SECTION II

Common Ethical Issues Across Practice Specialties

CHAPTER 3

Advanced Practice Nursing: The Nurse–Patient Relationship and General Ethical Concerns

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Our privileges can be no greater than our obligations. The protection of our rights can endure no longer than the performance of our responsibilities.

—John F. Kennedy,
"The Educated Citizen," Vanderbilt University 90th Convocation Address, May 18, 1963

Introduction

In this chapter we explore common issues faced by advanced practice nurses regardless of country of practice or specialty concentration. As reported in 2006, an estimated 24 countries have nurses practicing in advanced roles (Nieminen, Mannevaara, & Fagerström, 2011), and the number has likely increased since then. For this reason and where possible, the expertise of colleagues from countries outside the United States has been solicited to help understand and account for both similarities and differences in ethical issues faced by persons who are in a variety of roles and designations. For North America, and especially the United States, changes have been proposed (including the Doctor of Nursing Practice curriculum) for the preferred

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*The authors of this chapter shared equal responsibilities for updates and new content. Thus, the order in which the names appear is the result of a coin toss.

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education and credentialing of advanced practice nurses. To avoid confusion in this chapter, we use the acronyms APN (advanced practice nurse) or APRN (advanced practice registered nurse) to denote advanced practice nurses. Where the reader is likely to become confused, we spell out what we mean by a given acronym.

The first two chapters of this text laid the groundwork for APNs' understanding of their ethical responsibilities. Here it is important to consider the essence of the advanced practice role. There are commonalities as well as differences in issues faced by APNs across countries and settings. Contemporarily, there is wide interest in describing the scope and boundaries of such roles, as well as in deriving a coherent and internationally acceptable definition of *advanced nursing practice* (INP/APN Network, 2016). Concerns have been raised that the APN role is becoming more aligned with medicine than nursing and is used in some countries to "fill a gap" created by physician shortages (Rolfe, 2014), leading to a loss of focus on nursing values in patient care. Hanson and Hamric (2003) have synthesized a definition of *advanced practice nursing* from several important source documents and their own experiences of the development of advanced practice: "Advanced nursing practice is the application of an expanded range of practical, theoretical, and research-based therapeutics to phenomena experienced by patients within a specialized clinical area of the larger discipline of nursing" (p. 205). The International Council of Nurses (ICN) Nurse Practitioner/ Advanced Practice Nursing Network (INP/APN Network) proposes that, "A Nurse Practitioner/Advanced Practice Nurse [is] a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. A master's degree is recommended for entry level" (INP/APN Network, 2016).

Advanced nursing roles have existed for several decades in many countries: for example, midwifery and health visitors in the United Kingdom and other countries and nurse anesthetists in the United States. However, the first officially designated advanced practice role in the United States was that of nurse practitioner (NP) in the mid-1960s (Schober & Affara, 2006). Ketefian, Redman, Hanucharurnkul, Masterson, and Neves (2001) identified several critical factors that have been conducive to the development of these roles internationally. These are "environment; the health needs of society; the health workforce supply and demand; governmental policy and support; intra- and interprofessional collaboration; the development of nursing education; and documentation of effectiveness of the advanced role" (p. 152).

The APN role is nevertheless a nursing role that is distinguishable from other nursing roles only by the breadth and depth of responsibility to patients implied by the term *advanced practice*. This means, for example, that APNs often oversee a patient's total care in a given practice setting (e.g., primary care, anesthesia, midwifery, gerontology, etc.), and in alternate settings they also have expanded responsibilities. For example, in acute care they may be responsible for handling emergencies and ordering and carrying out invasive interventions. For this reason and in this sense, their moral responsibilities can sometimes seem more complex and onerous "than those of nurses who share [patient] oversight with other health-care professionals" (Grace, 2004b, pp. 321–322). Effective exploration of ethical issues faced in advanced practice, then, should reflect the implications of these broad role obligations. That is, although the ethical substance of situations may not differ from that faced by nurses in nonexpanded roles, advanced practice nursing ethics take into account the more extensive duties incurred in these roles.

The following inquiry focuses on a variety of ethical problems and concerns that are common across many advanced practice settings. Such concerns are also discussed in general nursing ethics textbooks and will not be unfamiliar to the seasoned clinician. Here, however, the implications of these issues are discussed specifically in terms of the APN's augmented responsibilities. In this chapter, in response to reviewer requests, we have expanded the analysis of ethical issues associated with the escalating use of social media and electronic health records and provided several cases at the end of the chapter for independent or group analysis. Illustrative examples are drawn from a variety of advanced practice sources and from our experiences as nurses and advanced practice nurses, as well as from cases shared by nurses in master's-level ethics courses taught by two of the authors. A more focused application of particular ethical issues and strategies for their resolution may be found in the later specialty chapters. Because it is not feasible to cover all issues that an APN is likely to encounter, it is suggested that any troubling issues that the student or graduate APN face that are not directly addressed in this text be brought up for in-class exploration with faculty and peers or explored with colleagues using the insights and strategies provided in Chapter 2, here, or in other resources. Other helpful resources include clinical ethicists, philosophers who have ethics expertise, ethics websites, and networking groups.

The next section is a comprehensive discussion of the demands of the nurse–patient relationship. Characteristics discovered to be essential for consistently good patient care and decision making are explored, with suggestions for their development. These qualities, which are sometimes called *virtues*, include the intentional use of intellect (thinking) to manage knowledge and affect (emotions and motivation) in decision making about good actions and persevering to carry out and evaluate those actions. Certain philosophers, such as Aristotle and more contemporarily Alasdair MacIntyre (2007), have argued that virtues can be developed through habitual practice. A person who develops a virtuous personality through habitual practice is predisposed to consistently engage in "good" actions. It is debatable whether all persons can become virtuous in this way or even that people who might be considered "good" persons always act in "good" ways (Doris et al., 2010; Kahnemann, 2011). Nevertheless, we should strive to develop qualities that are known to facilitate professional–patient relationships while remaining aware that circumstances "in the moment" are sometimes insurmountable and must be addressed at a different level. Examples of important qualities are discussed in more depth later in the chapter; they include such characteristics as empathy, veracity, transparency of purpose, cultural sensitivity, motivation to act, courage to act, and perseverance in carrying an act through.

A further important issue for all clinical and research settings is that of adequately informing patients (or their surrogate decision makers) about their options for care, treatments, and procedures. Thus, the parameters and demands of informed consent are explicated in this chapter, with the exception of informed consent regarding protection of human research subjects, which is discussed in detail in Chapter 6. Problems associated with the adequacy of informed consent to the provision of care and therapeutics include the issue of patients who lack decision-making capacity for a variety of reasons, persons who are difficult to engage with, and people who are making decisions that seem to be at odds with their own values. A further topic of investigation is that of privacy and confidentiality related to patients' health information. In this highly technological age, it is becoming increasingly difficult to adequately protect patient information from entities that do not necessarily have a patient's best interests in mind in seeking it. Additionally, inadvertent breaches of confidentiality can occur via the use of social media and in the use of electronic health records (EHR). Unethical use of social media can also lead to loss of trust in the involved profession (examples are provided later). The protection of information is multifaceted. One important aspect is transparency. The person at risk should be told for what purposes the data are required and to what uses they will be put, and (insofar as these are known) the risks and benefits of sharing the data. This is in addition to being careful about who can have access to a person's data.

Additionally, APNs often have concerns about how to maintain their personal integrity or self-respect when asked to participate in actions that contravene their deeply held values. Sometimes this is related to patient or peer requests to engage in something that is at odds with a nurse's values, or it may be related to conflicts within the healthcare system, such as managed care or institutional pressures to limit care. Some of the sources of these concerns, along with strategies to address them, are presented. Finally, because some practice problems end up as complex and extremely difficult to sort out, the issue of preventive ethics is woven throughout this section. Many so-called dilemmas can actually be prevented or diffused by good communication or an early understanding of the likelihood that unaddressed problems might cause critical difficulties for the patient in question and/or the patient's significant others.

Virtue Ethics: The Characteristics of Good APNs

Many people are attracted to the nursing profession because they see it as a practice that contributes to the good of individuals, as well as the greater societal good. This is true not just at the undergraduate level, but also for those who choose nursing as a second career and take an accelerated route to advanced nursing practice. Thus, the personal values of nurses are often congruent with the values of the nursing profession—for example, nascent nurses are drawn to the idea of contributing to the well-being of others—although it is also true that a nursing career may be viewed by some as one that offers a level of economic security.

The desire to contribute to the welfare of others is often considered a virtue (as opposed to the desire to hurt someone, which would be considered a vice). As Feldman (1978) writes, in acknowledging that something is good, we are noting its qualities "relative to some class of comparison... some feature of that thing in virtue of which [we] hold it to be good. This feature is its virtue, or good-making characteristic" (p. 234). This section explores the issue of virtue ethics as it relates to good APNs, where *good* is taken to be synonymous with *ethical*. Virtue ethics in healthcare practice is essentially the idea that a person can cultivate certain characteristics (virtues) that will predispose him or her to good actions related to the profession's predetermined goals. These goals are outlined in codes of ethics and in nursing's historical documents and reflect the reason nursing exists as a profession.

Contemporary proponents of virtue ethics almost all trace their influences back to Aristotle, although ideas about virtue can also be discovered in ancient texts on Eastern philosophy. Aristotle's idea is that a good or virtuous person is someone who possesses practical wisdom or prudence. The Greek term for this is *phronesis*. Practical wisdom permits a man (in ancient times women were considered subordinate to men) to understand both what is a good way to live and that living a good life necessarily means developing mutually beneficial relationships with others. To act well, a man must learn to habitually moderate emotional impulses by using reasoning. This is what is required to achieve the desired purpose of living a good life. Eventually, a person will habituate himself to always engaging in good action: he will become a good or virtuous person. The desirable or virtuous purpose of all human beings, according to Aristotle, is to live in accordance with their human nature. The essential characteristic of human nature—that which distinguishes human nature from the nature of all other beings—is rationality. The ability of human beings to use logical reasoning gives human beings purpose, and that purpose is the pursuit of a satisfying life. The Greek term for this is *eudaimonia,* often also referred to as *happiness,* although it loses something in the translation and does not mean happiness in any superficial sense of the term (Hutchinson, 1995).

Practical reason acts as a constraint on emotional and instinctual drives that can result in harmful actions on the one hand, and on the other hand in a lack of needed action or inadequate action. Reason mediates a balance between extremes of action. For example, according to Aristotle, courage is a virtue. Unrestrained courage can cause unnecessarily risky behavior, which is therefore irrational. Alternatively, timidity about doing something important is problematic and also requires reason to moderate action. Practicing the development of virtue eventually leads to the formation of a virtuous character. Additionally, a satisfying life, which is necessarily lived within society and in relationships with others, facilitates harmony in these relationships. It is noteworthy that for Aristotle being virtuous has a self-focus, but nonetheless a harmonious society is also requisite for a satisfying life. Thus, the actions of a virtuous man have the serendipitous result of contributing to the good of others.

How does this explanation of virtue pertain to the current project of understanding what characteristics are necessary for good practice? The answer is that contemporary moral philosophers, such as Elizabeth Anscombe (1958/1981), Bernard Williams (1985), and Alasdair MacIntyre (2007), have been interested in resurrecting the idea of virtue as a way to understand peoples' relationships to each other and to inform provider–patient relationships. This move represents, in part at least, a way around the problem that deontological and consequentialist ethical theories do not account for the contextual and relationship-dependent nature of human life in situations where moral decision making is needed. Neither do these theories always capture contingencies of healthcare providers' multifaceted and relationally oriented roles. Moreover, contemporary research in psychology and the cognitive sciences has uncovered occult aspects influencing human action that may not easily be within conscious control (Eagleman, 2011).

MacIntyre's work, though not resulting in a theory that can be applied directly to action, does provide some unifying ideas about virtues (Sellman, 2000, p. 27). The constituents of virtue, or those characteristics that make a person virtuous in MacIntyre's view, are context dependent. Thus, virtues may be "seen as supporting and maintaining particular ends" (Sellman, 2000, p. 27). Because virtues are seen as those characteristics necessary to support a particular end, goal, or practice, some common objections to the idea that a virtue ethic is helpful in healthcare practice are overcome (Armstrong, 2006; Begley, 2005; Sellman, 2000). Criticisms of virtue ethics include the observation that what is virtuous in one situation or in a given culture may not be considered virtuous in another. Therefore, there is no stable footing for the idea of a virtuous person, nor is there a list of virtues a person must possess to be virtuous.

An additional and potentially serious criticism is that there is no external criterion (within virtue theory) for judging whether the actions of a virtuous person are actually good. There is no "gold standard" for good actions. Moreover, the actions of someone who is thought to be virtuous will not necessarily always be good; that is, they may not always be aimed at achieving a good for a variety of reasons, or they may fail to achieve a good. Many factors can interfere with a good person's ability to do good actions, as listed in **TABLE 3-1**.

However, if certain virtues are viewed as pertaining to a particular professional practice and necessary for meeting the goals of that practice, then it is possible to evaluate a given action based on how well it addresses those goals. Because nursing is a practice profession with relatively well-articulated goals, it is possible to agree that persons who possess certain characteristics are more likely than those who do not to

TABLE 3-1 Factors That Interfere with Ethical Nursing Action

Locus	Factors
Agent related	Level of moral development Capacity to recognize ethical content; Chambliss (1996) discusses the phenomenon of "routinization of disaster" Openness to reflection Personal or emotional issues Energy levels Creativity Locus of control (powerfulness/powerlessness) Inability to connect with patient Fear of disapproval (peer or other) Disapproval of patient's choice Time of day—complexity of preceding workload or decisions Level of knowledge related to the issue Subconscious cognitive processes—effects of unexamined "universal" cognitive biases—overreliance on intuitions (Doris et al., 2010; Kahnemann, 2011)
Environmental	Pressures from peers—supervisors Competing demands (peers/patients/relatives/institution) Social sanction Economic and institutional conditions Time or resource constraints Conflicts of interest Job insecurity Catastrophic conditions

routinely engage in good practice and to be willing to address practice structures that interfere with good actions. A further consequence is that, as a profession, nursing must continue to investigate what the characteristics of a good nurse are and then nurture these traits during the education and mentoring of nurses. A big question for the profession itself is whether all prospective nurses are capable of developing the characteristics of good nurses. If not, what is the profession's responsibility (assumed by its educators) to weed out those who are incapable of being or becoming good nurses?

Virtues of Nursing

Nursing practice and the fulfillment of nursing goals, then, can be understood as requiring the development of certain facilitative characteristics. Indeed, by exploring what is needed to provide good nursing care to patients—as outlined in the literature and in codes of ethics—relatively quickly, it becomes possible to compose a list of virtues that it would be desirable for nurses to cultivate. Additionally, nursing curricula should include strategies for nurturing these characteristics (Haggerty & Grace, 2008). Begley (2005) has composed such a list; it includes compassion, integrity, honesty, patience, tolerance, courage, imagination, perception, perseverance, self-reflection, and many more. For her dissertation, *Optimizing Stewardship: A Grounded Theory of Nurses as Moral Leaders in the Intensive Care Unit*, Breakey (2006) studied characteristics of nurses who reportedly engaged successfully in end-of-life (EOL) decisions. Salient characteristics for this important nursing role included understanding the professional obligations of the role, the ability to empathize with others, and willingness to understand an issue in detail and to support others in their decision making using expertise and knowledge. The possession and exercise of any virtue within a nursing care setting will also rely on other interrelated virtues, the clinician's knowledge, and skills pertinent to the practice domain. Compassion for a cancer patient's suffering, for instance, without knowledge of how to mitigate it and/or the motivation to alleviate it, is an empty virtue. However, theoretical knowledge of pain management without experience in patient assessment, planning, delivery, and evaluation, or without understanding the meaning that suffering holds for the patient, is also problematic.

Two unpublished studies by one of the chapter authors, focused on understanding nurses' views of what the characteristics of a "good" nurse are, support these ideas. One study analyzed essays ($N = 42$) from a graduate nursing ethics class, and the other interviewed nurses from a variety of settings who had been identified by others as "good nurses" ($N = 11$). The major characteristics of "good" nurses are dependent on having a certain level of knowledge and expertise relevant to the setting. Roughly, these characteristics include perceptiveness, engagement, understanding of the nursing role as having obligations, good communication, the ability to collaborate, the ability to support others, and moral courage (the courage to act for the patient and/or family in the face of obstacles). Additionally, initial data analyses from the Clinical Ethics Residency for Nurses (CERN) project (Grace, Robinson, Jurchak, Zollfrank, & Lee, 2014; Robinson et al., 2014), along with ethics class discussions, support the assumption that being a "good" nurse requires nurses to understand and act on their obligations to patients, patients' families, and those they supervise.

These studies are examples of descriptive ethics. *Descriptive ethics* portrays what people think are good actions and good characteristics. It is differentiated from *normative ethics*, which mandates certain types of behaviors. A code of ethics provides the normative aspects of action (that is, what nurses should do and how they should do it), whereas descriptive ethics paints a picture of what is actually happening in practice or what nurses perceive as their obligation and appropriate action and what sorts of things get in the way of providing, or ensuring the provision of, "good" patient care. The two types of ethics, taken together, provide a bigger picture of what changes in education, environment, or policy may be necessary for good patient care.

For APNs, who may supervise, mentor, or collaborate with others, virtues such as leadership, cooperation, and discernment of the different needs of those with whom they interact are important to cultivate in order to meet professional duties. Chapter 5 discusses leadership characteristics in depth. The next section examines the idea that certain virtues are needed for interacting with patients who are faced with making decisions about their care. Patients give their consent to care implicitly, verbally, or in written form, depending on the invasiveness or risk of the proposed action. APNs are in the privileged position of assisting with, or empowering the patient to make, healthcare decisions that by their nature have some sort of effect on that patient's life. With this privilege comes added responsibility.

Informed Consent

The principle of autonomy, as discussed in Chapter 1, underlies the idea of informed consent. Because human beings have the capacity to reason, decide, and act and because they might be presumed to know better than anyone else what their interests are, all things being equal, they have the right to make decisions concerning their health care. They should (barring any incapacitating factors) be free from the interference of others, at least as far as personal decision making is concerned. This translates into the moral right of patients to accept or refuse healthcare treatments regardless of risk, given the possession of decision-making capacity and an adequate understanding of the risks of refusal and the potential benefits of treatment. As a reminder, *moral* and *ethical* are considered equivalent concepts in the context of healthcare practice (see explanation in Chapter 1). This moral right was legally validated in the United States with passage of the Patient Self-Determination Act (PSDA), ratified in 1991 (as part of the Omnibus Budget Reconciliation Act [OBRA] of 1990), which is discussed in more detail shortly. In the United Kingdom, the right to make autonomous care decisions is protected by the Mental Capacity Act (2005), and in several other countries the right is also legally protected. Regardless of whether or not there are legal protections for the healthcare professional in helping patients understand their human rights related to health care, understanding the generally accepted and fundamental right of persons to make their own decisions provides a strong foundation for advocating that patients' real needs be evaluated and met, including the need for information tailored to their level of understanding and preferences.

Types of Consent

People give three types of consent in permitting healthcare professionals to evaluate and act on their health needs. The first is implicit consent, the second is verbal consent, and the third is written consent. When a patient is unable to consent, as discussed later, then ideally an informed proxy makes a decision on the patient's behalf and with the patient's best interests (where these are knowable) in mind. *Informed consent,* then, is the process of interaction between a healthcare provider and person in which necessary information is exchanged and an appropriate level of understanding is gained to enable that person to make a decision about acceptable care, treatment, interventions, or courses of action in light of his or her preexisting values, beliefs, and lifestyle. One critical message implicit in this idea is that consent is not a static concept. Evaluation of current circumstances, patient understanding, and continued willingness to participate or proceed requires that consent be, for the most part, an ongoing process. Advance care planning (ACP) for acceptable interventions in the event of incapacity is discussed in later chapters.

Implicit Consent

In presenting to a healthcare delivery setting in search of assistance with health needs, a person is implicitly consenting, at minimum, to be evaluated for those needs. If the setting is an inpatient or institutional setting such as a hospital, the person might sign a form giving consent for certain routine evaluations. However, this form is general and does not detail all aspects of the evaluation, which may include tests and manual assessments such as a physical examination. Moreover, typically the admitting personnel charged with obtaining signatures have no or little medical or nursing knowledge. Thus, implicit consent is not usually very informed, and patients may well not understand what rights they have.

In primary care sites, those who present for care do not necessarily understand the customary routines of the practice site—nor are they required to accept them, although frequently both ancillary staff and clinic nurses do not act as if they understand this. For these reasons, nurses need to be ready to ascertain what the patient has understood, and what it would be helpful for him or her to know. If a patient objects to some aspects of routine care, nurses are responsible for discovering what underlies the objection, how important it is to gather the data in question, and whether acceptable alternatives may be offered. For example, a faculty colleague of the third author who is also a women's health nurse practitioner (WHNP) reported that she was doing a breast exam on a patient as part of the patient's yearly checkup. She asked the woman if she did monthly breast exams on herself. The woman replied, "No, I don't like to touch my breasts, and for that matter I don't like anyone else to touch them either—not even my husband." At that point, the WHNP realized both that she had not asked permission and had not sought to understand what, if any, meaning this particular act of assessment held for the woman. She apologized and the patient said she understood that it was part of the exam and had to be done. But in retrospect the WHNP wished she had thought to ask permission before beginning. She felt that this might have allowed the patient to discuss the issue with her, but the opportunity had been lost. Touching someone without that person's permission is also a legal consideration and may subject a nurse to legal charges such as battery or assault.

The preceding scenario, which happened early in the WHNP's professional life, made her more sensitive to the idea that patients can have good reasons for refusing even routine care and that they have a right to refuse it. However, nurses also have a responsibility to ensure that patients understand the implications of refusing evaluations, tests, or treatments and try to lessen any risks from this refusal by reformulating an acceptable plan of care. To illustrate this point, we give an example drawn from practice. A slightly overweight woman in her early twenties came to a primary care setting for treatment of a sore throat. It was her first visit. The office assistant, a nurse's aide, told her she had to be weighed as part of the "new patient" routine. The young woman refused. The aide tried to persuade her but to no avail.

The nurse practitioner heard arguing in the hall, went to investigate, and saw a very upset young woman. She brought the patient right away into an empty room, acknowledged how upset the patient was, and asked her what happened. She said, "I really hate being weighed—I don't see why it is necessary—they used to do that at the other clinic." It was explained to her that measuring a person's weight is in many cases a very useful assessment and was routine, but that in view of her reaction the providers would rethink the policy. In the course of the interaction, and because she could see that her concern was taken seriously, the patient confided that she used to be weighed weekly by her mother when she was a teenager and was physically punished for gaining weight. This opened an opportunity to help her further, and she eventually got counseling for unresolved issues with her mother.

After this, we changed our office policy and educated the medical assistants and aides about a patient's right to accept or refuse some of the routines that were not important for the given patient's care. If the routine was important—for example, weighing a patient with chronic heart failure—then rationale should be given. Alternatives, such as self-weighing and reporting significant changes, can be negotiated. Also, there are, of course, some cases in which weighing a patient becomes crucial. For example, some drug dosages are calculated based on weight. In surgical operating areas, intensive care units, and pediatric settings, accurate weights may be crucial to avoid the harms (nonmaleficence) of over- or underdosing patients with essential therapeutics. In such cases nurses remain responsible for anticipating and minimizing any possible harms, including psychological distress.

Verbal Consent

Although for many patients a host of routines covered by implicit consent cause neither distress nor affect their care in any perceptible way, in the cases described earlier, informed consent to care was important both for the patients' immediate well-being and for determining whether follow-up care was necessary or desired. Gaining informed verbal consent permitted the nurse to understand what else might be required to provide good care. Sound clinical judgment, as described in Chapter 4, facilitates identification of the patient's particular needs, which in both of the preceding examples proved to be more extensive than initially understood. Obtaining verbal consent to care—including evaluation, tests, therapeutics, and decisions about the best ways of managing chronic conditions—is synonymous with good APN practice in direct patient care and is dependent on establishing a nurse–patient relationship that is concerned with understanding the patient's vulnerability and needs and then addressing them.

Written Consent

The third type of informed consent is a written consent. Written consent "is intended to protect patients from... ethical or legal breaches and make formal their right to all relevant information, tailored specially to them" (Grace & McLaughlin, 2005, p. 79). Experienced nurses practicing in institutional settings are mostly familiar with *informed consent* as it relates to invasive medical procedures and perhaps to patients who are participating in research studies (see Chapter 6). In their definition of the term, Beauchamp and Childress (2009) acknowledge that "informed consent occurs if and only if a person or subject, with substantial understanding and in the absence of substantial control by others, intentionally authorizes a professional to do something" (p. 78). Although Beauchamp and Childress are explicitly discussing the necessary criteria for written and verbal informed consent rather than implicit consent, these criteria are also relevant for implicit consent.

In the case of proposed invasive procedures or surgery, the person responsible for carrying out or supervising the intervention is the one responsible for obtaining written consent. This is usually a physician, although increasingly it may be an APN. APNs who are qualified to carry out procedures or perform anesthesia are responsible for obtaining written consent. Staff nurses have responsibilities for ensuring that their patients are in a position to adequately understand what they are agreeing to. This has implications for the clinical nurse specialist (CNS) or nurse manager who serves as a floor resource, mentor, and educator and who sets the tone for the staff nurses on his or her unit.

Informed Consent: Ethical Problems

Informed consent, however, is a complex and tricky concept. For each person, the information needed for the person's consent to be "*substantially informed*" is different. For procedures or interventions that involve more than minimal risk (risk that is encountered in daily life), informing the patient should be viewed as a process because, for the most part, those faced with invasive procedures are already upset and anxious. Information processing under conditions of anxiety and stress is difficult, and studies have shown that people neither process nor retain information well under such conditions (Broadstock & Michie, 2000; Charles, Gafni, & Whelan, 1999; Kegley, 2002; Starcke, Wiesen, Trotzke, & Brand, 2016). The informing process involves understanding certain things about the patient. Nurses need to understand the patient's beliefs, including culturally based beliefs, values, and goals; the patient's ability to process information; and psychological, physiological, or environmental factors that might interfere with or facilitate processing of information.

Patient-related psychological factors that can interfere with information processing are such things as psychological denial of a physical illness or diagnosis, loss of hope, unreasonable expectations of an intervention, a desire to please a provider or significant others, lack of energy to think through possible options and how they relate to goals, and cognitive problems. Physical factors include pain, sedation, fever, and poor cerebral perfusion, among others. Provider-related problems include inadequate knowledge about a procedure and its potential side effects (for example, a lack of understanding of the full range of implications related to genetic testing as discussed in Chapter 9 on women's health); an inability to connect with a particular person, which can interfere with the project of tailoring information to that person's specific needs and abilities; lack of understanding of the origins or meaning of any cultural factors; lack of knowledge about existing options or objections to providing the full range of options (for example, provider beliefs about the moral status of emergency contraception); and self-knowledge related to prejudice or bias. Additionally, certain situations are fraught with communication difficulties. Examples of such situations include language barriers, hearing impairments, and patients who are perceived as "difficult."

This discussion focuses on three important complicating factors related to appropriately informing patients: (1) the provider's appeal to conscience in not providing patients with the full range of options legally available, (2) cultural considerations in informing patients, and (3) the issue of difficult patients. Early identification of potential communication problems and attempts to anticipate and address these problems has been termed *preventive ethics*. One important professional problem is that of withholding information or not offering the available range of options for a patient's situation because it is against the provider's conscience. The next section addresses this issue.

Conscience and Personal Integrity

The issue of healthcare professionals' refusal to provide patients with certain information and/or services has recently received publicity in the popular press in the United States. There are also reports from Europe of movements to protect healthcare providers who refuse care or limit information to patients based on conscience (Catholics for Choice, 2012). In 2010, the Parliamentary Assembly of the Council of Europe (PACE) debated the issue of the right of healthcare providers to conscientious objection (resolution #1763), urging states to provide patients timely access to legally permissible options (PACE, 2010). In opposition, the Swedish parliament has urged that their delegates work to change this resolution, reportedly because they overwhelmingly find it problematic that providers can withhold legally available options (Protection of Conscience Project, 2012). The ethical implications of refusing to disclose legally available options or to offer a full range of services have elicited renewed scrutiny on the part of moral philosophers, ethicists, and scholars in the various healthcare professions (Lamb, 2016; Wicclair, 2011). Appeals to conscientious refusal to provide certain options are usually based on one of the following arguments: (1) although legally available, the healthcare provider finds the option morally objectionable based on religious grounds or on the basis of other personal beliefs; (2) the provider believes that certain options are congruent with his or her beliefs, and others are not, and there is no obligation to reveal this bias to the patient; or (3) the provider believes that some available options are inferior or have too many side effects, and thus the provider is saving the patient from confusion.

As an example of the first argument, Jacobson (2005) highlights the case of registered nurse Andrea Nead, who did not want to "administer emergency contraception" (p. 27) as part of her role responsibilities. She claimed that she did not get a position she sought in a university health clinic because of her religious beliefs. Other examples (of the second and third arguments) from advanced practice settings include a colleague who referred patients in need of mental health services only to a Christian mental health facility, and another colleague who neglected to offer a variety of therapeutic options available for labor pains by encouraging patients to "have an epidural—it is a woman's best friend." In palliative care settings, refusal to provide adequate pain relief may result from providers' beliefs that they are contributing to a person's death.

The preservation of personal integrity is very important. It enables nurses to provide for a patient's good, sometimes against sturdy barriers and sometimes against the "generally accepted view" of what is permissible. *Integrity* means maintaining a sense of self as a whole. It is tied into ideas of personal identity (Benjamin, 1990). Loss of a sense of self and personal integrity has been associated with the experience of moral uncertainty and moral distress, as discussed in Chapter 1, especially when a nurse is unable to ensure that a patient receives the care that clinical judgment reveals is needed. These experiences can lessen an APN's confidence and resolve related to decision making. Provision 5 of the American Nurses Association's (ANA, 2015a) *Code of Ethics for Nurses with Interpretive Statements* upholds nurses' needs to care for the self, asserting, "The nurse owes the same duties to self as to others, including the responsibility to promote health and safety, preserve wholeness of character and integrity, maintain competence, and continue personal and professional growth." Additionally, many U.S. state laws (45 states) have conscience clauses that allow providers to refuse treatment or recuse themselves from participating in care based on philosophical or religious objection. Charo (2005) notes that conscience clauses in U.S. state law result from "the abortion wars" in the United States (p. 2471). That is, conscience clauses are "laws that balance a physician's conscientious objection to perform an abortion with the profession's obligation to afford all patients non-discriminatory access to services" (Charo, 2005, p. 2471). These laws are often broad enough to protect other professionals from the legal consequences of conscientious objection to certain procedures or treatments.

However, legal protection is not a good reason for a person to impose his or her beliefs and values on someone else. In fact, refusing to provide care because of personal beliefs requires that the nurse carefully consider the situation and understand the implications of this refusal. This is especially important when the nurse is in a strong (powerful) position relative to the person who is seeking legally available information or treatment. A nurse's ethical responsibilities for good care may often include following the considered wishes of patients for something with which the nurse does not agree because it is not what the nurse herself would want, because the nurse does not think it is in the patient's best interests, or because the nurse thinks it is misguided. However, it is important to keep in mind that a healthcare decision should not be based on a provider's preferences; ideally, decisions should be based on the lifestyle, culture, beliefs, and values of the person whom they will most affect. Thus, nurses must understand whether they have the facts straight, to what extent they are likely to be affected by going against what they believe, and how enduring the insult to their sense of identity is likely to be.

Moral distress is the feeling of disequilibrium experienced by nurses when they either cannot give the care needed or are asked to participate in care that they feel is wrong or harmful. The experience of moral distress and its residue (Webster & Baylis, 2000) can have long-lasting effects on nurses' practice. Some nurses leave the profession, whereas others may end up distancing themselves from certain patients because of repeated or serious experiences of emotional or ethical conflict. The question, then, is, "How do nurses preserve integrity while fulfilling their professional duties related to informed consent?" First, it is crucial to remember the almost inevitable inequality of any provider–patient relationship. Patients are vulnerable because of a lack of knowledge, skills, resources, or capacities in regard to meeting their health needs. They present to a provider trusting that their concerns will be taken seriously, the healthcare provider will be honest and transparent, and the healthcare provider will not either deliberately or unthinkingly hide available options or potential resources. In a sense, healthcare providers can be said to "hold the keys" to a wide variety of not-easily-available knowledge and have the necessary skills of interpretation for making distinctions clear. Such privileges should not be abused. The recently revised ANA position statement, *Risk and Responsibility in Providing Nursing Care* (ANA, 2015b) provides important guidance. "When moral objection is made, the nurse is obligated to provide for the patient's safety and ensure that alternate sources of nursing care are available." Both the revised and earlier statement (ANA, 2006), arguing that "[T]he nurse who decides not to take part on the grounds of conscientious objection must communicate this decision in appropriate ways [and] whenever possible, such refusal should be made known in advance and in time for alternate arrangements to be made for patient care," provide detailed criteria for determining what level of personal risk is acceptable and what further responsibilities fall to the nurse involved. Magelssen (2012) provided a set of criteria for determining the permissibility of conscientious objection for healthcare providers. He emphasizes that conscientious objection is permissible when the clinician's "moral integrity is [likely to be] disrupted. . .[by] a serious violation. . . of a deeply held conviction" (p. 19). He focuses on the 'plausibility' of the objection. A moral or religious objection should be able to withstand logical critique. Additionally, certain criteria should be met related to the likely effects of care refusals on the patient and the patient's rights to care. Finally, self-recusal from providing care is only acceptable when "the burdens to colleagues and healthcare institutions are acceptable and small"(p.19). Several integrity-preserving options are open to APNs in difficult situations. First, self-reflection should reveal the source and strength of the objection and whether the APN has a thorough grasp of the state of the science involved. For example, many objections to emergency contraception are based on inaccurate information related to how it works. The APN's objection may stand even after researching the facts involved; nevertheless, fact gathering is a professional responsibility. Sometimes the nurse is faced with choosing what he or she considers the "lesser of two evils" related to actions of conscientious objection. For example, the recently highlighted problem of fetal microcephaly caused by the Zika virus may cause dilemmas for nurses and others with strong religious objections to abortion and/or contraception in providing advice to those exposed (Zhang, 2016).

Second, the APN should answer the following questions: "If I needed information about a healthcare issue with which I was unfamiliar, what would I want from the specialist? How would I feel if I discovered the provider had selectively withheld options or information from me?" If after answering these questions the APN remains strongly opposed to participation in a legally available procedure or to providing certain types of information, the reason for not discussing options or not providing the requested care must be communicated to the patient. The patient should be enlightened about the fact that resources are available and/or referred to another provider who is willing to discuss the range of options or undertake the procedure (see Chapter 5 related to referral issues). The APN should clearly communicate that there are other options, but that the APN's own beliefs do not permit him or her to discuss them.

Further, if the APN personally does not object to providing certain types of information or interventions but is restrained by the institution or practice (e.g., in a setting that is managed by a religiously based organization) from discussion of options or undertaking the procedure, this should be acknowledged and appropriate resources provided.

Culturally Based Communication Issues

Other issues that serve as obstacles to obtaining substantially informed consent are related to culture differences and lack of fluency in the patient's language or the patient's lack of fluency in the language of the context. Although in Western cultures the idea of autonomy is valued, in many other cultures decision-making responsibility belongs to the head of the household or is a family affair. Trying to understand the beliefs and values of someone from another culture can be a perplexing and frustrating task. It can be difficult to separate issues of coercion and undue influence from the cultural norm. Additionally, the cultural norm in some cultures can be oppressive for a particular group, such as women, or (less commonly) may be age related.

What are the APN's responsibilities in such circumstances? There are no ready answers to such questions. It is an obligation of practice to learn more about a culture, if members of that culture are seen frequently in the APN's practice environment. In some cultures where there is evidence to show that certain practices are harmful (for example, female circumcision), the nurse can join with concerned others to understand more about the practice, the underlying assumptions of the practice, and what others have done either to change it or to provide appropriate care for its subjects. Most important, maintaining a nonjudgmental but interested affect is probably the most helpful both in ascertaining a person's needs and in providing assistance.

For language difficulties, certain considerations are important. Does the APN have a good interpreter? Are there ways to validate understanding and ensure that the interpreter has translated the intent of the APN's evaluation or information sharing? The following are some helpful hints synthesized from a variety of sources, including our own professional experiences.

In line with viewing informed consent as a process, time and patience are needed. More than one appointment or session may be required. It is helpful to speak in short units and have all parties take turns speaking—the nurse, the interpreter, and the patient. For exchanges involving complex information, the nurse should request the interpreter to report what the patient understood the information to mean for himself or herself in addition to conveying the patient's responses. This permits identification of areas of concern and facilitates patient understanding.

The nurse should look at the patient while speaking and be aware of the patient's body language and appearances of confusion or discomfort. The nurse must also validate with the patient if the nurse's perception is accurate and respond accordingly. Speaking directly to the patient is important, as in, "This will mean that you..." The interpreter will interpret everything, so the nurse should be careful not to say to the interpreter something that he or she does not want shared with the patient. Explanations should be supplemented with visual materials when possible. Practices may want to invest in video presentations in the patient's language as an adjunct, but this does not substitute for a fuller process of information gathering and giving. The focus should be on meeting the patient's needs, and not on any inconvenience or discomfort that the nurse feels.

It is best not to use family members for interpretation service (except for mundane matters such as what kind of food they like), especially not children. It can be a temptation to rely on a person's children because they may be more fluent in English (or the language of the provider) than their elders are, but interpreting is a heavy responsibility to place on them and inappropriately shifts family roles. A case study outlined in the Hastings Center Report (2004) describes the case of a 15-year-old daughter of a Chinese male immigrant. Her father was admitted with a cardiac problem. Circumstances were such that a Cantonese interpreter could not be found easily. The physician wondered if she should allow the daughter to interpret the situation for her father, including among other things, the seriousness of his condition.

Difficult Patients

All nurses have encountered patients whom they perceive as difficult in some way. Wolf and Robinson-Smith (2007) define *difficult patients* "as those whom nurses perceive consume greater periods of time than their condition suggests; they impede the work of the nursing staff with demands, complaints, and lack of co-operation" (p. 74). Sometimes it is not the patient so much as the patient's family that is perceived as difficult. Patients may seem or be difficult for a variety of reasons. Nurses may experience a dislike for them for unknown reasons. Perhaps the patient reminds the nurse of someone with whom the nurse argues, or the patient questions the nurse's knowledge or expertise. Perhaps the patient is violent, abusive, or argumentative. Patients may be difficult because of the complexity of their issues or the perceived hopelessness of their situations. Additionally, certain patients may be stigmatized by their lifestyle, obesity, or disease. Reports of patient violence toward nurses are also on the rise worldwide (Robert Wood Johnson Report, 2015). There are thus implications for nursing leaders related to protection and support of those with whom they work or for whom they are responsible.

Whatever the reason for the perception of a patient as difficult, APNs are still responsible for trying to meet these patients' needs. Wolf and Robinson-Smith's (2007) study investigates strategies that are used by CNSs in "difficult clinician–patient situations" (p. 74). Two frequently used strategies were demonstrating "respect for the patient" and "focusing on the issue at hand" (pp. 79–80). This includes avoiding labeling the patient and CNSs setting an example for others. A fairly recent example from the locale of two of the authors is that of Dzhokhar Tsarnaev, the younger of the two brothers responsible for the bombings at the 2013 Boston Marathon. Tsarnaev survived his capture with serious injuries. He was cared for by nurses at a major Boston hospital where many of the bombing victims had been treated. Nurses were asked to volunteer to provide care. "All of the nurses asked by supervisors to care for Tsarnaev agreed, the hospital said. The *Globe* interviewed seven of them, and all said that the ethical bedrock of their profession requires them to treat patients regardless of their personal history" (Kowalczyk, 2013). Maintaining a nonjudgmental attitude permits the sharing of information needed for the patient's decision making related to care preferences. Supportive environments are also critical for nurses to be able to adhere to their professional obligation to treat each individual with dignity. For example, as recounted by some of the nurses to a colleague (one of the chapter authors), some subsequently found themselves the object of disdain from those around them, and some also struggled with what it meant to have "cared for a terrorist" and experienced guilt for their moments of compassion for him.

Both of the strategies for dealing with such cases avoid bias and are aimed at trying to understand who the patient is and what underlies the patient's actions and affect in order to meet the patient's needs. In keeping to nursing's ethical ideals, we also avoid having to decide who is and who is not worthy of our attention. In other words, we honor the humanity of each person. In addition to the problems just discussed related to assessment of the patient's particular needs, the provider may also be subtly influenced to emphasize some aspects of information over others, as discussed next.

Other Influences on the Informing Process

Conflicts of Interest

Ensuring that patients' decision making is adequately informed for their needs also requires nurses to reflect on which other factors may be subtly influential, such that they are not readily or easily recognized. The ethos of the practice environment, economic or time constraints, the influence of drug company practices, and pressures from colleagues all have the potential to cause a subtle skewing of the information given to patients. Conflicts of interest (COIs) are pervasive in healthcare practice, regardless of profession. A COI exists any time there is pressure or temptation to act in a way such that a given patient's interests are not held as primary. COIs in professional nursing practice can be of several types: economic, such as when the financial pressures on a clinic or healthcare institution shift the primary focus off patient "good"; interpersonal, such as when a battle between providers for control of a situation causes loss of focus on mutual goals; and environmental, such as when others do not notice that there is a problem and put pressure on nurses to go along with the status quo. In addition, COIs may arise when appropriate resources or referring physicians are not available; in psychiatric and counseling practices, sexual or boundary-related issues can arise. Studies show, for example, that drug companies have been quite successful in influencing prescribing practices in the United States (Angell, 2004; Kassirer, 2005; Steinman, Harper, Chren, Landefeld, & Bero, 2007). An example from our experiences is that of the drug company representative who provides dinner for the local APN association. The representative brings samples to the office and urges us to try them with patients (Kassirer, 2005). Several studies have confirmed the suspicion that drug company gifts influence prescribing patterns (Coyle, 2002; Steinman et al., 2007; Wazana, 2000). Kassirer's book urges physicians to divorce themselves altogether from accepting drug company gifts. NP prescribing practices are perhaps not as amenable to study as physicians' are, but probably would mirror those of physicians.

As discussed earlier, ensuring that patients are well informed is a difficult task that must not be taken for granted. Ongoing self-reflection and reflection on nursing practice are crucial, as is remaining aware that conflicts of interest are everpresent and may result in subconscious biases that do not serve the patient well. Understanding the important elements of the process, as well as likely problem areas, necessitates vigilance. The other side of the problem has to do with the obstacles that exist for patients in apprehending and processing the information they need for decision making. The next section explores a concern related to informed consent: that of determining decision-making capacity. APNs in different roles and across specialties may be faced with the responsibility of determining whether a patient is reasonably capable of making an informed decision.

Decision-Making Capacity

How does an APN know when a patient is not able to make an informed decision? In some cases, the answer to the question is relatively easy. It is obvious, for example, that a comatose patient, a neonate, or a patient with advanced dementia cannot process information or communicate his or her wishes directly to a provider. For such patients, an alternate decision maker is necessary. This person acts as a proxy either to convey what the person's wishes would probably have been, given knowledge of the person's beliefs, values, and life goals, or to ensure the patient's probable best interests where no knowledge is possible (neonates) or available. The issue of decision-making capacity is especially pervasive in mental health settings and is addressed in detail in another chapter.

In other cases, determinations of decision-making capacity may be more difficult. Buchanan and Brock (1989) note that decision making in healthcare settings is almost always for the purposes of accomplishing a task and occurs along a continuum. In the United States, the issue of decision-making capacity was explored in depth by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, a group assembled by President Carter in 1978. This commission was formed in response to the increasing complexity of problems caused by biological and technological advances. Examples of such problems include how and when to determine death when it is possible to indefinitely prolong life artificially. What is the range of possible effects caused by the application of genetic innovations in health care? What can APNs do about health disparities? And, important for the purposes of this discussion, how do nurses ensure that patients are capable of making their own medical decisions and are not subject to undue interference by interested others who may or may not hold the patient's best interests as primary? The commission's report (President's Commission for the Study of Ethical Behavior in Medicine and Biomedical and Behavioral Research, 1982) concluded that minimal capacities for decision making are "1. Possession of a set of values and goals, 2. the ability to communicate and to understand information, and 3. the ability to reason and deliberate about one's choices" (p. 57).

These criteria are made more stringent when the risks are high and the patient seems to be making a choice that is not in concert with his or her own values and goals. Beauchamp and Childress (2009) note that in cases where the risk of action or inaction is relatively high (the possibility of serious harm exists), it is also important to assess for the voluntariness of the decision. That is, nurses should evaluate whether some internal or external influence is pressuring the person to make a particular decision (see the section "Informed Consent: Ethical Problems" earlier in this chapter). The following case is provided as an example of considerations related to decision-making capacity.

CASE STUDY: JENNY

Jenny is a 33-year-old woman brought into the emergency room from a homeless shelter by shelter staff. She is evaluated by Pauline Hill, an emergency department NP, who, after evaluating Jenny, determines that Jenny's provisional diagnosis is pneumonia accompanied by dehydration. Jenny is also confused and keeps saying, "How did I get here?" The shelter staff person tells Pauline that Jenny completed detoxification for alcohol and unspecified drug abuse just 2 weeks ago, was staying sober, and had just gotten a job. Currently, she is febrile with a temperature of 103.5°F and RR 36. Pauline determines that intravenous fluids and antibiotics are necessary because Jenny is in danger of sepsis. Jenny refuses treatment; she says, "I am trying to stay clean. I want to get my kids back." Pauline talks to Jenny about her worries, tells her of the proposed plan, and reassures her that she is not receiving anything that will set her rehabilitation back. At first Jenny seems to understand and acquiesces, but when it is time to insert the cannula, Jenny starts crying and yelling, "No, I don't want it! I can't have it!" When questioned further, it becomes obvious that Jenny has not retained the information that Pauline discussed with her, nor does she see the connection between treatment and achieving her goals. Pauline realizes that Jenny is not capable of making this decision because she keeps misunderstanding what is proposed.

There is a lot more that could be said about this case, including responsibilities to try to improve Jenny's ability to process information (oxygen, or a respiratory treatment) or to consider alternative courses of action that might achieve the purpose of resolving Jenny's immediate physical needs without further distressing her. However, the purpose of Jenny's case is to illustrate a problem with decision-making capacity for the task at hand. The risks of not treating are high and do not serve Jenny's goals of becoming physically capable of having her children returned to her and being able to care for them. Therefore, the nurse does need to treat the pneumonia and dehydration because not doing so could result in harm to Jenny, perhaps even death. Thus, the point is that, paradoxically, in treating Jenny against her will, which could be seen as not honoring her autonomy, the nurse is actually facilitating autonomous future decision making. A person cannot exercise autonomy when she is not alive to do so.

Proxy Decision Making

Proxy decision making is the act of deciding what healthcare actions are permissible for someone who temporarily or permanently has lost decision-making capacity, never had decision-making capacity (profound cognitive deficits), or is not yet considered to have sufficient maturity to make healthcare decisions (children). When children are involved, the proxy decision maker is usually a parent or guardian who makes decisions on the child's behalf. If developmentally appropriate, children may assent or dissent to a course of treatment. However, a child's dissent may be overruled by a parent or guardian when the risk of not treating is high. The issue of children and assent is discussed in more detail in Chapters 6, 8, and 13.

Types of Proxy Decision Making

In clinical ethics literature and practice, a hierarchy of three levels of proxy decision making is used to determine appropriate treatment for those who are or have become incapacitated. The first level is based on the principle of autonomy and aims to reproduce as nearly as possible what an incapacitated person's wishes would have been. The person may have previously formulated a written directive (also known as a living will or advance directive [AD]), or may have appointed a person who could accurately represent those wishes. When these formal arrangements do not exist, the healthcare team may be able to discern what a patient's wishes would likely be by gathering information about the patient from family members and friends. The second level is often called the *best interests standard*. Beauchamp and Childress (2009) note that sometimes "the patient's relevant preferences cannot be known" (p. 138). In such cases a surrogate decision is made based on quality of life (QOL). Thus, actions are favored if they are likely to provide the highest net benefits in terms of QOL. The best interest standard may permit overriding a surrogate decision maker's directions for treatment when the proposed treatment does not seem capable of benefiting the patient or may cause more harm than benefit. The third level is that of the reasonable person standard. It is used when neither level one nor two is applicable. For example, it is not possible to discern from neonates or profoundly cognitively disabled persons what they would want for themselves. In such cases a decision is made based upon what a "reasonable" person would want. This third level is problematic because it is hard to determine who is "reasonable" given the host of contextual factors involved in any decision-making process (Beauchamp & Childress, 2009; Grace, 2004b).

Legal Aspects

In the United States, what is accepted as legal surrogate decision making differs from state to state. This necessitates that APNs familiarize themselves with the laws of the state (or country) in which they practice. This section outlines some general issues associated with APNs' role in assisting their patients to be prepared for a variety of possibilities related to decision making.

Proxy decision making in health care may be needed for everyday healthcare decisions, for decisions related to an acute illness, and for EOL issues. Although many APNs do not work in a hospital setting, understanding a little about legislation related to EOL decision making, such as the PSDA (OBRA, 1990) in the United States, provides clarity about the reasons for such legislation and likely related issues. The PSDA applies to institutions that receive federal funding (almost all U.S. hospitals and long-term care facilities) and was meant to improve patient decision making especially concerning (though not limited to) EOL decisions. It was meant to improve providers' as well as patients' knowledge about patients' rights to accept or refuse therapeutics and interventions and providers' obligations to provide appropriate information. It was also hoped that providers would assist patients to think about what they would want in the event that they lost decision-making capacity.

Advance Directives

It is, of course, generally better for patients to have considered in advance what sort of care they would like and who might best serve as a good proxy decision maker on their behalf. Although such decisions may be made when patients are already critically ill, this is not optimal (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999; Marshall, 1995; Wolf et al., 2001). Adequate time, a low-pressure environment, and the assistance of a trusted health provider are probably the best conditions under which to process information. Thus, good APN practice means taking the opportunity to raise questions and provide necessary information related to the idea of proxy decision making if a patient appears receptive. Additionally, research (Parks et al., 2011) questioning prospective proxies and those for whom they were to make decisions found that "spousal proxies were more accurate in their substituted judgment than adult children, and proxies who perceive higher degree of family conflict [within their family] tended to be less accurate than those with lower family conflict" (p. 179). From our experiences in both critical care and primary care settings and from the research cited, it is very difficult to discuss such issues when a person is gravely ill, already receiving highly technical care, and in a noisy and hectic environment. Proxy decision making can be an arduous task at the best of times, but is made even more difficult with the potential loss of a loved one looming and when the decision maker may already be overwhelmed with circumstances and lack of needed clinical knowledge (Dionne-Odom, Willis, Bakitas, Crandall, & Grace, 2015).

Preventive ethics strategies include providers making routine a practice of discussing patient preferences at primary care or regular provider visits; helping patients to select an appropriate surrogate (that is, one who can separate personal desires and wishes from the preferences of the person in question); and encouraging patients to provide written instructions for their proxy. A reminder is needed that a proxy only makes healthcare decisions for another person in the event of that person's loss of decision-making capacity. When a proxy is obviously not making decisions that are in the patient's best interests, the proxy can legally be relieved of proxy duties.

Discussion about ADs need not be limited to the older population. McAliley, Hudson-Barr, Gunning, and Rowbottom (2000) studied adolescent attitudes toward living wills, or as they are alternatively known, ADs. Of the 107 participants in the study, the majority felt that it was "somewhat important" or "very important" for someone of their age to have a living will (p. 471). A study of young adults living with chronic illness also supported the idea that conversations about ACP are desirable (Wiener et al., 2008). The advent of ADs or living wills is relatively new. According to Clarke (1998), the term *living will* was invented in 1967 by Louis Kutner, a human rights lawyer and cofounder of Amnesty International, "in a law journal proposal" (p. 92). Kutner, having gone through a disturbing EOL scenario with a close friend, wanted to ensure the right of patients to determine how their last days should unfold in the event of a catastrophe.

The Patient Self-Determination Act: International Implications

The PSDA in the United States (OBRA, 1990) was conceptualized as a result of several landmark right-to-die cases. It relies on state laws related to EOL care and "was designed to encourage communication about end-of-life issues" (Grace, 2004b, p. 310). It requires institutions that receive Medicare and Medicaid funds (U.S. government funds), which includes essentially all healthcare institutions in the United States, to inform patients in writing of their rights to accept or refuse care. It was meant to increase healthcare provider knowledge and thus affect current EOL problems arising in tertiary care institutions.

The PSDA has not been as effective as hoped, and there are many documented reasons for this. A large study undertaken to understand prognoses and preferences for outcomes and risks of treatment conducted over several years, which initially involved observation but later added interventions aimed at improving the communication of patients' wishes, failed to show that patients' preferences were respected. Marshall (1995) and others have argued that this is because institutional hierarchies and power structures have not significantly changed as a result of the PSDA.

Others have noted a variety of concerns about ADs that might make some people reluctant to draft them and some healthcare providers reluctant to comply with them. The concerns include the idea that people do not like to imagine themselves experiencing serious illness or death. Accurately predicting what might be needed given a wide array of possibilities is difficult. Patients are afraid they might change their minds, but not in time to change their ADs, or that not accepting certain interventions might lead to their abandonment by caregivers (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007; Wolf et al., 2001). Additionally, there are cultural and minority fears about the untrustworthiness of predominantly white middle-class healthcare professionals (Baker, 2002); see the next section for further discussion.

Regulations related to the use of ADs, whether in the written form or in the form of an appointed proxy, vary from country to country. Regardless of the existence of regulations enforcing or supporting patients' previously articulated wishes, it is a healthcare professional's responsibility to help patients and those close to them think through what care and interventions they might wish for in the event of a loss of decision-making capacity. This permits advocacy and honors autonomy. Durbin, Fish, Backman, and Smith (2010) reviewed available research on the influence of educational interventions in improving AD completion. They found (perhaps not unsurprisingly) that a two-pronged approach—providing written and oral information—had the best effects on completion, but the results were not strongly compelling. More interventional research is needed.

Despite concerns about ADs, many professionals and ethicists who are involved in EOL care think that with time and custom more people will become involved in the process of advance planning for the event of lost decision-making capacity. The most effective plan is probably a two-part initiative: the appointment of a trustworthy representative who may or may not be a relative, and written instructions to assist the proxy. Understanding both the benefits and the criticisms of formal ADs allows APNs to assist patients in thinking about their specific advance planning wishes. In advanced practice, nurses are key to interpreting a variety of EOL scenarios in terms that are tailored to a particular patient's needs and level of understanding.

Advance Care Planning: Minority and Cultural Issues

Although ACP is generally thought to be a good thing, facilitative of an individual's choices, there are historical and cultural reasons for certain groups to view ACP with uncertainty and fear. Indeed, such fears (coupled with the ones noted earlier) may be in part responsible for the slow progress made in preparing and educating the public about the potential benefits of ACP. Johnstone and Kanitsaki (2009) draw attention to the problem in the United States and Australia in particular; it is likely that in other multicultural societies certain groups feel disenfranchised by society as well. "Emerging international research suggests that in multicultural countries, such as Australia and the United States, there are significant disparities in end-of-life care planning and decision making by people of minority ethnic backgrounds compared with members of mainstream English-speaking background populations" (p. 405). Moreover, public policies in these countries are not always sensitive to this problem. Johnstone and Kanitsaki (2009) note that the few studies that have looked at differences between cultural majority and cultural or linguistic minority groups within a society related to ACP reveal several tendencies on the part of minority cultures: a smaller number complete ADs; family involvement in discussions about decision making is preferred; ADs are viewed as an intrusive and legalistic mechanism that has no place in health care; and aggressive treatment is preferred, especially when patients have experienced prior mistreatment or bias (Bito et al., 2007, p. 260). In ethical terms, these patients' prior experiences, distrust of the system, and fears about undertreatment can paradoxically lead to greater harms (a nonmaleficence problem) from overtreatment or treatment that is futile for the intended purpose and causes unnecessary suffering. Strategies for APNs include engaging patients in dialogue about their cultural values, their prior experiences, and their fears. Planning for the future includes understanding what patients' goals are given a variety of scenarios and helping them to envision desirable courses of action.

▶ Veracity and Transparency

Veracity is an ethical principle underlying the idea of trust and fiduciary relationships. "Veracity or truthfulness in giving patients information about their health-care needs facilitates autonomous choice and enhances patient decision making" (Grace, 2004b, p. 315). However, the concept of veracity is more difficult to apply than it appears on the surface. It is fair to say that in ordinary life people are rarely completely truthful with friends, family, and strangers. People hold information back, either because they feel it could come back to haunt them or because to be completely truthful may well hurt another person. Nevertheless, "truthfulness has long been regarded as fundamental to the existence of trust" (Fry & Grace, 2007, p. 287), and, as noted earlier, trust is fundamental to the nurse–patient relationship. Patients are vulnerable because of their healthcare needs and must rely on nurses to help them. If APNs are not able to gain a certain level of trust with patients, then their data-gathering activities are likely to be frustrated. This, in turn, lessens the likelihood that nurses will be able to give holistic care, which in turn means that nursing goals are not met.

However, being too honest or giving patients more information than necessary for their decision-making purposes can also frustrate the project of attending to their needs. Clinical judgment is required to make determinations about acceptable levels of information for a given patient; that is, what will permit the patient's participation in decision making. For example, to the family nurse practitioner (FNP) caring for Ms. Jones, a 60-year-old in a rural family practice clinic, it has become obvious that her patient needs to add an antihypertensive drug to her care plan. Although for several years Ms. Jones has, with the FNP's help, managed to control her blood pressure by increasing her exercise regimen, reducing stress, and being careful with her diet, her blood pressure is starting to show a pattern of persistent elevation above recommended levels. She does not want to start taking blood pressure pills, but the FNP has done a good job of educating her about long-term effects of poorly controlled hypertension, so she is willing to start taking them now. What drug the FNP tries initially and how much information she gives Ms. Jones depends on what the FNP knows about Ms. Jones. Discussion of the side effects Ms. Jones is most likely to experience and how these match her lifestyle and preferences will facilitate a first choice. Explanation of likely side effects will also be tailored to this patient's needs. However, transparency about the extensiveness of what is known related to the drug and the amount of information the FNP gives are also important. These are all clinical judgments based on knowledge of the patient and, like many clinical judgments, they have some element of uncertainty. With Ms. Jones, it might be beneficial to discuss major side effects, whether these effects are acceptable to her, and what she should report to the FNP. Additionally, the FNP should acknowledge that there are possible side effects that Ms. Jones may not experience and that the best way to deal with this is to remain accessible for questions Ms. Jones may have if she experiences unexpected changes.

In palliative care or EOL care settings, problems of veracity can occur when relatives pressure nurses and others to withhold the truth about a condition from patients. Veracity has some implications in the care of patients from cultures where the patient is traditionally protected from knowledge of the criticality of the condition. "Decision making about whether to honor [the demands] of veracity in such cases must take into consideration what is known about the culture, the particular patient, the strength of his or her personal and cultural beliefs, and whether there is evidence about what sort of things the patient would like to know" (Grace, 2004b, p. 316). If a patient is asking questions about his or her condition, then nurses need to respond accordingly. Nurses need to draw on what is known or has been discovered (evidence) related to a person's needs to come to terms with his or her condition and nearness to death. However, nurses also may need to assist the family with their needs to fulfill cultural responsibilities. Resources may be found within the cultural community.

In pediatric settings, the issue of veracity is also complicated. Questions arise about how to communicate information in age- or developmentally appropriate ways. How do APNs interact with parents or guardians who seem overly protective or are working in ways that seem at odds with what is known about the child? This question is explored in depth in later chapters.

Privacy and Confidentiality

The healthcare principles of privacy and confidentiality are also derivations of the ethical principle of autonomy. The terms *privacy* and *confidentiality* are often lumped together as if they mean the same thing. Privacy, however, is "the broader concept and includes the right to be free from the interference of others" (Grace, 2004a, p. 33) and freedom to grant or withhold access to information about oneself. Justification for the right to privacy, as noted by Beauchamp and Childress (2009), "flow[s] from fundamental rights to life, liberty, and property" (p. 295). Confidentiality is related more specifically to the protection of a person's information, particularly the person's healthcare information. Beauchamp and Childress (2009) note that in healthcare settings, the right to privacy is most often a control right of sorts: it is the right to control both access to and distribution of information.

For Beauchamp and Childress (2009), a helpful distinction can be made between privacy and confidentiality in terms of the status of violations thereof. Confidentiality is violated when one person discloses information about another person, whereas when privacy is violated, one person gains access to another person's personal data. Rights to privacy and confidentiality in healthcare settings are contemporary recognitions. The reason for recognition of these rights is that a person's healthcare information can be used in negative ways that cause harm. In non-healthcare situations, the status of confidentiality is considered so important that it is protected by privilege and is "shielded from exposure by the legal system" (Grace, 2005, p. 114). For example, the clergy–supplicant privilege prevents courts from forcing clergy to reveal confidential information entrusted to them by congregants.

Limitations on the Right to Privacy

For healthcare providers, honoring privacy, which includes the maintenance of patient confidentiality, is important but does not supersede all other considerations. There may be occasions when an APN should break confidentiality to prevent serious harm to another person. The difficulty, however, lies in making the assessment of dangerousness: how imminent it is and how severe the likely consequences are. There are also legal limitations in different states and countries on the right to privacy based on likelihood of "harm to self" caused by certain proposed actions (discussed in more detail in later specialty chapters). Also, providers may be mandated to report certain suspicions of abuse, such as child or elder abuse.

The well-known *Tarasoff* case set a precedent in the United States related to limitations in provider–patient privilege. In October 1969, Prosenjit Poddar killed Tatiana Tarasoff. Poddar had been seeing a psychiatrist and told the therapist he was going to kill a woman, who was easily identifiable as Tatiana. At the time of Poddar's statement to his therapist, Tatiana was out of the country in Brazil. The therapist sought to have Poddar committed, but was unsuccessful because Poddar appeared rational. No one warned Tatiana or her family of the threat, and on her return Poddar killed her. The courts, in this case, aligning against the idea that psychiatrist–patient privilege is absolute, concluded that "once a therapist does in fact determine, or under applicable professional standards reasonably should have determined, that a person poses a serious danger of violence to others, he bears a duty to exercise reasonable care to protect the foreseeable victim of that danger" (*Tarasoff v. Regents of University of California*, 1976).

Beauchamp and Childress (2009) note three main areas where limits on privacy might require a "balancing of privacy interests against other interests" (p. 297). These areas are "(1) screening and testing for HIV infection, (2) ensuring effective treatments for patients with active tuberculosis (TB), and (3) human genetics" (p. 297). Contemporary issues of dangerousness to others include the deliberate dissemination to, or careless exposure of, others by someone with a transmissible disease, such as HIV or TB.

The Meaning of Privacy in Health Care

The concept of privacy is important to the earlier discussion of informed consent, although this was not explicitly stated. Essentially, the privacy principle means two things: (1) patients should have a say in who is allowed access to their bodies or, for the purposes of evaluation and treatment, other information; and (2) unless the patient gives explicit permission, there is a proscription against healthcare personnel sharing information gained, except for the purposes of helping that patient. In contemporary society, privacy and confidentiality concerns are exacerbated by the pervasive nature of electronic media, as discussed in more detail shortly. The ease with which information, including photographs, can be transmitted via cell phones and other devices, and the ubiquitous use of social media such as Facebook, Twitter, and so on, can lead to the careless exposure of patient information. For example, a mother in the neonatal infant care unit takes a photo of her baby and posts it on Facebook; inadvertently she has included the baby in the next incubator and the visiting parents. The protection of a patient's privacy has a variety of implications, both in institutional settings and in primary care. It requires nurses to think carefully about their actions related to patients, including what they tell referral sources, how they transfer information, and what the implications of testing are related to privacy and protection. It is a reminder not to take privileged access to sensitive patient information for granted. Respecting a patient's right to privacy means that when a student APN interacts with a patient as part of gaining clinical expertise, the student status should be revealed. In patient rounds, persons in the rounding group should be clearly identified. Patients can waive this right, but should be made aware of it.

The principle of privacy has numerous other implications as well; for the most part, though, concern for the delivery of good patient care will ensure that a patient's privacy is respected. For example, the privacy principle means that providers protect those who are not capable of protecting themselves from the intrusion of others, perhaps because they are not aware of the possibility that sharing personal information can affect such opportunities as job prospects and the ability to have health insurance. Providers in the United States should be aware of the so-called Privacy Rule and its impact on their practice. This rule is explored in more detail in the following section. It is impossible in this text to discuss the regulations surrounding privacy concerns in all countries that have such regulations; however, the implications of the Privacy Rule and ethical considerations concerning privacy and confidentiality are pertinent regardless of country of practice.

HIPAA and the Privacy Rule in the United States: History

According to Beauchamp and Childress (2009), "[p]rivacy received little attention in the law or legal theory until the late 19th century" (p. 294), and then it was concerned with protecting family life, child-rearing practices, and other areas of personal choice. Confidentiality as a subcategory of privacy refers to patient rights to have their healthcare information safeguarded. The irony of confidentiality is that in order to receive care, highly personal information has to be revealed to those who will be providing that care. Those providing direct care may sometimes need to share patient information with others whose expertise is important in meeting patient needs. Thus, illness itself makes a person vulnerable, and in trying to address illness a person also becomes vulnerable to those who have access to that personal information.

Prior to 1996, rights to privacy and confidentiality were protected by state or country laws, professional ethical codes, and ethical deliberation. The advent of large electronic databases for storing medical records, however, jeopardized providers' ability to protect their patients' records. Most who have been involved in health care in the United States, whether patients or providers, have become familiar with the Health Insurance Portability and Accountability Act (HIPAA); however, much confusion about this act remains (F. Anderson, 2007). HIPAA was enacted in 1996. Before HIPAA, if a person lost his or her job, he or she often also lost health insurance coverage, because health insurance in the United States for the most part is attached to a particular place of employment. HIPAA ensured that a person could continue coverage until regaining employment, at which point new coverage would begin with the work-associated health insurance company at the new employer. HIPAA was also supposed to expand coverage. Another section of HIPAA, the "Privacy Rule," was meant to standardize the use of health information across the country while providing privacy protection. Suggestions had been made for the development of a huge database that could track almost everyone's health care in the United States from birth to death. Thus, HIPAA was supposed to accomplish two somewhat contradictory tasks: (1) allow for the flow of information that would enable research and access to patient care records for the purposes of improving care and public health, and (2) act as a brake on covered entities' free use of medical information enabled by such a database. A *covered entity* is a person, practice, clinic, pharmacy, or institution covered by HIPAA. Essentially, a covered entity is anyone providing patient care services or undertaking research on human subjects.

Subsequently, a privacy rule was attached to HIPAA (United States Department of Health and Human Services, Office for Civil Rights, 2016). The Privacy Rule specifically covers all individually identifiable information, including written, oral, or computerized information. This went into effect in 2003. An important point to note is that if state rules about privacy are more stringent than HIPAA, then the more stringent standard applies. That is, state regulations trump HIPAA if they are more rigorous than HIPAA standards.

The problem with the Privacy Rule, as noted earlier, and the problem with maintaining privacy and confidentiality based purely on ethical considerations (i.e., without such a rule) is that it is impossible to delineate all imaginable scenarios related to privacy infringements, so clinical judgment, including ethical reflection, is still needed for its interpretation in specific situations. "A rule of thumb for health care professionals related to sharing information with others is to disclose only as much information as is necessary to permit optimal care and only information that is pertinent to the situation" (Grace, 2005, p. 115). Additionally, prudence and mindfulness are required when other people's healthcare records are in the APN's hands.

F. Anderson (2007) provides tips for ensuring that patient information is not overheard or overseen. Importantly, care must be taken not to leave information lying around and not to discuss patients in public places; the nurse must consider whether an outsider could identify the person being discussed if he or she overheard the conversation. In rural settings, maintaining confidentiality can be especially difficult. Providers are often members of the small communities in which they practice. It is not unusual for an APN to be asked about the status of a family member or friend's health in a grocery store or other local gathering place. Additionally, in rural settings office staff may have access to the records of family members or friends. Part of the APN's responsibilities in such settings is educating the staff about the implications of accessing information which they have neither a need nor a right to access.

In an *American Journal of Nursing* article, F. Anderson (2007), the privacy officer for her institution, provided and answered some questions that may be helpful in understanding the intent of the Privacy Rule; some of these suggestions also have utility outside of the Privacy Rule. Anderson posed some common questions to highlight confusions and to illustrate commonsense answers.

- Is it permissible to call or write to a community provider when referring a patient? *Yes, if the disclosure is for treatment purposes.*
- Am I allowed to e-mail a diagnostic report to another provider for treatment or consultation purposes? *Yes, but encryption is strongly encouraged.*
- May I videotape or photograph patients for teaching purposes? *Yes, but consent should be obtained or patients should be "de-identified"* (F. Anderson, 2007, p. 67).

Additional insights into APNs' experiences related to privacy and confidentiality are provided by Deshefy-Longhi, Dixon, Olsen, and Grey (2004). They conducted a series of studies aimed at describing the views of APNs and their patients related to the protection of healthcare data. Of nine issues identified in focus group explorations, six were identified by both patients and nurses. One of these mutual concerns was the issue of "breaches in privacy occurring through carelessness" (p. 387). Examples given included phone conversations that could be overheard, conversations about patient information that took place in public spaces, and patient information lying around or viewable on computer screens. Additionally, both groups worried that excessive regulation prevented needed information from being communicated to appropriate resources. Even the need to leave a telephone message for a patient at home posed concerns; nurses wondered how much, if any, information to leave. Additional concerns of the APN group were abuses of privacy related to the use of computers and problems attending to the privacy concerns of adolescents.

Social Media and Electronic Medical Records

Social Media

A contemporary challenge to privacy and confidentiality is the widespread use of social media by patients, providers, and healthcare organizations. The mechanisms of communication via social media weaken the control individuals have over their personal information. *Privacy* is the freedom to grant or withhold access to information about oneself; *confidentiality* involves protecting the redisclosure of private information divulged between two people in an established confidential relationship, such as the patient–provider relationship (Beauchamp & Childress, 2009). APNs and other healthcare providers may enhance their ability to protect patient privacy and confidentiality by keeping abreast of the benefits as well as potential misuses of social media.

Several nursing organizations have established social media guidelines for nursing and healthcare professionals (National Council of State Boards of Nursing, 2011; National Student Nurse's Association, n.d.). The 2015 revision of the *American Nurses Association Code of Ethics with Interpretive Statements* affirms, "The nurse has a duty to maintain confidentiality of all patient information, both personal and clinical, in the work setting and off duty in all venues, including social media or any other means of communication. Because of the rapidly evolving communication technology and the porous nature of social media, nurses must maintain vigilance regarding postings, images, recordings, or commentary that intentionally or unintentionally breaches their obligation to maintain and protect patients' rights to privacy and confidentiality" (ANA, 2015a, p. 9). Institutional policies and professional, legal, and ethical guidelines provide basic frameworks to guide ethical behavior related to social media use.

Since the early part of the 21st century, the Internet evolved from an information transmission forum in the form of static web pages to more dynamic and interactive information exchange, categorized under the broad heading of "social media." This transformation changed how individuals and organizations communicate and relate with one another. The nursing profession benefits from the use of social media through the enhancement of social and professional connections, exchange of knowledge among colleagues, and dissemination and discussion of health-related education, research, and best practices (Randolph, 2012), as well as for marketing pursuits (Malette, Cipollone, Sanchez, Smolinksi, & Carpenter, 2014). Many nurses find social media an effective vehicle for "venting" frustrations or talking through workplace issues (Westrick, 2016). Indeed, there are ethics forums and other resources available via social media.

The use of social media in health care has increased so rapidly that healthcare providers are often unsure whether their use of social media will have no impact, a beneficial impact, or a harmful impact on their patients, themselves, or their organizations. While social media may provide new opportunities for effective patient education and disease management, there is a potential risk of overstepping patient–provider boundaries, violating patient privacy and confidentiality, jeopardizing a nurse's employment opportunities, contributing to cyberbullying, or undermining the community's trust in healthcare organizations (Randolph, 2012; Westrick, 2016). State boards of nursing have disciplined nurses for misuse of social media, with the most serious consequences being termination of employment (Westrick, 2016).

Definition of Social Media

Social media refers to Internet or cell phone-based applications and tools for communicating information instantly to a large audience (Fillipo & Fencl, 2016; Melnik, 2013). Examples of social media include Facebook, Twitter, LinkedIn, Pinterest, Instagram, MySpace, Google+, Tumblr, Snapchat, and YouTube. Forums such as blogs and online chat rooms are also popular platforms in which participants build relationships with others who have similar interests (ANA, 2011a; Fillipo & Fencl, 2016; Henderson & Dahnke, 2015; NCSBN, 2011). People who use social media engage in the activity of *social networking*: the use of different forms of social media to create a public or semi-public profile within a bounded system. By providing access to one's own profile and viewing other's social media profiles, people create virtual communities that may actually impact their outward or public behavior, self-esteem, and sense of belonging to a group (Wisniewski, Xu, Lipford, & Bello-Ogunu, 2015).

Social networking involves maintaining a list of contacts with which one shares a virtual social connection. Viewers may have access to each contact's lists of social media connections (ANA, 2011a; NCSBN, 2011; Wisniewski et al., 2015) and thus learn about an individual's personal and professional associations. Prior to the advent of social media, the extent of an individual's social contacts may not have been as apparent or well defined. Keeping information private and confidential among one's social contacts has become challenging. Within the framework of social media, a healthcare provider may, for example, inadvertently post something on a "friend's" Facebook page, unaware that the friend is connected with one of the healthcare provider's patients and in the process, blur the provider-patient boundaries.

Use of Social Media in Health Care

A Facebook report notes that as of December 31, 2015, there were nearly 1.59 billion monthly active users worldwide. Nearly 60% of Americans over the age of 18 and 73% of Americans between the ages of 12 and 17 use Facebook. Another social media provider, Twitter, reported that 255 million tweets were sent daily in 2014. Patients, healthcare providers, and healthcare organizations all use social media tools for a variety of purposes to meet a variety of ends (Henderson & Dahnke, 2015).

Patient Uses for Social Media

Patients use social media for easy access to healthcare information. Social media has created virtual communities in which individuals can access affordable and convenient health information. Low- and middle-income HIV-positive patients participating in a Peruvian study reported that they had greater knowledge about HIV and health-related behaviors, felt better about themselves, and developed increased trust in research after joining a private Facebook page for the purpose of HIV education. Most participants found this setting acceptable and preferable to the vulnerable feeling of meeting in person, but some participants were concerned that their pre-existing online network would discover they are members of an HIV education class (Chiu, Menacho, Fisher, & Young, 2016). Patients also benefit from finding support communities such as www.patientslikeme.com (Melnik, 2013). In their research on social media, Wisniewski and colleagues (2015) concluded that there is a certain privacy paradox: Facebook users have a fairly high level of privacy concerns, but the benefits of emotional attachment through Facebook keep individuals involved.

Provider Uses of Social Media

Advanced practice nurses and other healthcare providers benefit, both professionally and personally, from social media use. APNs may network with others in their profession; exchange knowledge about new healthcare developments and research; disseminate and discuss health-related information, research, and best practices; and provide health education for the public (ANA, 2011b). Social media channels increase professional visibility. With social media's instantaneous communication, providers can reach out in emergencies to specialists worldwide for assistance to diagnose rare cases. In 2009, healthcare providers gave advice to chronically ill tsunami survivors through Twitter, facilitating the connection of patients to emergency resources. Those healthcare providers were able to reach a large audience of citizens in need (Melnik, 2013). Many providers use social media for professional reasons and maintain their own personal social media accounts as well in order to preserve the appropriate professional boundaries.

Most healthcare organizations have policies outlining appropriate use of social media in the workplace. For example, policies exist that address use of employee computers for personal use during work hours, websites that may or may not be accessed from employer computers, and limitations about what may or may not be posted to company websites (NCSBN, 2011). Employer policies typically do not address the APN's use of social media outside of the workplace (NCSBN, 2011), however. Nursing students at all levels of study should learn the social networking policies in both their clinical sites and educational institutions before utilizing any social media during their clinical training (Westrick, 2016).

Nurses often use blogs and other social networking sites as a source for handling challenging and emotionally charged issues, with the intent of receiving support from fellow colleagues. While the use of social networking to connect with other nurses may provide much-needed support quickly and from a wide audience, even the most careful attempts to keep patient information confidential may fail.

Clinic and Organization Use

Clinics and healthcare organizations have the potential to disseminate health information economically via social media (Melnik, 2013). Richter (2014) writes that when used effectively, social media can benefit hospitals through recruiting employees, increasing revenue, and increasing patient satisfaction. Educating consumers, acknowledging staff, and sharing news about awards are common uses of social media by hospitals. Seven out of ten U.S. hospitals use social media. Large, urban, nonprofit hospitals and hospitals affiliated with universities or health systems are more likely to employ social media; Facebook is the most commonly used method. These hospitals generally do not engage their consumers in reciprocal communication when using social media, however. There is some fear that by engaging consumers, they run the risk of privacy breaches and damaging their reputations with a potentially public display of negative comments and feedback. However, some hospital systems have invested in personnel to manage these concerns, and they do engage the public while keeping private information contained (Richter, 2014).

Ethical Issues Associated with Social Media

Confidentiality and Privacy Implications. Inadvertent breaches of privacy and confidentiality by healthcare providers on social media have damaged the reputation of organizations and undermined trust in the nursing profession. Such breaches risk strict punishments by the state board of nursing, thus jeopardizing individual nursing careers (ANA, 2011a; Melnik, 2013). In the United States, based on HIPAA (1996) and the HITECH Act (2009), state boards of nursing have and will apply strict sanctions to nurses who engage in unauthorized access, use, or dissemination of protected health information. There are also sanctions for knowing about breaches and failing to report them. Individuals who know about breaches have no more than 60 days to report the breach. For example, in *United States v. Zhou*, a research assistant in a rheumatology clinic looked at the health records of a celebrity and was sanctioned by the state board of nursing. "[Institutions] have generally taken a hard line against violations of patients' privacy rights on social media, choosing to terminate the offenders immediately" (Melnik, 2013, p. 8). In a prominent case at the Johnson County Community College Nursing School in Kansas, three nursing students were immediately dismissed from their programs upon the administration's discovery that they had posted a picture of an unidentified patient's placenta on social media (Westrick, 2016). A long legal process ensued. Ultimately, violation of patient privacy and confidentiality erodes the trusting relationship that is at the foundation of the nurse–patient relationship, discouraging patients from disclosing important information to the healthcare provider. The quality of patient care and trust in the nursing profession are thus placed at risk.

The use of social media creates unique situations of patient vulnerability. Advanced practice nurses who work in the operating room (OR) might face issues relating to social media and patient harm. Use of social media in the OR could potentially distract the team members during a procedure and increase the risk of infection from handheld devices (Fillipo & Fencl, 2016). Patients under anesthesia who have not given prior specific instructions about what is or is not permitted in terms of pictures or the like cannot consent to inclusion in social media. Recently, a surgeon photographed a celebrity undergoing a routine laryngeal procedure during an outpatient endoscopy without the patient's consent. After a series of errors, the patient died and the cell phone photograph was discovered during the investigation (Fillipo & Fencl, 2016). The family is suing the surgeon.

Blurring of Professional Boundaries. The boundaries between patients and providers are blurred by the use of social media. Patients may initiate a "friend" request to their provider through Facebook or may post a photo of their loved one and his or her nurse or the APN. There is an inherent risk in blurring the boundaries of the professional relationship (Henderson & Dahnke, 2015) when posting such photos. An APN's professional and private identities are "not entirely separate, not entirely merged, but are integrated" (ANA, 2001, pp. 18–19). Students in an ethics class for advanced practice nurses (2015) at the second author's institution reported receiving Facebook friend requests from parents of pediatric patients or families of NICU patients as a result of bonds developed from their children's long hospitalizations. Parents wanted to continue the relationship after discharge. Other parents felt that "friending" their nurse on Facebook would help them work through the grieving process and feel supported after their child passed away. Because the families were not the patients and the social media relationship would start after patient discharge, honoring the friend request seemed ethical and an act of kindness at first glance. However, after considering the far-reaching effects of such relationships—for example, the family depending on the nurse for healthcare advice, or even placing an undue burden on the nurse who receives multiple such requests—the ethical nature of these types of social network friendships requires further exploration. Nurses faced with these issues should consult their organization's policy and evaluate the harms versus benefits of blurring the professional boundary in this manner.

Risk for Harm to Patients and Providers. Nurses sometimes unintentionally post patient information on social media based on several myths about social media, including that:

1. Communications are private and accessible only by the person who wrote the information.
2. Photos and information may be deleted and rendered inaccessible when in fact they may be retrieved after deletion. Sometimes a photo is circulated so fast that it is already widely shared even when it is deleted soon after posting.
3. Omitting the name and other identifiable information will protect patient privacy and confidentiality.
4. Privacy settings are adequate to protect communications.
5. If you tell the receiver the information is confidential, the information will stay with that person.
6. If an individual thinks it is appropriate to post information, it is probably allowable.

In reality, there may be far-reaching implications, not previously realized (Westrick, 2016). All of the preceding are myths about social media and should not be used as reasons to justify posting or sending any patient information electronically.

Nurses have posted information about patients on blogs, social network sites, and other forums in which the patient was unintentionally identified. In some of these instances, the nurses mistakenly believed that leaving out the person's name or other identifying information would ensure protection of patient privacy. Actually, there are 18 identifiers that must be removed to protect the patient's privacy. Geographic subdivisions smaller than a state, such as a city, and date of service provided could be enough to compromise patient privacy. As noted by Henderson and Dahnke (2015), "A nurse who posts about caring for an 85-year-old female in her own city could cause the patient to be identified by content in the post" (p. 63). Even if the identity of the patient is never discovered, the nurse puts the patient at risk, especially since information saved to social media can be retrieved later, even if the user deletes the information (Henderson & Dahnke, 2015; NCSBN, 2011).

A benefit of social media is its ability to be uses as a tool for journaling, blogging, and having a sounding board in difficult or challenging situations. However, by using social media in this way, nurses risk harming the integrity of the profession, their institution, the healthcare team, and in turn, the individual patient (Henderson & Dahnke, 2015; NCSBN, 2011). In 2015, KOAT News reported the case of a nurse at UNM Sandoval Regional Medical Center who tweeted that she was bored in the ICU and wished the plug could be pulled on a patient to give her something to do (Fernandez, 2015). Corrective actions were taken by the employer because, although there was no breach of privacy, the statement put the profession in a negative light. It created an ethical issue related to breach of trust.

Tagging Facebook pictures and posts is another avenue by which Facebook users may unintentionally breach their friends' privacy. Tagging a person on Facebook creates a link between the pictures uploaded by one individual and to the tagged friend's timeline. The picture of the tagged friend will be available to all of their Facebook friends. Tagged posts do not always require the user's permission, so the picture may be shared against the tagged person's wishes. Tagging has been found to lead to higher levels of self-esteem, bonding, and acceptance, but does take the control over a patient's information away from the patient (Wisniewski et al., 2015). A risk of tagging is that nurses may inadvertently and unknowingly be seen by their patients, employers, and colleagues. Likewise, a nurse may view a patient's picture on Facebook, even if the patient is not on the nurses' friend list. For example, the nurse may be Facebook friends with a neighbor. She may not realize her neighbor is also Facebook friends with the nurse's patient. Through tagging, the patient may see photos of the nurse and vice versa. Some photos may be of a more personal nature than the nurse intends to share with patients. Both the APN and the patient lose control over the provider-patient boundary in these situations.

Guidelines and Recommendations. Although the guidelines provided here are mostly U.S. specific, they may be helpful to policy makers and nurse leaders in other countries who are supporting nurses in practicing ethically. The National Council of State Boards of Nursing (2011) recommends that nurses recognize their ethical and legal obligations to patients to protect confidentiality and maintain privacy. Nurses at all levels of practice should never transmit any patient-related images by electronic media. Nurses should avoid identifying patients by name or posting anything that might lead to identification of a patient. Nurses should not post any disparaging remarks about a patient, even when certain that the patient will not be identified. Nurses should enforce professional boundaries with patients and their families and be very careful about having contact with former patients on social media. All nurses should report breaches of confidentiality and privacy.

It will be helpful for nurses to understand the rationale for limiting this sort of contact so they can explain their reluctance to families in a way that facilitates family trust. Nurses should know and abide by employer policies regarding the use of employer-owned computers, cameras, and other electronic devices. Also, to avoid being accused of cyberbullying, nurses should not make unkind, threatening, offensive, or harassing remarks about colleagues. Nurse educators have a responsibility to understand the ethical pros and cons of social media and pass this knowledge on to their students. Lastly, nurses should not post content or speak on behalf of an employer unless authorized to do so. Employers have advisors who, ideally, understand the risks and benefits of social media related to their services.

The American Nurses Association's *Principles for Social Networking* (ANA, 2011b) include many of the preceding recommendations; in addition, the ANA reinforces the notion that patients, colleagues, institutions, and employers may all view one's postings due to the public nature of social media. Even strict privacy settings do not provide complete control over information dissemination. Professional associations also recommend keeping personal and professional online information separate. The National Student Nurses' Association draws on the recommendations of the ANA and NCSBN and in addition, recommends to student nurses that they be cognizant of the impact of any post made, understanding that faculty, employers, family, and classmates may gain access to their posts and form an opinion about their potential as future professionals. Student nurses should stay informed about privacy settings, as these often change. Also, student nurses should be aware that their professionalism could be affected by how their friends choose to post them on their sites. Westrick (2016) lists several nursing schools that have developed examples of social media policies for nursing programs, and she encourages all nursing programs to do the same.

While guidelines provide a framework within which to evaluate cases involving social media as they arise, some cases do not fit neatly into the frameworks and require additional critical analysis. Considering the benefits and risks of using social media, and the existing guidelines for ethical use, and drawing on the principles of autonomy, beneficence, nonmaleficence, and justice as well as the rules of privacy and confidentiality, analyze and discuss the cases that are provided at the end of this chapter. The following section takes up the issue of the electronic health medical record (EHR) and associated ethical issues.

Electronic Health Records

Background and Definition

The *electronic health record* (EHR), sometimes called the *electronic medical record*, is broadly defined as a "computer application that electronically stores individually identifiable health data" (Layman, 2008, p. 167). In both inpatient and outpatient healthcare settings, the EHR is used to maintain detailed patient records, document clinical interventions, and ensure the transportability of both the record and record-keeping (Bernat, 2013). Although EHRs have been commercially available since the 1970s (Cimino, 2013), the United States has been comparably slower than other countries in uptake of use (Anderson & Balas, 2006; Layman, 2008). Nevertheless, in 2010 the Patient Protection and Affordable Care Act (PPACA) included guidelines for the institution and use of EHRs, in an effort to "reduce paperwork and administrative burdens, cut costs, reduce medical errors and most importantly, improve the quality of care" (United States Department of Health and Human Services, 2015). The guidelines mandated that by 2014, all healthcare providers (public and private) "adopt and demonstrate 'meaningful use'" of EHRs in order to maintain their current levels of Medicare and Medicaid funding (University Alliance, 2013). Thus, American healthcare systems are moving toward universal adoption of the EHR.

Uses and General Benefits of the EHR

The EHR is used in primary, secondary, and tertiary care settings (Häyrinen, Saranto, & Nykänen, 2008) by nurses, physicians, and other healthcare providers such as respiratory, physical, and occupational therapists. Its primary purpose is to document patient progress; however, it also serves several other functions, including documentation for legal, regulatory, and quality considerations (De Ruiter, Liaschenko, & Angus, 2015). The EHR is not standardized across the United States, so the actual appearance and function of the record and types of programs used are diverse.

The improved transportability, access, and purported accuracy of the EHR (Bernat, 2013) are major benefits. Because documentation is computerized, the EHR is more legible than handwritten records (Cimino, 2013), thereby reducing the risk of errors from misinterpretation of poor handwriting. The electronic nature of the EHR reduces or eliminates the need for a paper record; this ideally ensures easier portability and access to records via computer systems across health networks (Bernat, 2013; Cimino, 2013; Layman, 2008), all at a decreased cost (Layman, 2008). Many EHR systems also have built-in safeguards, such as warnings about potential drug interactions and reminders about health maintenance tasks such as appointments, and some have the potential to continuously monitor patient data in order identify dangerous trends and alert providers (Cimino, 2013). While there are obvious benefits for providers and healthcare organizations, there are benefits for patients as well.

Use by Patients

The EHR has revolutionized the way patients are able to both access their own medical records and communicate with their providers though capabilities such as e-mail and messaging systems (Layman, 2008). For example, some healthcare systems enable patients to have access to their records through the Internet. This allows patients to see provider's notes and test results online (Layman, 2008), which may expedite the process of finding out test results and may also improve accuracy of the medical record by empowering patients to correct errors they notice (Pyper, Amery, Watson, & Crook, 2004). The online and computer-based nature of the EHR can help with health promotion by facilitating the ease with which patients can make appointments and by sending automated reminders about routine preventive care (Layman, 2008).

Use by Providers

The EHR incorporates a variety of functions used by providers, including daily charting, documentation of physical assessments and examinations, medication order entry, medication administration records, medical and nursing notes and care plans, documentation of past medical histories, and admission and discharge summaries (Häyrinen et al., 2008). In addition to these documentation functions, some providers perceive the EHR as reducing error, increasing productivity, and reducing costs (Anderson & Balas, 2006). Many hospitals and outpatient settings now have computers in patient rooms and exam areas, so providers are able to chart in real time, in the presence of the patient.

Use by Healthcare Organizations

The portability of the EHR facilities the transferability of the medical record across institutions; rather than faxing patient information, many organizations now have EHR systems that communicate with each other (although this capability is far from universally available). This function ensures that the most recent and accurate patient information is available, particularly in emergent situations such as an inpatient admission in a new medical center.

There are multiple safety benefits to the EHR. In addition to access to up-to-date information, the EHR can reduce medical errors (J. Anderson, 2007). Furthermore, organizations in which the EHR is used in conjunction with other associated safety systems such as medication barcoding have demonstrated cost savings (J. Anderson, 2007).

The EHR has additional uses at an organizational level. For example, healthcare organizations can use the data generated by the EHR to develop health databases (Layman, 2008) for purposes such as data mining and research (Bernat, 2013). As mentioned, institutions can also incorporate important billing and quality elements into the EHR in order to better track various priorities to ensure reimbursement (De Ruiter et al., 2015).

Electronic Health Records: Potential Ethical Issues

Despite its benefits, the EHR is not without its challenges. The very purposes that the EHR serves make it vulnerable to multiple ethical issues of which APRNs, along with other providers, should be aware. In particular, EHRs raise issues of confidentiality and privacy.

Privacy and Confidentiality. The EHR, by definition, stores individually identifiable health data protected under HIPAA and subject to the Privacy Rule. As described previously in this chapter, violations in confidentiality involve disclosure of information without the person's consent, and violations of privacy involve a person gaining access to another person's personal health data. Breaches in both privacy and confidentiality are possible with the EHR, and privacy concerns have historically been major barriers to the adoption of the EHR (J. Anderson, 2007).

The EHR is vulnerable to potential breaches in security given its portable, network-based nature. When breaches do occur, they are usually accidental and involve lost or stolen laptops and external data storage (Layman, 2008). Accidental disclosure of patient information can also occur through practices such as leaving computer screens open in a public area, such as a nurses' station.

However, breaches in confidentiality can also occur through willful inappropriate sharing of health records (sharing patient information without consent), or through hacking of computer networks. For example, in 2011 a U.S. hospital had 2,000 X-rays stolen by Chinese hackers (Akpan, 2016). Some reports estimate that the United States has had nearly four data breaches per week in 2016 so far (Akpan, 2016). It is also possible for privacy to be breached when clinicians uninvolved in a patient's care access the EHR, such as when a celebrity's records are accessed without his or her knowledge or consent. While this is a possibility with the paper record, it is much more challenging to control with the EHR (Bernat, 2013). Patient privacy can be also violated when data collected in the EHR are used for research and data mining without explicit consent. This practice also constitutes a violation of autonomy (Layman, 2008) and fidelity; patients trust their providers and the healthcare system to properly protect their health information.

Other Ethical Issues. Along with confidentiality and privacy concerns, there are additional ethical considerations related to the EHR. Many EHR systems incorporate timesaving elements such as templates for notes and assessments in which providers can point and click, copy and paste, or select prepopulated data. These built-in functions can inadvertently lead to problems such as ambiguity over authorship, misleading notes and records, and impairments in communication due to inaccurate notes, all contributing to a risk of patient harm (Bernat, 2013). Disease-based template selection, for example, can lead to inadvertent misdiagnosis (Bernat, 2013). Templates can also blur important patient information, both by depersonalizing descriptions of the physical assessment and by forcing the inclusion of extraneous information; these factors contribute to a phenomenon called "note bloat" (Cimino, 2013) in which charting and documentation become longer and take clinicians more time to complete, but are less directly relevant to the particular patient's status.

The EHR can become burdensome from a time perspective when products or systems function functioning (J. Anderson, 2007) and when the amount of documentation required is excessive (De Ruiter et al., 2015). This is particularly problematic when organizations use the EHR to document data for billing purposes and other legal and institutional priorities (such as regulatory/accreditation and quality improvement/safety considerations) (De Ruiter et al., 2015). The time-consuming nature of these uses forces clinicians to take time away from patient care in order to chart, or to focus on the computer during interactions rather than the patient (Bernat, 2013; De Ruiter et al., 2015). De Ruiter and colleagues (2015) argue that this represents a shift in priorities with the EHR, which has led to a "de-emphasis on the patient's narrative as a source of input into the health record, accompanied by a shift towards representing the patient as a set of data points or metrics" (p. 4).

Other considerations surround patient access to the EHR. While patients may appreciate the ability to access lab and test results earlier, for example, it may be problematic if sensitive test results are disclosed without the APRN or provider being present to help interpret their meaning or to offer counseling and support. There is also ongoing dialogue about the benefits and risks of enabling patients of mental health providers to access notes. While many institutions with "open note" policies have excluded this population from being able to access records, others have argued that such exclusions are unnecessary (Kahn, Bell, Walker, & Delbanco, 2014).

Finally, even the role of business must be considered. For example, one clinic in Maine lost complete access to its EHRs due to a billing dispute with the software vendor (Rowland, 2014). This rendered the clinic unable to look up even simple pieces of information, such as patient allergies. Thus, considerations of ownership, location, and intended use of the data must play a role in evaluating the safety of the EHR.

Guidelines. In the United States, HIPAA serves as the regulatory guideline for protection of individually identifiable health information (United States Department of Health and Human Services [USDHS], 2016). In addition, The Health Information Technology for Economic and Clinical Health (HITECH) Act was enacted in 2009 in part to address privacy and security concerns associated with the EHR by increasing penalties associated with breaches (USDHS, 2016). Other countries, such as Germany, have released guidelines concerning the use of patient information for purposes such as secondary research (Layman, 2008).

Professional organizations have also developed recommendations for APRNs regarding the EHR. The American Nurses Association has released a position statement in support of the use of EHRs (2009). In it, they emphasize a focus on patient safety and quality care, and highlight that the "principles of privacy, confidentiality, and security cannot be compromised" (ANA, 2009). They also call for a standards-based EHR (ANA, 2009) which, while present in other countries, such as the United Kingdom, is not a characteristic of the EHRs used in the United States where there are many vendors competing for a share of the market (J. Anderson, 2007).

Additionally, Provision 3 of the ANA's *Code of Ethics* affirms the nurse's responsibility to maintain patient privacy and confidentiality, particularly through ensuring data security when working with an EHR (ANA, 2015a). The International Council of Nurses (2012) also calls for the use of "recording and information management systems that ensure confidentiality" (p. 6). Collectively, these regulatory standards and recommendations from professional nursing organizations provide a starting point for APRNs to seek guidance regarding the use of the EHR.

Analysis of Problems and Potential Problems Associated with EHRS

While the breadth of potential ethical issues facing EHR users is broad, a principled approach to action can aid in ensuring that patient confidentiality is protected in line with professional obligations and guidelines. Although EHR users include healthcare professionals, organizations, and patients, patients are at the greatest risk of adverse outcomes from EHR security failures, as the EHR primarily functions to collect and store personal health data.

As described earlier, a breach in confidentiality occurs when a patient's protected health information is disclosed without the patient's consent. This type of action violates the fiduciary relationship between provider and patient, and is a violation of the patient's autonomy. Breaches in patient confidentiality present a risk to patients on multiple levels. Patients can face retribution from employers or insurance companies if private health data are released without their consent. Depending on the scope of the disclosure, patients may also be at risk for social stigma and related psychological sequelae. Consequently, disclosure of a patient's private health data can result in actual harm.

A breach in confidentiality also negatively affects the individual patient's and general public's perceptions of the provider or healthcare organization at fault. In this way, the consequences not only impact the person affected by the disclosure, but also negatively impact the fidelity of the patient–provider or patient–organization relationship. Nursing has long been considered one of the most trusted and ethical professions; mistakes such as these can put this reputation at risk. Hence, consequences of a breach in confidentiality can be far-reaching at a system level.

APNs must keep in mind the vulnerability of those whose data are being recorded in the EHR, and must act diligently to protect this information. Guidelines, such as those previously described, have established that this is an obligation of the profession. Several recommendations can aid in protecting patients, APNs, and organizations from inadvertent disclosure of patient information.

Recommendations

Several governmental resources provide information and recommendations about the EHR to providers, patients, and organizations, along with specific actionable steps to accomplish them in order to be in compliance with the HIPAA Privacy Rule and the Security Rule. The U.S. government's Health IT website, for example, recommends that providers implement safeguards to protect patients' health information, set reasonable limits on uses and share the minimum necessary information, and have procedures in place to limit who can access a patient's health information (HealthIT, 2013). Some additional measures include password protection of the EHR system, encryption of stored information, and maintenance of an audit trail to monitor who accesses information (Rodriguez, 2011). If providers choose to access medical records from home, they must ensure that their home computers offer the same level of security as the computers in their place of work (Texas Medical Association, 2015).

The Health Resources and Services Administration (HRSA) recommends additional safeguards for organizations utilizing EHRs (HRSA, 2016). These include workstation use and design security measures, such as computer screens that lock after a period of inactivity; routine audits; and separation of sensitive information from easily accessible information in order to prevent inadvertent access. HRSA (2016) also recommends restricting the movement of hardware (such as phones or computers) that contain health information. APRNs can help to ensure that patient confidentiality is protected through the diligent use of these protective measures.

Summary of Benefits and Harms Associated with EHRS

The EHR has many benefits, including enhanced safety and timesaving functions. Nevertheless, APRNs must be aware of the ethical issues involved in use of the EHR, and the potential risks that come with imprudent use of the system. An awareness of these issues, and familiarity with professional and organizational guidelines and recommendations, can help ensure that patient privacy and confidentiality are protected and maintained.

Summary

This chapter discussed ethical issues that are common to advanced practice across settings and countries. Although the context of practice for the authors is the United States, many ethical issues faced in our context apply more broadly across countries and settings, although the laws that apply may differ. Regardless of the content of laws governing the conduct of health professionals in different countries, interpretation of those laws often requires ethical analysis. Moreover, rigid enactment of a given law without ethical analyses may harm a particular patient. Thus, APNs may have difficult decisions to make regardless of the legal implications. An argument for the APN to engage in ongoing professional and personal development in the interests of good patient care was made. The possession of certain nursing virtues is necessary both for facilitating patient decision making and protecting patient information. These virtues are not all or nothing—there are barriers to practicing well. Mindfulness allows the APN to maintain focus, and ongoing knowledge acquisition along with institutional or clinic supports facilitates moral agency. We reinforced the idea that professional nursing practice at the advanced level is *nursing* practice rather than medical practice and is based on nursing goals and perspectives. All healthcare practice that involves individual human beings is ethical in nature because of professional goals. The broad importance of honoring the ethical principle of autonomy was the assumption underlying discussion of the topics in this chapter. Patients have the right to make personal decisions both about what care will or will not be accepted and who may have access to personal information and for what purposes. The APN has responsibilities to help patients safeguard these rights. Unfortunately, as hard as APNs work to secure information, insurance companies and other groups that are privy to the private health information of individuals and families are not always so scrupulous. An expanded discussion of the contemporary ethical implications of social media and electronic medical records was added to assist APNs in their decision making.

Cases and Discussion Questions

Cases

1. Karen, APRN, eats lunch with two APN friends at a local restaurant on her days off. She lives in a large city and works in urgent care 3 days per week. During lunch, she receives a Snapchat from her friend, Russell, who works with her at the urgent care center. Russell likes to Snapchat Karen on her days off just to say, "Hello." The Snapchat lasts 10 seconds and then disappears. Karen's lunch dates look over her shoulder to catch a glimpse of Russell, since they have not seen him for a while. The Snapchat image shows Russell smiling, but also shows a vague profile of a male patient surrounded by two security guards in the background. Karen does not recognize the patient, but Russell did say there were some "unexpected guests" in urgent care today. Karen and her friends discuss whether the patient might be the injured politician they heard about 1 hour ago on the news, who had to cancel his political rally due to an unexpected health concern. The politician's story is all over the news. Are there any ethical issues in this case concerning the use of social media? If so, what are they? Does the Snapchat breach privacy or confidentiality in this case? Does Karen have a moral responsibility to report Russell's Snapchat to her superiors? Does the fact that Snapchat photos disappear in 10 seconds affect the ethical analysis of this case? How would you handle the case if you were Karen? Explain your reasoning.
2. Glenn is a family nurse practitioner at a community health center. He has three children in the local schools. His teenage daughter tells him that one of her friends sent a couple of nude photos around to her classmates during school hours. She thinks everyone has deleted them, but she is not sure. She did catch a glimpse of one of the photos. Research the laws in your state or country. Does Glenn have any legal obligation as a mandatory reporter to become involved in this situation? What are Glenn's ethical responsibilities? What would you do if you were Glenn?
3. Gretta is an APN in a family practice clinic in a small community. She suspects that one of her patients, Chloe, who is also her 14-year-old daughter's Facebook friend, has been using drugs and alcohol, but Chloe won't admit this in clinic. Gretta is worried about her. It would be easy to access Chloe's social media information through her daughter's Facebook page. Gretta and her daughter have an agreement that Gretta may look at her daughter's social media sites once per month, as many parents do to monitor usage. Is there anything ethically wrong with quickly glancing at Chloe's Facebook page in the process, given that Gretta would not otherwise have access to Chloe's pages? Why or why not? Justify your answer.
4. You are an advanced practice nurse managing a busy primary care clinic. Susan, who is one of the RNs in the clinic, reports that she saw Jennifer, the pediatric nurse practitioner, in a Facebook photo last night. Jennifer was smiling and standing in front of the reception desk at the clinic. Craig, one of Jennifer's adolescent patients, was checking in, and he and his mom smiled

and waved at the cell phone camera too. No names were tagged to the photograph. When Susan asked Jennifer about the post, Jennifer said, "Craig's mom said it was fine for me to post this picture. She told me to tag her so she could have a copy too but I forgot to tag her." Is this a breach of patient confidentiality? Are there any other ethical concerns? Why or why not? If so, who is responsible? As the manager of the clinic, how would you address this issue? If you were the clinic manager, what would you include in the social media policy at your clinic?

5. You are an advanced practice nurse working as a hospitalist (supervising care for a group of hospitalized patients) at an urban health care institution. Fred is a 37-year-old male in the ICU. He arrived 5 days ago after a receiving a gunshot wound to his head. He is on a ventilator and has been unresponsive since he arrived. His family would like to post a picture of the patient on Facebook to ask their social networking community for prayers. The nurses felt uncomfortable with this request and asked you, as you made your rounds, if you could stop the family from posting the photos. Are there any ethical issues involved in this situation? What are the harms and/or benefits to the patient, staff, or organization if photos are posted? What is the most ethically appropriate course of action and why? What would you do if you were the hospitalist?
6. Jane is a clinical nurse specialist for an intensive care unit. One of the nurses, Karen, is providing care for a retired physician who used to work at the hospital. His two sons are also physicians in the hospital. Karen tells Jane that the sons, who stopped by to visit their father, were speaking in detail about his lab work and radiology results. Karen discovers that they have this information because they looked him up in the EHR system, to which they have access to because they are employees of the hospital. Karen is uncomfortable and asks Jane for help in thinking through the problem. Jane discovers that her physician colleagues in the ICU do not see a problem with it. How should Jane help Karen and the unit in dealing with such issues? Is it ethically problematic for the patient's sons to have access to their father's records? Why or why not? What sorts of actions should be taken?
7. Steve is an APN on an inpatient progressive care unit (PCU; a level of care between intensive and regular floor or ward). One of the patients has been on his unit for several weeks and he and the rest of the team have developed a close bond with her. The patient's health status has improved, and she is transferred out of the PCU to a medical floor. Steve is no longer part of her care team. He finds himself wondering about her status, and looks her up in the EHR to check on the progress notes written about her. Is Steve justified in this action? Are there other ways to alleviate his concern? How does this align with HIPAA's or other countries' privacy policies?
8. Lucy is an APN in a primary care office, where her best friend is also a patient (though her friend sees another provider). Her friend has recently had lab work done, and calls Lucy to ask her to look the results up in the EHR system. Should Lucy look up the results? What are the potential ethical implications of Lucy accessing the record and divulging the information to her friend?

Discussion Questions

1. A case study outlined in the Hastings Center Report (2004) describes the case of a Chinese immigrant man who was admitted with a cardiac problem. Circumstances were such that the physician could not get a Cantonese translator in the middle of the night, and he wanted the patient's 15-year-old daughter to translate for her father; among other things, she would be discussing the seriousness of the man's condition.
    - What are the implications of asking an adolescent to interpret for a family member?
    - What information would an APN need to decide the appropriateness of this course of action?
    - What risks are involved?
    - How would you resolve this issue for the current situation? In the future?
2. Have you cared for a patient whom you would describe as difficult? Explore the situation you encountered with classmates or colleagues. Identify assumptions that you made about the patient. What is the basis for these assumptions? Did you think the patient was responsible for the characteristic that made him or her difficult? In what ways was he or she responsible? How would you have liked the person to have acted? Have you ever been considered difficult or felt that you were misunderstood? What would you have liked those around you to consider?
3. Joe, a 17-year-old patient, is scheduled for a sports physical at your clinic. After examining him, you decide to draw a complete blood count because he complains of feeling a bit "more than usually tired" after 30 minutes of shooting hoops. Joe asks you to tell his dad what you are doing because "he gets antsy when he has to wait." You bring Joe's dad into your office to talk to him, and he asks you to draw extra blood for drug testing and not to tell Joe what you are doing. The father says, "I just know he is taking something."
    - What is the main issue in this case?
    - What are the APN's responsibilities?
    - Discuss with classmates or peers how this situation should be addressed.
4. What is the relevance of discussing advance directives (ADs) for care, in the event of incapacitation, with your population of patients? (Neonatal intensive care unit nurses may have to imagine caring for another population.)
    - Do you have an AD? Why or why not?
    - What innovative approaches to educating patients about ADs might be used?
    - What obstacles would you anticipate (e.g., personal, environmental, time-constraint, cultural)?
5. You are the chief nursing officer in a healthcare institution/system and have received some patient and staff complaints as well as praise for a game called Pokémon Go. Research the game and anticipate what some of the patient and staff feedback might be. Propose a policy statement about the use of this game in healthcare facilities. Include ethical issues that may arise from participation in this game.

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