Ethical Reasoning and Informed Consent in Occupational Therapy

Penny Kyler-Hutchison

Key Words: consumer participation • decision making • autonomy • informed consent

Two major ethical theories, the teleological and the deontological, are defined and briefly discussed. A subsequent discussion explores how the ethical principles of informed consent and patient autonomy operate in medical decisions. The application to occupational therapy is left for the reader's judgment.

This article is intended to share a perspective that may be helpful in understanding the relationship between ethics and clinical practice. By presenting to the readers two major theories of ethics, I hope to familiarize them with the formal language of ethics and help lay the groundwork for a more in-depth examination of ethical dilemmas specific to occupational therapy.

What is bioethics, and how does it relate to occupational therapy? Many occupational therapists either ignore the issue of bioethics, assume that the physician in charge will resolve all ethical questions, or feel that the issue is not relevant to the performance of their duties. All should, however, give it serious thought.

Ethics is the branch of philosophy that examines voluntary human action to determine what types of activity or actions are right and wrong. A definition of bioethics, a type of ethics that concerns medical workers, is given by Beauchamp and Childress (1983): "Biomedical ethics [bioethics] is one type of applied ethics...the application of general ethical theories, principles and rules to problems of therapeutic practice, health care delivery and medical and biological research" (preface, p. i). The modern field of bioethics began in the early 1960s.

As an occupational therapist and an ordinary member of society, one has a philosophical framework for determining what course of action to take in a given situation. This framework is based on religious beliefs, parental values, societal values, and the unique environment in which the therapist lives. The philosophical framework of the medical community, on the other hand, is based upon the prima facie duty, and on the concept of primum non nocere (above all, do no harm). This concept, which indicates that duties of certain kinds are binding, is found in the Hippocratic oath, the American Occupational Therapy Association (AOTA) code of ethics, the American Nurses' Association code of ethics, and other health professionals' oaths or codes of practice. As part of the medical community, occupational therapists make decisions within this ethical framework when deciding what course of action to take in the care of a patient; thus, such decisions are ethical decisions.

Ethical Theories

Any ethical system has three components: actions and judgments, principles, and theories. Actions and judgments are the final result of applying a certain code of ethics to a given situation. The actions and judgments we take are based on our principles, that is, our notion of right and wrong.

Principles determine what actions we should take or what judgments we should make. Major ethical
principles are the principles of autonomy, the right of the individual to self-determination; the principle of beneficence from the maxim primum non nocere; the principle of veracity, the duty to tell the truth and not to deceive others; and the principles of justice or fairness. Principles, in turn, are derived from theories.

Theories are the foundation of ethical systems, and are the rationale behind any course of action or judgment. There are two major ethical theories, the teleological and the deontological. Teleological ethical theory can be described as theory based on values whose relative worth is determined by human beings. It can be understood by examining utilitarianism, a teleological ethical system.

Utilitarianism is expressed in the writings of David Hume (1711-1776), Jeremy Bentham (1748-1832), and John Stuart Mill (1806-1873). Bentham, an English philosopher, economist, and jurist, said that utilitarianism’s aim was to achieve the greatest happiness for the greatest number (Beauchamp & Childress, 1983, p. 19). Utilitarianism is familiar to us in this popular usage, even though how to achieve the greatest happiness for the greatest number can be debated.

The term utilitarianism is sometimes said to be teleological (from the Greek telos, meaning end) because in utilitarianism the worth of actions is gauged by their ends and consequences. This principle is commonly stated as the ends justifying the means. Utilitarian theory states “that there is one and only one basic principle in ethics, the principle of utility. This asserts that we ought, in all circumstances, produce the greatest possible balance of value over dis-value for all persons affected (or the least possible balance of disvalue if only evil results can be brought about)” (Beauchamp & Childress, 1979, p. 25).

An example of utilitarian theory involves the legal case of Tarasoff v. Regents of the University of California (Beauchamp & Childress, 1983). In this case Prosenjit Poddar, a psychiatric outpatient at the University of California Medical Center, killed Tatiana Tarasoff, a student at the university. It was alleged that 2 months prior to the murder, Mr. Poddar confided to his psychologist, Dr. Moore, his intentions to kill an unnamed girl. When pressed for her name, he readily identified her as Ms. Tarasoff to Dr. Moore. On Dr. Moore’s request the campus police briefly detained Poddar. However, because Poddar appeared rational he was released. Dr. Moore’s supervisor concurred with the release and directed that no further action be taken to detain Poddar. No one warned Ms. Tarasoff that she might be in danger. The majority justices, who decided for the plaintiffs, held that the danger of violence a psychiatric patient presents to another person obliges the doctor in charge of the patient to use reasonable care in protecting the intended victim, possibly by delivering a direct warning. In this case the rule of protecting confidentiality was weighed against the value of protecting a person from violent assault. Although confidentiality is of great concern in the therapist–patient relationship, a utilitarian would say that the value of a human life outweighs the consideration of confidentiality. Thus the case was decided on utilitarian grounds.

In the second major theory, deontology (from the Greek deon, meaning duty), right and wrong are judged not on the basis of values determined by human beings, but on the basis of moral obligation, or duty. Immanuel Kant, a German philosopher (1724–1804), is generally regarded as the individual who first clearly articulated this theory. Deontologists maintain that actions must be determined by duty, and that the concept of duty is independent of the concept of good. Whether an action is good does not depend exclusively on whether it produces a nonmoral good. A Christian acting in accordance with the Ten Commandments is a good example of deontological theory at work. Deontologists believe that the duties of one individual to another spring from the relationship they have to each other, and that actions of the past create obligations in the present that, in turn, dictate other actions.

An example of deontological theory at work in medicine is the case of a 5-year-old girl who needed a renal transplant because of progressive renal failure secondary to glomerulonephritis (Beauchamp & Childress, 1983). After discussion with the patient’s parents, the physician in charge decided to proceed with plans for a kidney transplant. The girl’s two siblings were too young to be donors, and the mother was not histocompatible. The father, however, was found to be histocompatible. The nephrologist met alone with the father, gave him the results of the tests and told him the prognosis for his daughter, which was uncertain. The father, for several reasons, decided not to donate, but asked the physician to tell his family that he was not histocompatible, lest he be accused of allowing his daughter to die. Although the physician was uncomfortable with the request, he agreed to tell the man’s wife that for medical reasons the father should not donate a kidney.

The physician in this case made his decision on deontological grounds. He had to decide whether to tell the truth or break a physician–patient confidence, and he decided to keep the confidence. Was he wrong to intentionally deceive the wife? Or was he justified in lying because the protection of confidentiality...
takes precedence over truth telling? Was the lie justified because of the evil it prevented (breaking the confidence)? A deontologist would hold that the lie was justified because, having entered into a relationship of confidentiality with the father, the physician was bound by that relationship. Since the wife had no right to know what reason her husband had given the physician for not donating his kidney, deceiving her was justified.

Both theories have something to offer to the medical professional faced with a decision about patient care. A strict utilitarian point of view may not be totally acceptable because of its lack of respect for the individual's autonomy. A strict deontological approach may not be totally acceptable either because of its reliance on past acts and duties. Occupational therapists, in making decisions that affect their patients' welfare, unconsciously consider these two approaches on a daily basis. They rarely make decisions solely on their understanding of ethical concepts, however. A lifetime of religious beliefs, parental values, social values, and the unique environment in which they live may all affect their decisions.

For occupational therapy to be effective, the therapist must enable the patient to become an active, responsible and responsive participant in the care and treatment provided. An ethical approach to treatment, which comprises the concept of informed consent, is one way of ensuring this participatory role for the patient.

Informed Consent

According to the AOTA code of ethics, Standard 1, Related to the Recipient of Service, "The occupational therapist demonstrates a beneficent concern for the recipient of services and maintains a goal-directed relationship with the recipient." (AOTA, 1984, p. 799). The guidelines further state, "Occupational therapists recognize each client's individuality and worth as a unique person" (AOTA, 1984, p. 799). How can occupational therapists demonstrate this beneficent concern for patients? How can they ensure this active participation in treatment? These questions are best answered by understanding the concept of informed consent as it applies to occupational therapy.

Most ethicists hold that respect for human beings demands respect for their right of self-determination in health care as in other areas of life. It is this principle of autonomy, the right of self-determination, that is largely responsible for the emphasis on informed consent.

From the utilitarian perspective, the justification for informed consent is that decisions based on it will offer the greatest protection and benefit to everyone involved, health professionals, patients, and the medical institution. From the deontological perspective, there is a moral duty to seek a valid consent because the consenting party is an autonomous person who should have the final say on decisions that affect his or her welfare.

The modern doctrine of informed consent arises from the concern in English common law for non-consensual touching or battery. The precedence for the concept of informed consent in U.S. law was noted in 1914, when Justice Cardozo stated, "Every human being of adult years and sound mind has as a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages..." (Pozgar, 1979, p. 95).

In the 1960 landmark decision, Nathanson v. Kline, it was argued that "Anglo-American law starts with the premise of thoroughgoing self-determination. It follows that each man is considered to be a master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of lifesaving surgery or other medical treatment" (Pozgar, 1979, p. 224).

The idea of informed consent as shared decision making arose from legal cases such as the one cited above. In considering the issue of informed consent, the President's Commission for the Study of Ethical Problems (President's Commission, 1982) recommended that based on a particular patient's values and goals, the patient and provider collaborate in a continuing process intended to advance the patient's interest both in his or her health and his or her right to self-determination. It is in such a collaborative effort that decisions about treatment that best promote a patient's health and well-being can be made. Informed consent, then, is shared decision making.

If the patient and the provider must collaborate to reach a decision, how can the therapist ensure that the patient is equipped to give his or her informed consent? How much and what type of information should be imparted? How well must it be understood? Is the consent valid if given under pressure or if the individual is considered irresponsible? These questions can be answered by dissecting the concept of informed consent into four elements:

1. Disclosure of information
2. Comprehension of information
3. Voluntary consent
4. Competence to consent

Disclosure of Information

How much and what type of information should be given to patients? Information given should include disclosure of contemplated procedures, alternative procedures available, anticipated risks and benefits,
and, in the case of research, a statement offering the person the opportunity to withdraw from treatment at any time. For instance, occupational therapists using transcutaneous electrical nerve stimulation (TENS) with patients who are in pain should explain the benefit of pain reduction as well as the risk of potential electrical shock or skin breakdown. Similar risk or benefit statements are particularly important when splinting and fracture bracing are indicated. The occupational therapist in mental health often explains the risks or benefits of increased independence in activities of daily living, with the concomitant responsibility of adhering to societal norms and mores.

Determination of what is considered adequate information to give for informed consent is most often based on the "reasonable person" standard. This standard, used in both the medical and legal communities, requires that information to be disclosed be judged by a hypothetical person who would be a layperson, not a medical expert. Whether the information is adequate is measured by the significance this hypothetical "reasonable person" would attach to a risk or benefit in deciding whether to submit to a treatment or a procedure. Most patients weigh the information by considering such factors as how long the treatment will take; if it will add to the quality and value of life; if it will allow or interfere with the pursuit of an important goal; and if the degree of suffering involved and the costs, financial and otherwise, to themselves or others will be worth it.

In certain cases, however, there is no ethical demand that physicians disclose information to patients who have specifically requested that they not be informed. It is still widely agreed that information may be legitimately withheld from a patient when the physician thinks such information would be substantially detrimental to the patient's well-being. This "therapeutic privilege" of the physician is based on the concept that the first responsibility of health practitioners is primum non nocere. (President's Commission, 1982).

Comprehension of Information

Sufficient disclosure of information by the health profession is not enough; the patient must be able to comprehend that information. Limits to comprehension may be caused by immaturity, irrationality, fear, anxiety, or unfamiliarity with medical terms. For information to be understood, it must be given in an unbiased manner and communicated in terms easily understood by the reasonable person.

Some health professionals argue that many patients are never fully qualified to evaluate the risks and expected benefits of treatment; therefore, the chances that the patient would really understand the implication of a decision to undergo or reject treatment are remote. This point of view can be traced back to the Hippocratic oath, "...perform [these duties] calmly and adroitly, concealing most things from the patient while you are attending to him" (President's Commission, 1982, p. 80). There is a difference between being fully informed and adequately informed to make a decision, however. A patient is inadequately informed if he or she has just enough relevant information to make a decision. Even though many patients can never be fully informed because they lack the knowledge to truly evaluate risks and benefits that a health professional would have, to be truly ethical in their dealings with their patients, health professionals should do what is possible to adequately inform them and, insofar as possible, allow them to act as autonomous individuals who can make informed decisions.

Voluntary Consent

Voluntariness, in regard to informed consent, refers to the ability of the patient to determine his or her goals without undue influence or coercion. There is truly a precarious balance between coercion and reasonable pressure to decide.

Coercion operates when one person influences another to act in a certain way by offering an excessive reward, by using an irrationally persuasive technique, or by forcefully manipulating him or her. The President's Commission (1983) states that there must be respect for the competent patient's right to self-determination, that is, the final authority to decide should be left to the patient. As health practitioners we must support the right of self-determination by competent patients. Mutually satisfactory decisions usually result from the process of collaborating and sharing information. Even when satisfactory decisions do not result, however, the primacy of a patient's self-determination and the importance of honoring the patient's own concept of well-being warrant leaving the final authority to decide with the patient.

While coercion should not affect the patient's decision, some form of pressure always does. Individuals always make decisions in the context of competing needs and wants. Such things as legal obligations, family interests, or financial considerations often cause undue pressure. Although they are inducements for decision making, however, they are not coercive. Consent may be voluntary and valid, even when pressure plays a significant role in decision making, as long as the patient still feels that he or she can act as an autonomous individual. A patient's choice is binding when it is freely selected and, thus, voluntary. It is not binding when the decision was made through coercion.
Competence to Consent

The concept of competence is multidimensional. Competence and incompetence are judged by assessing the effect of any physical or mental disorder on the patient's ability to make an informed decision. That a patient lacks the capacity to make a health care decision requires an assessment of his or her ability to understand relevant information and to communicate this understanding to health providers.

One way to attain such an assessment is to employ the "mental status" examination (Folstein, Folstein, & McHugh, 1975), which measures orientation to time, place, person, mood, affect, content of thought, and perception. This examination helps judge the ability of the patient to comprehend abstract ideas and to make reasonable decisions based on them. Often, the primary physician solicits opinions from neurologists, psychiatrists, and/or psychologists to help him or her assess the patient's competence to consent to treatment. The objective of such an assessment is to diminish the possibility of error in deciding whether patients are competent enough to take an active part in their own course of treatment. "Decision-making capacity should be found to exist only when people lack the ability to make decisions that promote their well-being in conformity with their own previously expressed values and preferences" (President's Commission, 1983, p. 172).

By ensuring that the requirements of the four elements of informed consent—disclosure of information, comprehension of information, voluntary consent, and competence—have been fulfilled, health professionals strengthen the relationship between themselves and their patients. By allowing patients to make decisions based on their comprehension of their situation as far as they are able to comprehend it, occupational therapists can be sure of treating them ethically. This ethical approach to patient care allows patients to act as informed, autonomous persons who will subsequently arrive at appropriate decisions concerning their own health care.

Refusal to Consent

Although the ethical treatment of patients demands that everything be done to fully equip them to make decisions affecting their care, adult patients who are conscious and mentally competent do have the right to refuse treatment. The American Hospital Association's Patient Bill of Rights states that the patient has the right to refuse treatment to the extent permitted by law and if the patient has been informed of the medical consequences of this action (Beauchamp & Walters, 1982). This is true for any medical or surgical procedure, even when the procedure is, in the opinion of the treating physician, necessary and essential for life. From the legal perspective, failure to respect patients' right to refuse that their bodies be touched could result in physicians being liable for assault and battery. From an ethical perspective, failure to respect this right of refusal is failure to respect the autonomy of the patient.

Summary

Occupational therapists must provide a supportive environment that facilitates patients' efforts to make decisions about their own health care. Understanding bioethics is important for occupational therapists because it makes them aware of their patients' need for autonomy and self-determination in making these decisions. The principle of informed consent is based on recognition of the patient's autonomy.

In dealing with patients, occupational therapists must show them a respect that is based on acknowledging the in-calcuable worth of the individual. To deny this worth is to deny the individual's autonomy. Respect for the individual's autonomy allows those who are mentally and emotionally capable of doing so to give their informed consent or lack of consent to treatment. Only when patients are able to give their informed consent to treatment can we say that they are truly active and responsive participants in treatment.

References


