. What are some ways to protect Aidan's autonomy?
3. If you were the administrator of St. Mark the Ascetic Hospital, what action would you take?

Case Information

"It hurts! It hurts! Nothing has ever hurt like this!" Twenty-one-year-old Aidan Emerys attempted a frontside boardside on his skateboard. When there was a problem with his Ollie, his fall caused a break in his kneecap and he was admitted to Saint Mark the Ascetic Hospital for knee surgery. Before going to his room, he needed to have blood drawn for laboratory tests and an intravenous line (IV) placed. At St. Mark's, these procedures are done in the intensive care unit (ICU).

At the ICU, Aidan noticed a group of people standing around. A nurse told him that she needed to start an IV as part of the preparation for his surgery. He knew the stick might hurt, but he could take it. He was a man. However, the nurse said, "I can't get this in. I'll have to try again." The next stick hurt even worse, but Aidan thought he could take the pain if this was the last one. However, he did not appreciate having an audience of people watching his ordeal.

The nurse said, "You have bad veins so I am going to have to get someone else to try this." From out of nowhere another nurse appeared. This nurse tried to insert the IV in another spot, but again it did not work. She said, "I just blew this vein." All Aidan knew was that it hurt beyond his ability to "suck it up." He began to feel nauseous and someone handed him a basin. He was sick in front of the whole audience in the room. However, he was not finished. A new face appeared. This man said, "I am from the lab and I need to have some blood for your tests." He inserted yet another needle in Aidan's arm.

Before leaving the ICU, a nurse told him that she would send another nurse to his room to insert his IV. This person was known for his ability to insert IVs in difficult patients. Aidan was still terrified. He also felt humiliated that he was sick in front of all those people. He thought, “How can I survive in this torture chamber?”

Responses and Commentary on Questions

1. How does this case illustrate the concept of patient autonomy?

First, you must understand that informed consent means that patients give permission for procedures that may invade their privacy and their bodies. These procedures are needed for treatment and healing. However, informed consent still requires us to respect patients’ autonomy as much as possible.

Think about Aidan’s situation. First, there were three attempts to find a suitable vein for an IV. Each attempt was more painful than the previous one and Aidan was to blame for the lack of success! No one asked him about his level of pain or provided any acknowledgement of his personhood. He was just another case, expected to take the pain and remain cooperative. In addition, he was required to submit to these attempts in front of witnesses. No one told him who these people were or why they were present. How do you think he felt about his ability to exercise self-rule? Did he have any autonomy?

In addition, Aidan was told that he had to supply a blood sample for the lab before he could be taken to his room. Imagine how embarrassed he was. He was exhausted from the pain and smelled awful, yet he was supposed to submit his body to more pain for the sake of the laboratory. This was just expected; no compassion or explanation was given. Again, you can see a lack of respect for his autonomy. It is no small wonder that he sees St. Mark’s as a torture chamber.

2. What are some ways to protect Aidan’s autonomy?

First, remember that Aidan is just another patient and this is just another day in the ICU. The nurses have had difficulty with IVs before and they have seen people vomit from pain before. This is nothing new. However, this is Aidan’s first experience with any hospital procedure. For him, this is not just another day. Could his autonomy be protected in this situation?

Even though he signed an informed consent form at admission, Aidan did not know the specifics of what would happen on admission. The first thing that should have happened in the ICU was some introductions. Simply explaining to him who was in the room and why they were there would have reduced the anxiety of being

observed by an unknown audience. Then, the nurse could have explained why she was inserting an IV and what she was going to do. This would have given Aidan the opportunity to understand why the pain was necessary.

When the nurse was not successful on her first try, she could have called in her back up. This person should have been the nurse who was especially trained in inserting IVs. Explaining the need to do this without blaming Aidan for having bad veins would have protected his dignity and decreased his unnecessary pain. In fact, he may have even been spared the embarrassment of being nauseous in front of everyone.

You should also consider the laboratory technician who watched Aidan's ordeal and insisted on getting his samples. He could have taken the time to explain why this additional pain was necessary and been compassionate in his attitude toward Aidan. For example, he could have assured him that he would get the sample as quickly and painlessly as possible so Aidan could be taken to his room for rest. Even a minor attempt at honoring Aidan as a person and preserving his self-respect could have gone a long way.

3. If you were the administrator of St. Mark the Ascetic Hospital, what action would you take?

This case shows the need for policies and procedures that go beyond informed consent. Of course, Aidan did provide written permission for the procedures to be performed, but he did not consent to the treatment that went with them. As administrator, you can work with the appropriate clinical staff including the director of nurses and clinical laboratories to define protocols. For example, one protocol could be only the necessary personnel are present when a patient has a procedure and that all persons in the room are introduced to the patient.

There also needs to be protocols for what happens in a difficult case. How many times should a patient be "stuck" in order to insert an IV? Is three times an acceptable number? At what point should the backup IV expert be called? At a minimum, there should be more communication with the patient and more compassion shown.

This case also makes a great argument for continuing education. The ICU nurses are generally experts at insertion of IVs. However, it does not mean that periodic sessions to renew and sharpen skills are not needed. More importantly in this case, an increased awareness of patient autonomy and the need for communication and compassion is needed. Perhaps some case studies and discussions or even role-plays about how patients feel and how they should be treated would prevent the torture chamber image of St. Mark's in the future.

Web Resources

The following are Web sites that provide additional information about areas in this chapter.

HIPAA Information

<http://www.hhs.gov/ocr/hipaa/>

Patient's Care Partnership (AHA)

<http://www.aha.org/aha/issues/Communicating-With-Patients/pt-care-partnership.html>

References

- American Hospital Association. (2003). *The patient care partnership: Understanding expectations, rights, and responsibilities* [Brochure]. Chicago: Author.
- Beauchamp, T. L., & Childress, J. E. (2008). *Principles of biomedical ethics* (6th ed.). New York: Oxford University Press.
- Boyle, P. J., Dubose, E. R., Ellingson, S. J., Guinn, D. E., & McCurdy, D. B. (2001). *Organizational ethics in health care: Principles, cases and practical solutions*. San Francisco: Jossey-Bass.
- Dosick, R. W. (2000). *The business bible: Ten commandments for creating an ethical workplace*. Woodstock, VT: Jewish Light Publishing.
- Hoffman, P. B., & Nelson, W. A. (Eds.). (2001). *Managing ethically: An executive's guide*. Chicago: Health Administration Press.
- Office of Civil Rights. (2008). *Understanding HIPPA privacy*. Available at: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>. Accessed May 16, 2009.

