2.3: Ethical Concerns in End-of-Life Care

In the sick room, ten cents' worth of human understanding equals ten dollars' worth of medical science. -Martin H. Fischer

Learning Objectives

- Define ethics and the role of ethics in medical decision making.
- Identify basic ethical principles and concepts.
- Examine difficult decisions in end-of-life care.

Ethics in Medical Decision Making

Ethics is a branch of philosophy that is focused on understanding the moral principles of people and how they make decisions based on what is considered morally right or wrong (Merriam-Webster, 2014). There are often ethical issues that can arise in the context of end-of-life care, particularly when patients and families make decisions regarding the care they will accept or not accept. As nurses, sometimes our morals and values are in conflict with those that our patients have, and this can cause some distress for the nurse. By having an understanding about some of the issues that can arise during end of life decisions, the nursing student or novice nurse can be better prepared for what to expect and how best to handle ethical issues.

As discussed in Chapter 5, patients’ goals of care are what patients place highest value on and would hope to achieve in regard to their illness. These goals are based on the patient’s moral principles and values. These are the goals the patient wishes for in terms of their illness. Often as patients near the end of life, many difficult decisions will have to be made. Some of these are related to what kinds of medical treatments they would want to have if they were no longer...
able to make their own decisions. In the clinical setting, it is not uncommon to witness conflicts between the patient’s wishes and those of their family. Sometimes, there can be conflicts between what the clinicians believe to be best for the patient and what the patient and family want to have done. Other times, the insurance or health care system has specific criteria that may come in conflict with the goals and values of the patient or family. This was evident in the recent national news story about 13-year old Jahi McMath (Fox News, 2013). In this case, the family wanted to continue to keep their young daughter on life support which conflicted with what the health care facility wanted. After several evaluations, the child was determined to be medically brain dead, and therefore continuation of medical treatments was considered to be futile. The goal of this chapter is to provide a basic understanding about ethical principles and to explore issues surrounding the issues that can arise during end of life decisions in patients who are nearing the end of life.

Basic Ethical Principles and Concepts

Nurses need to possess a basic understanding about the scope of practice and standards of care. This can be found in the Standards of Professional Nursing Practice from the American Nurse Association (ANA, 2010). Additionally, nurses should refer to the Code of Ethics for Nurses with Interpretive Statements (ANA, 2015). These resources should assist the nurse with their expected behaviors and role within the professional discipline of nursing.

Autonomy, beneficence, nonmaleficence, and justice are four of the basic ethical principles used to guide nurses and clinicians in the care and decision making of patients. Many of these same standards apply for nurses who are involved in clinical research as they are a way to ensure that people’s rights are protected as guided by specific moral principles.

Respect for autonomy

This principle is described as an agreement to respect another’s right to self-determine a course of action and to support another’s independent decision making (ANA, 2015). Sometimes it can be difficult to see a patient make a decision about their health that the nurse does not personally agree with or that the nurse does not feel is the best decision for that patient’s individual circumstances. As nurses, we must support and advocate for our patients’ rights, including their right to make decisions. While a nurse might not agree with a patient’s decision, they must support it. For example, a nurse has been caring for an elderly gentleman for several months as he has been receiving treatment for cancer. This patient has decided to stop his cancer treatments and focus on spending time enjoying his family for the time he has left. While the nurse has grown fond of this patient and would not want him to die, they must respect the patient’s wishes and choices for his own medical care.

Beneficence

Beneficence is the principle of “doing good” and has been suggested as having four distinct parts. These include:

- Not to inflict evil or harm.
- To prevent evil or harm.
- To remove evil or harm.
- To do good or promote good.
Sometimes it might be difficult to differentiate between doing good and doing no harm, which is nonmaleficence, because it is often easier to determine what is clearly bad or harmful more than what might be good or a benefit. Kennedy Swartz recommended that there is a greater obligation to not cause harm than there is to do something that might benefit the patient. Nurses should keep that in mind when assisting patients with difficult decisions.

**Nonmaleficence**

Nonmaleficence is the principle of refraining from causing unnecessary harm. Although some of the interventions that patients receive might cause pain or some harm, nonmaleficence refers to the moral justification behind why the harm is caused. Sometimes harm may be caused to a patient in order to prevent them from further harm. If the act is for a greater good for the patient and is not meant to deliberately harm them, it is justifiable. An example of this is the all too common clinical situation that occurs in end-of-life care. A patient whose death is imminent is in pain and requires pain medication to maintain comfort. The patient is very close to death with irregular respirations around 8 breaths per minute. The nurse needs to administer the pain medication but fears that giving it may hasten (or accelerate) death. According the Code of Ethics for Nurses (ANA, 2015), the nurse may “not act deliberately to terminate life”; however, the nurse has a moral obligation to provide interventions “to relieve symptoms in dying patients even if the intervention might hasten death.”

**Justice**

Justice is the principle that governs social fairness. It involves determining whether someone should receive or is entitled to receive a resource. The Code of Ethics for Nurses (ANA, 2015) states that nurses’ commitment is to patients regardless of their “social or economic status.” In healthcare, sometimes the benefits must be balanced with the burdens to determine who is eligible to receive some type of care. As mentioned in the beginning of this chapter, medical futility is continuing to provide a medical intervention or treatment that would not provide a cure or benefit to the patient. As with the young Jahi McMath, who was determined to have brain death, continuing to keep her alive on life support would be futile, as there is little or no hope for recovery. So this decision was considered just, as discontinuation of life support was not based on her age, ethnicity or socio-economic status. It was based on her medical diagnosis.

Some additional terms that accompany ethical principles include informed consent and capacity. Informed consent respects a patient’s autonomy and enables him/her to make an informed decision based on factual and accurate information. If a patient is not informed that declining to have a needed surgery would result in his death, then they cannot make an informed decision. If once this information is disclosed and the patient decides not to elect the surgery, it is an informed choice based on the facts. Capacity refers to the ability of a patient to understand information and to make choices or consent to care. So using the same example about whether or not to have a life-saving surgery, if the patient was cognitively impaired because he had Alzheimer’s disease, he would not have the decisional capacity to make an informed choice. If he was cognitively intact and decided not to elect surgery, then that would be his right.

**Difficult Decisions in End-of-life care**

Caring for patients who are nearing or at the end of life often enables nurses to bear witness to the complicated and
difficult decisions that patients and families must make surrounding many sensitive issues. Although nurses have their own morals, values, and beliefs, they sometimes do not correspond with the patients’ values, beliefs, or wishes, and an internal conflict for the nurse can ensue. Some of the medical treatments and decisions we will discuss are simple and others are more complex. Regardless of the intervention or treatment, the nurse should focus on helping the patient weigh the benefits and burdens of the intervention, rather than focus on the intervention itself (Kennedy Swartz, 2001). Now we will discuss some of the difficult decisions that patients often need to make in end-of-life care.

### Withholding/withdrawing of medical interventions

One of the dilemmas that can occur relates to the cessation of medical interventions in patients. Sometimes these interventions range from minor, such as a non-life sustaining medication, to more complex, such as mechanical ventilation. The rationale for stopping these interventions is often based on the fact that the burdens are outweighing any benefits the patient may get from it. Sometimes life-sustaining therapies may prolong suffering at the cost of decreasing the patient’s quality of life. Patients and their family often decide to stop medical interventions based on some of these factors. One of the most heart-wrenching decisions that family members often have to make is about withdrawing life sustaining treatments (life support) from patients. This is why advance directives are so important. Advance directives are documents that enable patients to make their decisions about medical care known to their family and health care providers, in the event that they are unable to make those decisions themselves (National Cancer Institute, 2013). If a family member knows for sure that their loved one would not have wanted a particular medical intervention done, it may help to alleviate some of the burden they may feel about making the decision. It also helps prevent the initiation of some life sustaining treatments beforehand, in which case no decision will be need to be made to withdraw that intervention. It also can help reduce overall costs of futile medical care (Coyne, Smith, & Lyckholm, 2010).

### Do not attempt resuscitation (DNAR)

In 2005, the American Heart Association has changed from the more recognized acronym for do not resuscitate (DNR) to DNAR (Breault, 2011); however, depending on the location, the more traditional DNR terminology may still be used. If a patient has an order for a DNR or DNAR, it means that the patient has elected for cardiopulmonary resuscitation (CPR) to not be initiated or administered in the event of a cardiac arrest. CPR could include the use of chest compressions, cardiac drugs, and the placement of a breathing tube. Electing to have or not to have CPR is a difficult but common medical decision that patients nearing the end of life often make. The success rate of CPR has been low, around 18%, among all hospitalized patients who arrest over the past 50 years (Berry & Griffie, 2010), and it is well known that the percentage is even lower among patients with advanced illnesses such as terminal cancer or end stage heart failure. A “do not intubate” (DNI) order often accompanies a DNR order, which states that the patient elects not to be intubated with a breathing tube if they go into cardiac arrest. Chest compressions and the use of cardiac medications could still be used.

### Allow natural death (AND)

Allow natural death is a more recent terminology some health care institutions have adopted to use instead of the traditional DNR orders. Whereas a DNR order states that no attempts should be made to start CPR in a patient, an AND order states that only comfort measures are taken to manage symptoms related to comfort. An AND order simply allows the patient to remain comfortable while not interfering with the natural dying process.
Medical order for life sustaining treatment (MOLST)

Sometimes also referred to as physician order to life-sustaining treatment (POLST), these newer forms of advance directives were developed in order to improve the communication of a patient’s wishes about life-sustaining treatments among healthcare providers and settings. It is currently in use in 26 states across the United States (Polst Organization, 2014).

Hastening death (Principle of double effect)

The principle of “double effect” refers to some decisions that clinicians have that will produce both desirable and undesirable effects (ELNEC, 2010). The example given earlier for non-maleficence, in which the nurse administers a pain medication in order to alleviate a patient’s pain and suffering but this same intervention may also contribute to a hastened death, is also an example of “double effect.” The medication will reduce the pain but also further reduce the patient’s respiratory rate to a level that is inconsistent with life. In the case of double effect, the nurse or clinician should always consider what the intended effect of the intervention is. Is the pain medication being administered to reduce pain and suffering, or is it being given to further reduce the patient’s respirations?

Terminal/palliative sedation

Terminal sedation (more recently called “palliative sedation”) is an intervention used in patients at the end of life, usually as a last effort to relieve suffering (Knight & Espinosa, 2010). It involves sedating the patient to a point in which refractory symptoms are controlled. The goal is to control symptoms, and the patient is sedated to varying degrees of consciousness to achieve this. The intent is not to cause or hasten death, but rather to relieve suffering that has not responded to any other means. Often the patient is sedated to a point at which they are unconscious. Table 8.1 shows the four criteria required for a patient to be considered for palliative sedation.

<table>
<thead>
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<th>Table 8.1 Criteria Required for Palliative Sedation</th>
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<td>Patient has a terminal illness</td>
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<td>Severe symptoms present are not responsive to treatment and intolerable to patient</td>
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<tr>
<td>A “do not resuscitate” order is in effect</td>
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<tr>
<td>Death is imminent (hours to days)</td>
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(Knight & Espinosa, 2010)

The fourth criteria is the most difficult to determine; however, one study found that the mean time between initiation of terminal sedation and death ranged from 1.9 to 3.2 days (Fainsinger et al., 2000). Terminal sedation has been compared with slow euthanasia and assisted dying; however, they are not the same thing. The key difference is based on the intent or purpose of the intervention. The intent is not to hasten death but to relieve suffering that cannot be relieved by any other available method. In assisted dying or physician assisted euthanasia, the intent is to produce death in order to relieve suffering. Palliative sedation has been supported as a means to alleviate suffering by the United States Supreme Court, and the Hospice and Palliative Nurses Association is in favor of its use (Hospice and Palliative Nurses Association, 2003).
Assisted dying

Assisted dying is defined as “an action in which an individual’s death is intentionally hastened by the administration of a drug or other lethal substance” (Volker, 2010). Under this general definition, there are two distinct subcategories that include assisted suicide and active euthanasia. In assisted suicide, the patient is provided with the means to carry out suicide, such as providing a lethal dose of a medication. In active euthanasia, someone other than the patient is the one who carries out the action that ends the patient’s life (Volker, 2010). In the United States there are four states that have laws allowing assisted dying. The state of Oregon was the first to pass the Death with Dignity Act in 1997, and since then, Washington, Vermont, and New Mexico have followed suit (Volker, 2010). The vast majority of ethical codes from the main nurses’ organizations prohibit the involvement of a nurse in the assisted dying of patients. The Oregon Nurses Association issued a statement that grants nurses the right to refuse involvement in the care of a patient who has elected assisted suicide.

What You Should Know

- Nurses caring for patients at the end of life have a moral and professional obligation to follow the guidelines depicted in their professional and ethical standards.
- The absence of an advance directive can make end of life decision-making difficult for families of dying patients who are no longer able to speak for themselves.
- Nurses need to advocate to ensure that their patients’ goals of care are met while following ethical principles.

References


