CHAPTER 2

Autonomy

In the age of technology and social media, is autonomy still important?

Points to Ponder

1. What are the key issues for the healthcare administrator (HCA) that relate to informed consent?
2. Why is confidentiality so important in patient care?
3. Is it ever appropriate to withhold the truth from a patient?
4. What is the significance of fidelity to the success of HCAs?

Key Terms

The following are this chapter’s key terms. Look for them in bold.

authorization  informed consent
competence  reasonable person standard
disclosure  veracity
fidelity  voluntariness

INTRODUCTION AND DEFINITIONS

Principles of ethics have their foundation in ethics theory and assist with making decisions about one’s personal and professional choices. In health care, there are four commonly used ethics principles: autonomy, beneficence, nonmaleficence, and justice. This chapter presents information about the principle of autonomy and its application to healthcare practice. Current concepts of autonomy are derived from the Greek definition of autonomy as self-rule and self-determination (Summers, 2014). While protecting autonomy may be more difficult in
the age of electronic medical records and social networks, Kant, Frankl, and others support autonomy because of their belief that people have unconditional worth and deserve respect.

Application of the principle of autonomy must assume that people are free from the control of others and have the capacity to make their own life choices. In health care, people also must have the right to hold views that are incongruent with those of the healthcare establishment. For example, if a patient is a Jehovah’s Witness and does not believe in blood transfusions, he or she has the right to refuse such treatment. The word “choice” is a key element in this principle. How does this relate to the healthcare administrator? Administrators must understand that people should be free to choose to be compliant or not compliant with their physician’s instructions. Patients and their families 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.

However, autonomy is more than just making informed choices. It is also concerned with how individuals are viewed and treated within the healthcare system. Therefore, if autonomy is an ethical principle for any healthcare organization, certain standards should prevail. Healthcare organizations must create standards for protecting autonomy and respond to state and federal legislation on this issue. For example, this chapter includes an examination of 2013 revisions of the Health Insurance Portability and Accountability Act of 1996 (Title II) (HIPAA) rules that have increased awareness of the need to protect autonomy (Department of Health and Human Services, Office of Civil Rights, 2013).

Informed consent is not the only aspect of autonomy that affects the practice of health care and the responsibilities of healthcare administrators. This chapter focuses on autonomy as truth-telling, through a discussion of what telling the truth means in healthcare situations. Autonomy can also be expressed as fidelity: What does it mean to keep one’s word to patients and employees?

**AUTONOMY AS INFORMED CONSENT**

Legal and ethical considerations come together when applied in the area of informed consent for treatment. Case law and legislation view informed consent 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.
Sometimes, autonomous consent is implied through a person’s actions. For example, a person makes an appointment with his or her dentist and keeps that appointment: Consent for treatment is implied. However, even with this implied consent, there is an ethical (and often legal) duty to obtain specific written consent. In addition, if nonroutine treatments are required, there may be additional procedures to obtain consent. Another example of implied consent happens when a person cannot express consent, but needs treatment. Suppose a traffic accident occurs in which a person is injured. Emergency personnel rush this person to the emergency department, and she is not conscious when she arrives. If the patient’s injuries are life threatening, given that a reasonable person would want treatment and there is no surrogate to give consent, the emergency physician can assume consent and treat the patient (Munson, 2008).

What is informed consent? Beauchamp and Childress (2012) present a model that clarifies this term and serves as a basis for discussion. Informed 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 (Chell, 2014). Exceptions to the child rule exist as well. 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. Voluntary decisions are as simple as they seem. Practitioners may think that they know what is medically best (paternalism), but patients sometimes make different judgments about their own health. To give voluntary consent, patients should not feel that they have to please their practitioners or be coerced by physicians who may suggest dire consequences will ensue if the patient does not accept the treatment plan. Whether the coercion is actual or perceived, patients under duress do not freely choose to participate in the treatment.

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 to maintain funding for his study. This researcher finds a suitable subject and promises the person that he or she will receive benefits from participating 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.

In addition, patients have the right to refuse treatment as part of informed consent. This means that they can choose not to comply with the practitioner’s treatment plan. When this occurs, beneficent practitioners or family members may try to force patients to comply or question their competence to make decisions. These situations may exist even when treatment is futile (such as at the end of life) and are especially difficult when children are involved. In some cases, refusal of treatment issues may even involve the courts (Vaughn, 2010).

Disclosure is a major element in both legal and ethical aspects of informed consent. It seems like a simple thing to tell patients information about their condition, methods of treatment, and alternatives for that treatment. However, this process is far more complex than it appears at first glance. Many states dictate what is called a reasonable person standard with respect to what should be disclosed 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.

For patients to make informed decisions 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, some alternative treatments, such as the use of herbs or holistic medicine, appear 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 the patient can decide if he or she is able to pay for them if the treatments are not covered by the health maintenance organization.
Making efforts to ensure the patient understands the disclosures and the treatment plan is an ethics obligation when seeking informed consent. When the medical news is not good and/or the required treatment is painful and risky, patients can become emotional. These emotions, in turn, may affect the individual’s ability to make sound decisions. Therefore, requiring a signed consent too soon after such news is given might not be appropriate action. Ignoring the patient’s human reaction to his or her state creates the risk of obtaining uninformed consent. Conversely, delaying the consent procedure too long can impede treatment and potentially cause a negative outcome. Dealing with this ethics dilemma of when to ask for consent requires excellent communication and a sense of appropriate timing.

Achieving understanding also requires comprehension. Comprehension may be challenging because consent forms are often full of legal and medical jargon and are written at a relatively high reading level. When one combines the emotions of dealing with illness with the complexity of the consent form, one can see that a true understanding of such forms might not be possible. Another challenge to comprehension is the patient’s level of health literacy. Health care has its own language, and most patients do not speak “healthese” fluently. There is also an assumption that patients can do their own healthcare research on the computer or smartphone. However, not all patients have access to information technology or the desire to use it. Therefore, written materials, at the appropriate level of health literacy, are still an important contributor to comprehension.

Cultural differences may also affect the ability to provide informed consent. For example, many patients do not have English as their primary language, in which case comprehension of the information on consent forms becomes even more challenging. Even if these forms are translated into a person’s primary language according to National Culturally and Linguistically Appropriate Services (CLAS) Standards (Department of Health and Human Services, Office of Minority Health, 2013), the patient may not understand the medical terms used. Again, healthcare administrators have the responsibility to put policies, procedures, and forms in place that enhance patient 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, healthcare professionals must consider the patient’s decision to implement the treatment plan and the appropriate authorization. This final step can require the use of additional personnel to verify that the patient fully understands the consent form and the procedures as described when he or she gave consent to proceed. While the clinic or hospital may use nonphysician personnel during the process of
obtaining informed consent, ultimately the responsibility for ensuring that truly informed consent is given lies with the physician. Therefore, he or she must be willing to verify informed consent with the patient.

This discussion shows that the issue of autonomy as informed consent is highly complex. It is important for healthcare administrators to know their level of responsibility for ensuring that consent is truly consent and that patients are given full, understandable answers to their questions. Administrators must also maintain proof of consent and ensure that this proof is confidential and secure. In addition, they address the need for language-appropriate consent forms and translators as needed.

**AUTONOMY AS CONFIDENTIALITY**

One deals with the principle of autonomy when keeping information about a person’s identity, family, health status, and treatment procedures private. This aspect of autonomy also extends to information that administrators know about employees and their families.

Healthcare administrators have many duties when it comes to confidentiality, some of which extend into the legal realm because of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). For example, HIPAA includes a Privacy Rule that set standards for protection of medical records and personal health information (PHI), which involves both providers and health plans. It limits disclosures and allows patients to examine and receive a copy of their medical records. The Security Rule under HIPAA sets up standards to protect electronic medical records. HIPAA is concerned with patient record confidentiality in a time at which the reach of technology is rapidly expanding (Department of Health and Human Services, Office of Civil Rights, 2013).

In March 2013, new HIPAA regulations went into effect. These regulations affect the Privacy Rule, the Security Rule, and the handling of breaches of these rules. They pay greater attention to issues related to confidentiality and increase penalties for security violations. While these new regulations may be challenging for healthcare institutions, private practice, and insurance companies, their ethics intent is to increase the protection of confidentiality (Department of Health and Human Services, 2013).

What do patients expect with respect to confidentiality? Patients believe that they have a right to privacy. They want 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, 2012). This expectation goes all
the way back to the time of Hippocrates, when physicians were cautioned not to disclose what was said in confidence.

Is there absolute confidentiality in healthcare settings? The answer is “no.” It is, of course, necessary to share private information about patients to treat their conditions. Nurses, physical therapists, radiation technicians, and many others may need access to patients’ information to treat those patients appropriately. However, this access must follow HIPAA rules and requires patient consent. Specifically, only those who have a legitimate need to know patient information should have access to the medical record and health information. Healthcare administrators need to create and enforce appropriate safeguards to ensure the protection of medical information from access by those who do not have a need to know this information.

On the surface, this sounds straightforward, but safeguarding confidentiality in today’s healthcare system is not as simple as a locked file cabinet. Technology and the electronic transfer of records increase the risk of inappropriate access to confidential information. In addition, there are problems safeguarding confidentiality beyond those related to technology. Within the structural procedures at a hospital or clinic, certain practices can automatically threaten the patient’s confidentiality. For example, what happens when a patient’s surgery takes place in an outpatient surgery setting? Prior to this surgery, healthcare professionals need to discuss the patient’s medical history, but this discussion may be held in a cubicle. Only a curtain separates the patient from the other occupants in the room, so there is no confidentiality. It is easy to see that the structure of some healthcare settings may make maintaining confidentiality difficult at best. Even so, health administrators and practitioners need to make every effort to ensure there is respect for this part of autonomy.

Actions in the informal organization that can threaten confidentiality can be even more subtle. If staff members do not receive frequent training in confidentiality, discussions about interesting cases can occur in hallways, elevators, the 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 the administrator’s responsibility to reduce the likelihood of such conversations by designing and enforcing appropriate policies and procedures, and by providing frequent training. In addition, administrators need to conduct informal observations to evaluate if training is working, through “management by walking around.”

Patient confidentiality is not an absolute even when appropriate practices and procedures are in place. On some occasions, the law or ethical practice makes it necessary to break patient confidentiality. For example, legally mandated exceptions include reporting certain diseases, traumatic events such as gunshot wounds, and incidents of child
abuse. In the case of mental health providers, there is also a duty to warn others if a client threatens to be violent. Utilitarian theory supports these exceptions to confidentiality, as they represent means to serve the greater good for the greater number or to prevent greater harm.

Other issues of confidentiality also create complex ethical challenges. For example, should employers have a right to employees’ or job applicants’ medical records? If so, can the employer use the information found there to avoid hiring a person if he or she has an expensive pre-existing condition? Suppose an employer asks for information about employees’ use of tobacco and refuses to hire anyone who smokes. Does this practice violate confidentiality and autonomy? What if a patient has a diagnosis of a genetic condition that could affect the health of his or her family members? Should the physician tell the patient’s relatives even if the patient does not want the information discussed with them? To whom does the physician owe a duty in such a case? These questions are just a few examples illustrating how complicated confidentiality can be when considered in its full ethical context.

Another area to consider is the confidentiality of private employee information. Depending on an administrator’s position in the health facility, he or she may have access to very private information about employees and their families. It is imperative that all administrators recognize the need to maintain confidentiality with employee information and not to share it with those who have no need to know. Because administrators are in a position of authority, violation of employee confidentiality might not only be a breach of trust, but also lead to dismissal. Therefore, it is vital for healthcare administrators to keep private information private.

**Autonomy as Truth-Telling**

Should a person always tell the truth? Kant would say that truth-telling meets the categorical imperative and telling the truth should be universal. Beauchamp and Childress (2012) consider it one of the obligations of health care. Imagine working as a healthcare administrator if one could not assume that people were telling the truth: Administrators would drown in “proof paperwork” because they would have to document every conversation and every meeting. Contracts and verbal agreements would be all but impossible to negotiate.

Truth-telling or veracity is a key part of the business of health care. When patients interact with people in the healthcare system, they make an assumption that veracity exists. Likewise, practitioners must assume that their patients give truthful information. Confidence in truthfulness is the basis of trust that underlies decisions for effective treatment and patient healing.
Given the patient’s right to truthfulness, one could assume that it is always ethically correct to tell the truth. However, health care presents situations where universal truth-telling might not be the best position. To understand this statement, consider the utilitarian position on truth-telling. One should always weigh the benefit against harm before disclosing the absolute 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. But what exactly does this mean?

Professionals in health care often have to give bad news about a condition or treatment and even news of impending death. 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 there is a diagnosis of end-stage cancer for 90-year-old patient, 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 about the condition and its prognosis, but 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?

It seems that 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, 2012). This decision is justified as ethical because no one ultimately knows how well a person can do under treatment. Predicting treatment results and death may deal with statistical data and not human determination. In dealing with the truth in stages, providers also 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 it is motivated by compassion.

Truth-telling is not limited to the clinical aspects of health care. Health administrators are in positions of power. Their power can affect those with whom they work, the patients whom they serve, and the larger community in which they live. This power also carries with it the ethical responsibilities of truth-telling. In fact, the American College of Health Care Administrators (Darr, 2011) specifically addresses the issue of truth-telling with respect to individuals’ qualifications and responsibilities to their organizations. Truthfulness is also featured in several areas of the American College of Healthcare Executives’ Code of Ethics (ACHE, 2011).
On the surface, being truthful seems like an easy thing to do. However, there can be times when it is extremely difficult to be completely truthful. For example, when there is a possible need to downsize the staff, does the healthcare administrator tell the whole truth? If he or she does, there is a possibility that the best staff will seek employment elsewhere. It is also possible that senior executives do not want full disclosure, so as to protect their fiscal interests. Therefore, administrators might also find themselves engaged in truth-telling in stages, just like the clinical staff.

Even in their daily interactions with staff, administrators must remember the power of words and appreciate how carefully they should be used. An administrator’s view of the truth can destroy or enhance performance depending on its delivery. Therefore, one should consider one’s words carefully. This admonition applies to both spoken and written communication. Spoken words can have great emotional impact on others, and written words can come back to haunt one’s career. In this electronic age, administrators also need to consider the content of e-mails when considering truthful communication. In the business world, e-mail is not just a friendly exchange; it can be evidence of an administrator’s truthfulness on any given issue. In addition, administrators should consider the truthfulness and appropriateness of Tweets, posts to Instagram, and other electronic communications even when not in the work setting. One’s image is important and maintaining professionalism should always be uppermost in the healthcare administrator’s mind.

Silence can also provide a certain truth because it implies consent. Administrators must have the courage to speak their thoughts about an action or a decision, even when it might challenge their career status. Finally, they must be aware that lying, while expeditious at the moment the lie is uttered, might cause the end of their careers. Once the lying begins, administrators have to spend energy keeping track of lies and remembering to tell others the same lies to cover them up. Eventually, the lie and its cover-up are likely to fall apart, at which point they can lead to a loss of integrity and even to the loss of position (Dosick, 2000).

**AUTONOMY AS FIDELITY**

Fidelity means keeping one’s word to others, or promise keeping. In ethics, fidelity 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. Respect for the individuality of other people implies that it
is ethical to honor those persons by keeping promises. Even the utilitarianists agree with this aspect of ethics, because promise keeping has the ability to 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. People made business deals with a handshake, and only scoundrels failed to uphold their promises. 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. In addition, vendors with which healthcare administrators do business count on fidelity as part of the success of their businesses.

Health care is also a trust-based business. This means that the community expects fidelity. The community considers it a norm that healthcare personnel keep their word to treat patients with dignity and fairness, and provide care that is appropriate and effective. The Patient Care Partnership document created by the American Hospital Association (2003) provides information on the promises expected by patients. This organization asserts that fidelity is not only an ethics duty, but also a right for all patients, and emphasizes that healthcare personnel and organizations should honor this right.

The ethical imperative of promise keeping is also part of the mission statement of most healthcare organizations; the community, in turn, interprets this statement as an indicator of the organizations’ business position. For example, if an organization touts its mission when advertising its services, it has an obligation to honor those promises. Suppose a hospital uses the mission statement “Grant Hospital: Demand Excellence” in its television, print, and radio campaign. Because of patients’ interpretation of the word “demand,” the ad campaign could backfire, leading to a flood of patients “demanding” services. When their demands cannot be met, is fidelity lost? This example makes the point that promises should be taken seriously on all levels and healthcare organizations should be able to deliver on their promises.

Fidelity also means that mission statements should be specific enough to be truthful, but not so crass as to offend the community. For example, healthcare administrators would not accept a mission statement that says “Profit Is Number One” because that statement negates the patients all together. Patients and the community think that they should be the organization’s number one concern. Likewise, a mission statement should not be something vague, such as “Optimum Health for All People,” because that is an unattainable promise. As part of their ongoing duties, administrators should remember to review mission and other statements frequently to ensure that they truly reflect the organization’s commitment to service and ethical behavior. In addition,
administrators are obligated to make sure all employees understand the meaning of fidelity toward this mission in their daily work behaviors.

Fidelity is also an ethics obligation to employees. If an administrator makes promises about any aspect of the employment relationship, he or she must honor those promises. Likewise, it is important to be careful about perceptions versus actualities. Words are powerful, and employees can easily view them as promises. This is why administrators need to be aware of what they say and when they say it. For example, if an administrator is discussing benefit changes with employees, he or she 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, or when making changes to accommodate the ACA implementation.

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 between keeping one’s word to the patient and being loyal to third-party payers’ demands. Is one loyal to those one serves or to those who pay for services? For example, payers typically require gatekeeping and other functions to provide appropriate levels of care at the least amount of expense. However, when managed care organizations that engage in such practices pay bonuses to physicians for controlling this access, an ethical problem can occur. Will 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? Gatekeeping and other fiscal arrangements are appropriate for the bottom line but could present real ethics problems for patient fidelity.

Other challenges arise in regard to fidelity to patients. 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 addition, for public health actions, 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 the responsibility for fidelity shouldered by healthcare administrators? Certainly, administrators need to be aware of the impact of fidelity and see that promises are kept. This can entail periodic reviews of the mission statement, training efforts, and observation to see if the mission is being met. Administrators also have an
obligation to maintain fidelity where any business contract is concerned. This requires understanding the words and the intent of the contract before they sign it. They must also be able to communicate the features of the contract to those affected by that the contract. In the case of third-party payers, this communication effort includes patients as well as employees. Finally, using the Kantian question, “If I were the patient or the employee, would I want this promise kept to me?”, can guide administrators 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. The administrator’s responsibility is to be aware of challenges within organizations and to do whatever is possible to maintain the right of autonomy for patients, employees, and the community.

**Cases for Your Consideration**

**The Case of the Misguided Relative**

Think about the chapter information and consider the following questions. Sample responses and commentary will follow the case.

1. Which violations of autonomy happened 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. Which actions could the family take?
5. If you were the administrator of this clinic, which action would you take?

**Case Information**

*The Scene:* The office of Dr. Randy Williams, internist, in Smalltown, USA. The date of the case predates the HIPAA rules.

*The Situation:* Mr. Basil Carpenter was suffering from problems with urinary insufficiency and frequent urination so he went to his physician, Dr. Williams. Dr. Williams performed an ultrasound in the office and saw a shadow in Mr. Carpenter’s kidney. He explained to Mr. Carpenter that this might be a tumor and that he needed a consultation with a
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 he needed further test results 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 his father 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’s 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’s office, Basil walked into hysteria of unknown origin.

Responses and Commentary on Questions

1. Which violations of autonomy happened in this case?

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, she should keep the information that she found, no matter what the relationship with the patient, confidential. Kant would be very upset because Ms. Jensen 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. Utilitarians would also find this action inappropriate because it has 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 Mr. Carpenter 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. Does this sound like an exaggeration? Certainly not, when one considers the obsession with celebrities in today’s electronic age.

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 or used ethical egoism by giving the family important information that Basil or his new wife might not choose to share. 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 had ever told her not to do this. Of course, the motive could have been more purulent—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, consider Ms. Jenson, who just put her job in jeopardy to inform her cousin of some family news. Also consider Basil’s ex-wife, who was upset enough to contact their son, Hamilton. How was she feeling? Basil is her son’s father and his loss could be very painful to her child. Of course, one 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 also had the option of waiting for the full story before he called Sandra. Again, one could wonder about his motivation and his response to the news, but one cannot deny the effect of this misinformation and the chain of grief that it caused.

Poor Sandra: She waited for Basil’s return from Dr. Williams’s 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 about Basil? Imagine if you walked 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 find complete 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 incidents where whole communities can be affected. Healthcare professionals must always be aware of their power and use it ethically.

4. Which actions could the family take in this situation?

At a minimum, 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’s office.

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

First, from the minute you received the information about what transpired, you would have the obligation to investigate. Document what the family tells you about the situation. Remain calm, listen
Cases for Your Consideration

attentively, and provide assurance that you will take action about the situation. Next, 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 you have all of the information, 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 should review current policies and procedures to make sure they are clear about confidentiality. Review all HIPAA rules and regulations and the new standards for reporting violations of confidentiality to be sure that your organization is complying with those standards. In addition, determine that the current staff understands the policies and their implementation. You might want to have an in-service education meeting to review confidentiality procedures with all staff members. In addition, you might consider doing some nonintrusive observations to see if staff members are actually implementing confidentiality procedures. These actions would help prevent any future legal actions regarding the violations of confidentiality and provide a response for any HIPAA investigations.

The Case of the Valiant Skateboarder

Think about the chapter information and consider the following questions. Sample 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, which action would you take?

Case Information

“It hurts! It hurts! Nothing has ever hurt like this!” Twenty-one-year-old Aidan Emerys had attempted a frontside boardslide 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).

In the ICU, Aidan noticed a group of people standing around. A nurse approached and told him that she needed to start an IV in preparation for his surgery. He knew the stick might hurt, but he could take it.
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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.

Then 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, it is important to 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 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 told he was to blame for the lack of success! No one asked him about his level of pain or provided any acknowledgment 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, a person told Aidan that he had to supply a blood sample for the lab before he could be taken to his room. Imagine how embarrassed Aidan 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, there was a great lack
of respect for his autonomy. It is no small wonder that he saw 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. But 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 Aidan 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 backup. 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.

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 Aidan 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, which 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 that 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 need to be protocols for what happens in a difficult case. How many times should a patient be “stuck” 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 to treat them would prevent the torture chamber image of St. Mark’s in the future.

Web Resources

The following websites provide additional information about topics covered in this chapter.

Department of Health & Human Services, Office of Minority Health
http://minorityhealth.hhs.gov

HIPAA Information
http://www.hhs.gov/ocr/hipaa/

Patient Care Partnership (AHA)

References


