Focus on Advance Directives

3.0 Contact Hours

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Note: All dosages given are for adults unless otherwise stated. The information on medications contained in this course is not meant to be prescriptive or all-encompassing. You are encouraged to consult with physicians and pharmacists about all medication issues for your patients.

Purpose

The purpose of this continuing nursing education course is to provide healthcare professionals with information about advance directives.

*Focus on Advance Directives* explains advance directives (ADs) and the issues that surround the use of ADs in healthcare facilities.

The course explores the nurse’s role and responsibilities related to ADs.
Learning Objectives

After successful completion of this course, you will be able to:

1. Define advance directive.
2. Identify the positions of professional organizations and The Joint Commission (TJC) concerning patient’s rights and advance directives.
3. Describe the provisions of the Patient Self-Determination Act concerning advance directives.
4. Identify the role of state law in advance directives.
5. Describe examples of decisional incapacity.
6. Describe the conditions under which healthcare providers appeal to advance directive.
7. Identify the extent to which Americans are making use of advance directives.
8. Describe cultural and religious influences related to advance directives.
9. Define the two major types of advance directives.
10. Define the relationship between advance directives and Do-Not-Resuscitate (DNR) orders.
11. Identify issues related to advance directives.
12. Describe limitations on adherence to advance directives.
13. Describe examples of the nurse’s role and responsibility related to advanced directives, specifically:
   • To advocate for the patient’s wishes and comfort.
   • To communicate continuously with patients and families.
   • To know and adhere to facility policies.
   • To seek clarification and resolution regarding ethical conflicts related to the use of advance directives.
Glossary of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
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<td>AD</td>
<td>Advance directive</td>
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<td>AHA</td>
<td>American Hospital Association</td>
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<td>AMA</td>
<td>American Medical Association</td>
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<td>ANA</td>
<td>American Nurses Association</td>
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<td>AND</td>
<td>Allow natural death</td>
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<td>DNR</td>
<td>Do-Not-Resuscitate</td>
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<td>DPAHC</td>
<td>Durable Power of Attorney for Healthcare</td>
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<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
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<td>HMO</td>
<td>Health maintenance organization</td>
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<td>NLN</td>
<td>National League of Nursing</td>
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<td>PSDA</td>
<td>The Patient Self-Determination Act</td>
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<td>TJC</td>
<td>The Joint Commission</td>
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Introduction

As a healthcare professional, it is likely that you are familiar with the term advance directive. The issue of advance directives and a patient’s right to make decisions about medical care is more applicable today than ever before. Advances in medications and technology, as well as changes in family structure and lifestyle all play a role in an increased need for patients and their caregivers to address this important issue in advance of catastrophic illness or injury. Advance directives are not just for the aged or infirm. Unexpected situations that could result in end of life can occur at any time.

An advance directive might include information about a patient’s wishes concerning medical power of attorney, a living will, and/or a request for a “do not resuscitate” order. This course explores the components of an advance directive, the role of healthcare professionals in regards to an advance directive, as well as information about the history of patients’ rights.
Advance Directives: A Patient’s Right

Advance directives (ADs) express a patient’s wish to receive or not to receive treatments and procedures. ADs may also be used to designate a particular individual to make healthcare decisions for the patient when the patient is “decisionally incapacitated”; that is, unable to make decisions due to a permanent or temporary disruption in a person’s cognitive abilities. An evaluation of cognitive abilities is made by a physician and often in consultation with a psychiatrist if the person is alert but there are concerns of thought disturbances due to depression, mental illness or other causes of thought disturbances (Casey & Walker, 2010).

- Cognitive abilities can be affected by anesthesia, head injury, severe illness, post cardiac arrest, meningitis, coma, and assorted other injuries or disease processes that can alter normal mentation.

Advance directives help guide caregivers and/or the patient’s surrogates in making decisions for the patient when the patient is unable to do so, usually when the patient is in a terminal or irreversible state. By documenting a patient’s wishes at a time in advance of decisional incapacity, ADs allow patients to direct their own care. Thus ADs occupy an important place in the bigger picture of patients’ rights and self-determination.

Patients’ rights have both legal and ethical roots:
- The individual’s right to autonomy as guaranteed in the 14th Amendment to the United States Constitution.
- The ethical principle of self-determination.
History

For more than 100 years, nurses have advocated for patients’ rights. In 1905, Alta Bates challenged physicians’ practice of making unilateral care decisions on behalf of their patients. Bates, founder of the Alta Bates Medical Center in Oakland and Berkeley, California, pressed for the initiation of standards of care and patients’ rights. Fifty years later, legal entities and professional societies began to emphasize the specific rights of individuals in the healthcare setting.

In the late 1950s, the first cases regarding informed consent came before the courts; establishing the importance that the patient understand pertinent information as well as consent to a treatment or procedure. In 1959, the National League for Nursing (NLN) published a position statement referring to the patient as a partner in healthcare with the ultimate goal of self-care. In 1979, the American Hospital Association (AHA) formalized its views by publishing twelve patient rights in Patients’ Bill of Rights. In 2003, AHA replaced Patients’ Bill of Rights with Patient Care Partnership: Understanding Expectations, Rights and Responsibilities. The document, which is available in eight languages, describes six general categories of rights including the right to involvement in care (AHA, 2003).

Both the American Nurses Association (ANA) and the American Medical Association (AMA) endorse patients’ rights in their ethical statements and position papers (ANA, 2004; ANA 2010b; AMA, 2011).
The Joint Commission (TJC) Standards

The Joint Commission (TJC) evaluates healthcare facilities using standards which, among other mandates, require healthcare facilities to:

1. Respect the rights of patients
2. Involve patients in decision making regarding care and treatment
3. Address wishes of patients regarding end-of-life decisions
4. Inform patients, and when appropriate, notify families, regarding the outcomes of care, including unintended outcomes
5. Assure confidentiality, privacy, security and advocacy
6. Manage patients’ pain
7. Provide patients with information regarding their rights
8. Communicate effectively with patients about their care
9. Respect patients’ right to refuse care

Patients’ Rights

Patients’ Rights continues to receive the attention of law makers as the United States Congress studies bills to offer patients such guarantees as the right to:

- Sue health maintenance organizations (HMOs)
- Access emergency care
- Access specialists
- Receive pain control
- Access mental health services (TJC, 2010)
**The Standards Today**

Two federal laws enacted in the 1990s required healthcare facilities to protect patients’ rights in specific ways. These laws apply in all 50 states. In 2003, The Health Insurance Portability and Accountability Act of 1996 (HIPAA), in addition to other provisions, began to require healthcare facilities to take specific measures to assure privacy and confidentiality of patients’ personal health care information. HIPAA does not complicate the disclosure of personal health information to an individual who is designated as the patient’s surrogate decision maker. A person holding a valid health care power of attorney, under the law of any state is a personal representative for the purposes of HIPAA. Under HIPAA, “a [provider] must divulge to the individual’s personal representative whatever protected healthcare information that person requests about the individual, unless the provisions regarding abuse, neglect or endangerment apply (CMS, 2011).” The representative is entitled to receive whatever information is relevant to the healthcare decision-making authority which is granted to the individual in the power of attorney document.

Earlier, The Patient Self-Determination Act (PSDA), enacted under the Omnibus Budget Reconciliation Act of 1990, set forth requirements related to ADs. PSDA requires that facilities which receive Medicare and Medicaid funds provide written information to patients about their rights under state law.

**These rights include:**

1. The right to participate in and direct their own healthcare decisions.
2. The right to accept or refuse medical or surgical treatment.
3. The right to prepare an advance directive.
4. Information on the provider’s policies that govern the utilization of these rights.

The act also prohibits institutions from discriminating against a patient who does not have an advance directive. The PSDA further requires institutions to document patient information and provide ongoing community education on advance directives (CMS, 2011).
The Patient Self-Determination Act (PSDA) Compliance

This act (PSDA) impacts all healthcare providers that accept Medicare or Medicaid reimbursement, including hospitals, nursing homes, health maintenance organizations, hospice programs, and others. To comply, providers must (Casey & Walker, 2010):

- Develop written policies concerning ADs
- Ask all new patients if they have ADs and document the answer in the patient’s chart
  - The patient is not required to have an AD
  - The patient is not required to provide a copy of an AD if the patient does have one
- Provide written material to patients regarding:
  - Institutional policies relevant to these issues (such as an institutional policy to not perform abortions or not withdraw nutrition and hydration) and
  - Patients’ rights under state law to:
    - Make decisions concerning medical care
    - Accept or refuse any medical or surgical treatment
- Formulate an AD
- Educate staff and the community served by the institution about ADs
- Ensure that patients are not discriminated against on the basis of whether or not they have ADs
The Standards Today (cont.)

Upon admission, adult patients should receive written policies which explain how the facility implements patients’ rights, including informed consent in treatment decisions, timely access to specialty care, and confidentiality protection. Patients must receive this information written in understandable terms.

Once the patient receives the information about the consequences of creating or not creating ADs and decides whether to create an AD, the healthcare facility must assure that the patient’s decision is documented in the medical record. The facility must also ensure that the patient’s decision does not influence the provision of care; the facility cannot discriminate against the patient based on this decision (CMS, 2011).

- **Treatments that should be discussed:**
  - Mechanical ventilation
  - Nutritional and hydration assistance
  - Dialysis
  - Resuscitation
  - Other end of life treatments such as antibiotics, pain medication, etc.
  - Organ donation

*(Mayo Clinic, 2011)*
Process of Advance Planning

Individuals usually do not create ADs upon demand at the time of admission to a healthcare facility. Rather, an AD is the product of the process of advance care planning. The process of advance planning evolves as an ongoing dialogue between an individual, the primary care provider or other health professionals and the individual’s family and significant others. The dialogue includes (Casey & Walker, 2010; Jones et al., 2008):

- Reviewing the possibilities the patient should expect in the future
- Discussing these possibilities with the patient, family/caregivers, and other relevant healthcare workers to make sure everyone has the same expectations
- Identifying the patient’s viewpoint
- Avoiding the use of medical terms
- Identifying the goals most important to the patient
- Reviewing the plan of care with the patient
- Anticipating and preparing for emergencies
- Offering a contact number to call with questions
- Providing a link to supportive services

Advance Directives and State Law

Federal law mandates rights for patients, but individual states implement laws to protect those rights. Some states have adopted laws which guarantee specific patient protections, such as name badges worn by hospital staff, and assignment of an attending physician. Laws and requirements differ among states. Know the law in the state in which you are practicing.
State Law Regulations

States laws regulate:

• Informed consent.

• Order of surrogate decision makers, for example: children in birth order, followed by spouse, then by other designated relationships to the individual. When a patient designates a particular individual in an advance directive, the patient’s choice supersedes the state’s listing.

• Advance directives, an individual’s right to make decisions regarding terminal care (Natural Death Acts, Living Will Acts or Death with Dignity Acts) and related issues.

State Definitions of AD Situations

Each state defines the situation in which an AD takes effect. In general, the definitions provide that:

• The patient is irreversibly decisionally incapacitated. For example, a brain injury may render an individual irreversibly decisionally incapacitated. An individual may be decisionally incapacitated due to the effects of anesthesia, but anesthesia is reversible.

• The patient is terminally ill, or in an irreversible state, or in a persistently unconscious or prolonged vegetative state.

In addition, an AD may specify certain criteria to be met, for instance that life is sustained only by mechanical ventilation. Before appealing to an AD, all desired therapeutic options should be considered.
States’ Differentiation

States differ in the definition of terms and the requirements for establishing the conditions described. For example states may require the opinion of two physicians to establish the prognosis, or the patient’s primary physician and a psychiatrist to establish decisional incapacity. Some states describe the patient’s condition that triggers the AD simply as decisionally incapacitated and terminal. Many states provide simple forms for persons wishing to prepare ADs.

No legal cases have been reported in which families initially agreed to withdrawal of therapy but later changed their minds and sued the physician or other healthcare professionals for stopping life-sustaining therapy. However, several successful lawsuits have been brought by families when patients received life-sustaining or emergency therapy that had been explicitly refused, such as resuscitation. When the patients survived, in a severely compromised state, the families sued on the basis that the therapy had been refused and the hospital was responsible for further care of the patient resulting from the therapy (Casey & Walker, 2010).

States’ Natural Death Acts

States’ Natural Death Acts protect the healthcare professional, patients and their families. They provide:

- Protection for healthcare professionals from criminal, civil, or professional (usually licensure) sanctions if they participate in allowing a natural death.
- Protection for patients and their families from determining the death to be a suicide rather than allowing a natural death.
- Upholding patient rights of dignity, autonomy, and self-determination (Casey & Walker, 2010).

For further information on individual state laws, resources can be found at:

- http://www.nhdd.org/state-specific-resources/
The Nature of Advance Directives

ADs are not ends in themselves but rather are a part of ongoing communication regarding goals of care and continuing plans to ensure patient’s preferences are honored and palliation is provided. An individual can revoke the AD at any time by simply stating that he has changed his mind. A competent individual’s informed consent always supersedes any AD. For example, when an anxious pre-operative patient who has already received pre-operative medications asks to have an AD disregarded, healthcare personnel should respect that patient’s wishes.

Advance Directives Statistics

Since 1991, in order to comply with PSDA, admitting personnel in healthcare facilities have been asking patients whether they have ADs. Yet some form of AD is in place for only an estimated (Casey & Walker, 2010):

- 36% of Americans
- 15% of hospitalized persons
- 5% of ICU patients older than 65 years
- 43% of the terminally ill cancer patients had ADs
Executing an AD

Executing an AD (Center for Practical Bioethics, 2011):

- Any competent adult can complete an advance directive.
- Advance directives cannot be completed by anyone other than the individual to whom it applies (e.g., a wife cannot complete an advance directive for her husband even though she may be his legal surrogate).
- Forms can be obtained from any primary healthcare provider, hospital, nursing home, or health maintenance organization as indicated in the PSDA.
- A lawyer is NOT needed to complete a valid advance directive. However, ADs must be witnessed. Individual states dictate who may witness and how many witnesses are required for a living will. Certain states require that the witnesses be non-interested parties.
- An AD can be rescinded at anytime for any reason. The standards of competency for rescinding an AD are less stringent than the standards that are required to execute an AD.

A patient under the influence of pain medication would be considered competent to rescind an AD.

Therapies Covered By an AD

Therapies which can be covered by an AD (Center for Practical Bioethics, 2011):

- Any therapy.
- Life-sustaining therapy (including mechanical ventilation, blood transfusions, dialysis, antibiotics, etc.).
- Some states specifically include artificially provided nutrition and hydration because these types of treatment have been the most problematic treatments to withdraw.
Legal and Lingual Details of Ads

All states recognize ADs. When constructed according to state guidelines, ADs are legally binding. The use of an AD is ethically and legally appropriate only when the individual is incompetent. Most apply only in terminal or incurable conditions or in conditions described in the AD.

When language such as “terminal” or “incurable” is used in the AD, the healthcare provider must interpret the terms and determine the patient’s status. Similarly, words such as “heroic measures” or “extraordinary means” are open to interpretation. During the advance care planning process, the professional who assists the patient should clarify terms, intentions and preferences with the patient to render the AD as free of misinterpretation as possible.

ADs in the United States do not permit euthanasia (Casey & Walker, 2010). Some AD forms offer the choice to keep the patient comfortable even if efforts hasten death. Such efforts are known as double effect, since they produce a palliative effect, but also an effect which may cause an earlier death. An example would be withdrawing oxygen as requested by a patient who is terminally ill with pulmonary fibrosis and initiating a midazolam (Versed) drip. Terminal sedation or palliative sedation is distinct from assisted death (purposely providing the means for suicide) and active euthanasia (causing a patient’s death to terminate suffering) (Truog et al., 2008).
Cultural and Religious Implications

ADs are more frequently completed by Caucasian, middle to upper class individuals than by individuals from other ethnic groups (e.g., African American, Hispanic, Korean, American Indian, etc.). Studies have suggested that minority groups in America fear being denied beneficial treatment at the end of life more than they fear receiving excessive therapy (Froman & Owen, 2003). Hence, many members of minority groups prefer not to complete an advance directive. A study comparing Caucasian physicians and African American physicians found that African American physicians were more aggressive in maintaining life sustaining treatments for their patients and also in making choices for their own ADs. The researcher concluded that the African American physicians’ preferences were more related to cultural factors than to educational or socioeconomic factors (Barnato et al., 2009).

Religious beliefs also affect decisions reflected in ADs. Particular religions may prohibit certain treatments or may take positions about sustaining life. However, never assume that a patient’s membership in a particular cultural or religious group predetermines the values and preferences of that specific individual (Casey & Walker, 2010).

Type of Advance Directives

Each of two types of ADs serves a different purpose: The Instructive AD provides instructions concerning the use of particular therapies or classes of therapies. The instructive AD applies only when the patient is in an irreversible state or other terminal condition as described in state law or in the AD. A person executes an instructive AD to prevent unwanted, futile, invasive treatments, or treatments which are morally unacceptable to the individual. A living will is the most common example of an instructive AD. Living wills usually specify treatments which the person does not wish to have in the event of an irreversible condition. Such treatments often include cardiopulmonary resuscitation, mechanical ventilation, enteral feedings, intravenous hydration or blood transfusions. Often language is introduced to clarify terms such as extraordinary measures. Such language might specify that treatments be evaluated in the light of benefits and burdens to the patient.

- Types of Advance Directives:
  - Instructive
    - Living Will
  - Proxy
    - DPAHC
    - Substituted Judgment
Living Will

A living will might also be used in a different way, to request that everything be done to prolong life. The patient might limit interventions to only those that reduce pain and suffering. Despite every effort to make a living will clear and unambiguous, professional judgment is usually required to establish a prognosis and to differentiate actions which limit suffering from actions which sustain life.

A limitation of the living will is that not every treatment option can be foreseen. As the patient’s condition deteriorates, unanticipated treatments might be considered. The need for specificity in a living will, listing every treatment a patient wishes to accept or reject, creates a less flexible AD than the proxy AD (Casey & Walker, 2010; TJC, 2011).

The Five Wishes

The five wishes document outlines end-of-life choices in five categories. Each category includes a number of specific choices which an individual can select or reject. Space is also provided for writing in preferences which the document does not list.

1. The person I want to make decisions for me when I can’t.
2. The kind of medical treatment I want or don’t want to have.
3. How comfortable I want to be.
4. How I want people to treat me.
5. What I want my loved ones to know.

_The Five Wishes_ includes personal, emotional and spiritual aspects as well as medical treatments. For example, an individual can indicate wishes such as:

  - Dying at home
  - Receiving warm baths
  - Having someone hold his hand

_The Five Wishes_ document also provides space to indicate choices for final arrangements. Thirty-five states accept _The Five Wishes_ document and many others recognize the wishes expressed when accompanied by an AD that meets state guidelines.

For further information, visit: [http://www.agingwithdignity.org/five-wishes.php](http://www.agingwithdignity.org/five-wishes.php)
The Proxy AD

*The Proxy AD* provides for another person to make treatment decisions for a patient.

- Most commonly a proxy AD takes the form of a Durable Power of Attorney for Healthcare (DPAHC). The DPAHC designates a specific person to make treatment decisions according to the patient’s wishes. The DPAHC may also be called an appointment directive because it appoints an individual as decision maker. Powers of attorney may be executed to appoint a surrogate to make decisions about aspects of life other than healthcare – for example, financial decisions. The DPAHC applies only to healthcare decisions and has no implications for other aspects of an individual’s life and affairs. Similarly, powers of attorney executed for aspects of decision making other than healthcare have no bearing on healthcare decisions.

- The person named as DPAHC makes timely care decisions during stressful times. Before officially naming a DPAHC, a person should communicate desires regarding terminal care to be sure that the designated proxy fully understands and will carry them out when necessary – even if those wishes differ in some ways from the personal beliefs or desires of the DPAHC.

- Like the instructive AD, the proxy AD is relevant only when the patient is incompetent. But unlike the instructive AD, the proxy AD might be used when the patient is temporarily decisionally incapacitated, but not in a terminal or irreversible state (Casey & Walker, 2010).

- The appointment directive AD is well suited to families who operate under a family decision-making model, instead of the more common western or American model which emphasizes personal autonomy. Korean-American and other Asian cultures, as well as many African American and Hispanic families operate under this model (Friedman, 1998).

- When a specific individual has not been designated, others having relationships to the patient as specified in state law should be consulted.

- Oral statements about treatment preferences made to the patient’s physician, to family members or others may also be considered.

- When a proxy decides for a patient in the absence of explicit directions given in advance by the patient, one of two standards applies (See SIDEBAR: Standards for Surrogate Decision Making).
  - The substituted judgment standard in which proxy decides as the patient would have chosen if the patient were able to choose
  - The best interests standard
Communicating End-of-Life Preferences

Clearly communicating one’s preferences for end-of-life care with the designated healthcare decision maker is essential. Yet, probably because of the sensitive and difficult nature of such communication, a mutual understanding is often lacking. In one study, 50% of terminally ill cancer patients and their caregivers disagreed on treatment interventions at the end of life and most had not discussed the matter (Casey & Walker, 2010). These findings are consistent with other research which documented that more than half of the participants studied had not discussed their feelings about healthcare decisions with anyone, yet they assumed that close family members would somehow know their wishes when the need arose (Casey & Walker, 2010).

It is most effective for the patient’s proxy and physician to each have copies of both the (current) living will and the DPAHC. This helps the proxy to be sure of the patient’s precise wishes and provides support for the proxy’s decisions when communicating with physicians and nurses.

Qualifications of Surrogate Decision Makers

- Physicians, nurses, and other healthcare professionals are not on the list of surrogates. Healthcare decisions are never a ‘democratic’ decision in which the healthcare team takes a vote.
- Healthcare decisions are not MEDICAL decisions but rather are MORAL choices. Hence, the people who share the patient’s moral community are selected by state law to act as surrogates.
- Under some state laws, if there is more than one person in a category (such as adult children), consensus of all the individuals in the category is required for decision making. For example, if this law is the case in your state, treatment could not be withdrawn unless all the surrogates unanimously agreed.
- State law, however, can only reflect the social norm for moral communities. People whose moral intimates or family do not reflect this social norm should complete a durable power of attorney for healthcare (a proxy directive) to specify the person or persons whom they would wish to make choices for them should they become incapacitated. Examples of moral communities not reflecting the social norm include non-married partners, people with estranged family members, or unmarried elders with no adult children (Casey & Walker, 2010).
Standards for Surrogate Decision Making

Substituted judgment standard: doing what the patient would have chosen if the patient were able to choose. There are three different forms of evidence of an incompetent person’s previous wishes or preferences for treatment. Some states require written evidence for certain decisions.

1. Written evidence: Advance directives, such as a living will, directive to physician, refusal of blood products or other statements of wishes such as a videotape, audiotape, or personal letters.
2. Verbal evidence: conversations with family, friends or professionals regarding one’s wishes.
3. Relational evidence: personal knowledge of an individual; knowing the history of a person’s prior choices, values, and other relevant information.

Healthcare professionals can assist families to make choices based on substituted judgment by cueing them better. For example, instead of saying, "What do you want us to do for your mother?" Saying, "What do you think your mother would have wanted if she were able to speak for herself?"

Healthcare providers should discuss with each patient the identity of the individual(s) who would be the patient’s legal surrogate under state law. For patients who prefer a surrogate different than that specified by state law, healthcare providers should:

• Assist the patient to complete a proxy directive.
• Ensure that this information is recorded in the patient’s medical record.
• Encourage the patient to inform the designated surrogate of their selection, to provide the surrogate with a copy of the proxy directive, and to discuss wishes for end-of-life care with the designated surrogate.

States vary in definitions of substituted judgment. For example:

• Missouri requires clear and convincing evidence of wishes to discontinue life support.
• New York State obligates healthcare providers to provide treatment unless it is almost certain that the patient would have refused.
• Laws in Hawaii, Connecticut and Maryland provide that a physician decides based on previous conversations with the patient.

Best interests’ standard: If no information exists about what a person would have wanted, surrogates are obligated to do what is in the patient’s best interests. Who determines what is in a person’s best interests can be problematic (Casey & Walker, 2010).
ADs and Informed Consent

Informed Consent Laws protect the right of a competent patient to consent to or refuse any and all recommended therapies, including life-sustaining therapies with several exceptions. These exceptions typically are based on public health concerns such as involuntary treatment for drug-resistant tuberculosis, mandated childhood immunizations, mandatory reporting laws, etc.

Informed Consent Laws also protect the moral right of an incapacitated patient to have a surrogate or surrogates consent to or refuse any and all recommended therapies, including life-sustaining therapies. These laws also specify that surrogates are held to a higher standard. Surrogates are not allowed to make unusual, eccentric, or poorly reasoned choices for others without strong evidence that the choice reflects the patient’s wishes (i.e., is a substituted judgment). For example, refusal of blood for a patient who is a Jehovah’s Witness generally requires the surrogate to produce written evidence of the patient’s wishes. A surrogate would not be allowed to refuse blood on the basis of the surrogate’s religious beliefs and objections. Written evidence of a patient’s wishes is not required by law for most treatment decisions (AMA, 2011).

States delineate special requirements for decision making for minors.
Do-Not-Resuscitate (DNR) Orders

Do-Not-Resuscitate has recently been re-termed “Allow Natural Death” (AND), although the adoption of this new term has presented challenges (Jones et al., 2008). DNR orders and ADs are related, but differ in some important ways (Center for Practical Bioethics, 2011; Mayo Clinic, 2011):

• An AD may help a physician or others decide if a DNR order is the ‘right’ decision for a particular patient.
• BUT an AD is not necessary in order for a physician to write a DNR order (with the exception of New York State where some interpret an AD as necessary to write a DNR order for an incompetent patient).
• A hospital-based DNR order should not require the patient's or family's signature but does require the physician’s signature on the order and usually is accompanied by a progress note documenting the patient or family’s discussion with the physician about the order and their informed choice to forego CPR. Requiring the signature of the patient or family surrogate decision maker on a DNR order is not recommended because it places an unnecessary emotional burden on that person. Since most physicians’ orders do not require a co-signature by the patient or surrogate, the DNR order should not.
• Conversely, an AD does require the patient's signature but does not require the physician’s signature or participation in completing the directive.
• A patient with an AD should not be assumed to be a ‘no code’ patient!
• Portable or Community-based DNR orders (known in some states "EMS-No CPR" legislation).
• Community-based DNR orders allow emergency medical services (911) to respond to emergency calls but to not perform CPR should the patient arrest.
• Approximately half the states in the US have legislation allowing for out-of-hospital no code orders that can be honored by "first responders" such as EMS personnel."
## Ads and DNR or AND Orders: A Comparison*

<table>
<thead>
<tr>
<th>How does a person obtain one?</th>
<th>Advance Directives (e.g., Living Will)</th>
<th>Institutional-Based DNR Orders</th>
<th>Community-Based DNR Orders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Can obtain from many sources including the web, hospital, MD, clinic, etc.</td>
<td>Physician writes an order in the medical record.</td>
<td>Forms can be obtained only from a healthcare provider.</td>
</tr>
<tr>
<td>Who signs the documentation?</td>
<td>Only the person to whom it applies.</td>
<td>The physician.</td>
<td>The physician and the patient of their legal surrogate.</td>
</tr>
<tr>
<td>When does the document “take effect” or apply?</td>
<td>Only after the patient has been declared terminal or is in a state covered under state law (e.g., PVS or coma)</td>
<td>Immediately.</td>
<td>Immediately.</td>
</tr>
<tr>
<td>If the person should suffer a cardiopulmonary arrest, what should occur based on the document?</td>
<td>Start CPR and evaluate situation when stabilized and communication is possible with the patient or their legal surrogate.</td>
<td>Do no begin CPR.</td>
<td>Do no begin CPR.</td>
</tr>
<tr>
<td>Does the documentation represent informed consent?</td>
<td>No. Document is a written statement of person’s wishes. Does not require disclosure of specific information by a healthcare provider and, hence, does not represent an informed decision.</td>
<td>Yes. Order results from a discussion between MD (or team) and the patient or legal surrogate. Like any other order for treatment, informed consent should have occurred.</td>
<td>Yes. Form is signed by both the MD and the patient or the patient’s legal surrogate. For is written evidence that informed consent has occurred.</td>
</tr>
</tbody>
</table>

*(Center for Practical Bioethics, 2011; Mayo Clinic, 2011; TJC, 2010)*
Levels of Resuscitation Efforts

In some settings, such as the operating room, a facility may create levels of resuscitation efforts in order to clarify goals in various situations. For example, the American Society of Anesthesia has described four levels of resuscitative efforts, ranging from Level 1: full suspension of DNR in the operating room and full resuscitation to Level 4: limited resuscitation to be used for the DNR patient who is undergoing work up for metastatic cancer preoperative resuscitation would be based upon the extent of disease identified during surgery (AORN, 2008). If a patient who has a DNR order experiences an emergency unrelated to his terminal condition, such as choking on food, the DNR order does not apply.

The DNR order can be acted upon immediately by any healthcare professional should the patient experience cardiac or respiratory arrest. However, DNR orders are often disregarded. DNR orders are sometimes lost when a patient is admitted to an acute care setting from a nursing home. Critical care personnel sometimes ignore DNR orders (Castillo et al., 2011).

Did You Know?
A DNR order does NOT mean "comfort care only," but is written evidence that an informed consent discussion has occurred between a physician and a patient or the legal surrogate(s). The extent and depth of the relationship between patient and physician is a key factor in putting DNR orders in place. Research on the effect of a DNR order on quality of care has yielded mixed findings, ranging from no effect observed in the intensive care setting to a limiting effect observed in the nursing home setting (Center for Practical Bioethics, 2011; Truog et al., 2008).

Issues Related to Advance Directives

In the best of all possible worlds, a patient gives clear and specific directions through an AD to protect against futile measures, prolonged suffering and unnecessary medical expense.

Some research indicates that patients who wrote and then discussed their living wills or related issues with their doctors used less intensive care, underwent fewer procedures, and experienced shorter final stays in the hospital than those without living wills (Casey & Walker, 2010). However, other research findings show that the current situation falls short of the ideal.
Circumstances for AD Utilization

Researchers have documented circumstances that one might expect to be affected by a more systematic approach to advance care planning (Casey & Walker, 2010; Castillo et al., 2011):

- Nearly one-half of do-not-resuscitate (DNR) orders were written 48 hours before death
- Nearly one-half of terminal patients spent 10 days in the intensive care unit
- Less than one-half of the patients’ physicians knew their patients’ preference regarding resuscitation
- 10% of the patients had ADs
- 25% of MDs unaware of their patients’ ADs

Studies have demonstrated that specially trained nurses facilitating physician-patient communication concerning DNR preferences, advance care planning and pain management are beneficial (National Consensus Project for Quality Palliative Care, 2009).

Limitation on Adherence to Advance Directives

After patients have completed ADs and provided copies of them to relevant physicians, the physicians are legally required to adhere to the stipulations of the ADs. Once patients have provided copies of their advance directives to a hospital, the hospital staff is legally obligated to adhere to the stipulations of the ADs. The only exception to this obligation occurs if healthcare professionals believe that the patient was NOT fully informed about the consequences of the decision or competent to make the decision at the time the AD documents were completed and signed. Yet, research findings indicate that healthcare providers do not always respect ADs.
Statistics

Studies have reported that in the intensive care unit, expressed wishes are not followed 25% of the time.

96% of critical physicians said they had withheld or withdrawn life-sustaining therapy and that most had done so frequently:
- 83% of physicians unilaterally withheld or withdrew (82%) treatment they considered medically futile.
- 34% continued treatment against the wishes of patients or surrogates and gave these reasons:
  - Belief that the patient has reasonable chance of recovery: 77%
  - Belief that the family was not acting in patient’s best interest: 39%
  - Fear of malpractice charges: 19%

The Role of Courts

The courts have supported doctors and hospitals for respecting ADs. Though the courts are reluctant to play a role in the death of a patient, the courts are also reluctant to punish doctors and hospitals for withdrawal of life-sustaining treatments when directed by ADs (Castillo, 2011; Crane, Wittink & Doukas, 2005).

The PSDA intends to give the patient the right to choose and limit the physician’s role to advising, delivering care, and deciding for a patient only in extreme situations of incapacity, emergency, lack of available healthcare proxy or patient’s waiver of decision-making to the physician. However, some studies show that 62% of ADs are never given to the MD and that ADs are often misinterpreted.
Reasons Why Ads are Ignored

Some of the reasons that Ads are ignored in facilities in the United States include:

- Lack of facility leadership in encouraging ADs.
- Contentment with current status with respect to ADs.
- Adverse financial incentives.
- Failure of the patient and family to inform the treating physicians of an AD.
- Failure of the patient and family to bring the ADs from the home or nursing home.
- Failure of the treating physician to note and acknowledge the AD.

Nursing Responsibilities Regarding Advance Directives

ANA adopted a strong patient advocacy position on the self-determination issue, stating the individual nurse’s responsibilities as follows (ANA, 1991a):

- To deliver nursing care in a way that meets the needs of the individual.
- To deliver care that is consistent with the goals of the individual with respect to level of health and quality of life.
- To educate and advocate for patients, ensuring that they are fully aware of all options and their consequences and can make informed choices about their healthcare.

And, specifically regarding the PSDA, “nurses should play a primary role in implementation of the Patient Self-Determination Act. It is the responsibility of the nurse to facilitate informed decision-making for patients making choices about end-of-life care” (ANA, 1991b). This responsibility includes evaluating changes in the patient’s perspective and health status.
The Nurse’s Role in ADs

For many Americans, an institution is the last place of care. According to one estimate, 20% of Americans die in an intensive care unit. Nurses can expect to be present not only at death, but during the time when patients and their families are making decisions about end-of-life care. The nurse’s role as advocate and the nurse’s expertise in communication are essential in end-of-life care and decision making (ICSI, 2008).

Advocate for the Patient’s Wishes and Comfort

The nurse’s role is to advocate for the wishes expressed in the patient’s ADs. If no AD exists and the patient is decisionally incompetent, advocate for locating and consulting the surrogate decision maker as specified in state law. Facilitate communication between the attending physician and surrogate. Advocacy may simply take the form of letting the surrogates know at what time the doctor usually makes rounds so that they can clarify their views with the doctor and ask their questions. Facility policies may identify particular staff members to involve, but no facility policy is likely to conflict with acts of advocacy such as keeping abreast of the wishes of patient and family and assuring that the attending physician is aware of these wishes.

Focus on comfort measures regardless of the choices a patient and family make regarding end-of-life care. Carefully access and manage pain. Aggressively assess the patient’s comfort level in performing the activities of which he is capable. Are there means of relieving discomfort related to position, dry mucous membranes or other symptoms related to the patient’s disease, medications and treatment? Are there resources for spiritual comfort? Are concerns of the family addressed? (National Consensus Project for Quality Palliative Care, 2009).
Communicate Continuously with Patients and Families

After the death of loved ones, family members identified unmet communication needs during the shift from aggressive to palliative care (National Consensus Project for Quality Palliative Care, 2009). Families want:

- Timely information
- Honesty
- Clarity in language, use of lay terms and explanation of the implications or various treatments, for example, one respondent said, “It took me forever to realize that a ventilator was life support.”
- Mutual understanding of the situation and the plan among all clinicians and team members
- Listening with understanding – hearing and clarifying misunderstandings of information, hearing concerns accurately
- The most accurate information possible about when death may occur
Communication with the Patient’s Family

Families express the need for a continuous flow of information. Sometimes, the information needed is information that has already been provided, but not heard, understood or remembered. Do not hesitate to repeat information that you believe the family has already heard. Ask the family member to repeat back to you his understanding of what you told him. The family becomes your patient in a sense as you provide end-of-life care. Because the nurse spends more time with the patient and family than other members of the team, the nurse can facilitate communication more effectively than other team members.

- Facilitate communication between patient, family members and other caregivers.
- Create a setting conducive to interaction.
- Allow family members physical closeness, permission, opportunity, support and instruction to touch the patient.
- Be physically and emotionally present for family members as well as for the patient.
- Communicate frequently with physicians and other team members. If necessary, clarify the family’s understanding, or misunderstanding, of the situation, the care provided and the prognosis.
- Offer emotional support and treat family members with respect – even when you answer the same question for the same person multiple times. Family members who authorized the withdrawal of life-prolonging treatments for their loved ones greatly appreciated, and needed, the involvement and support of the nurse in working through their emotions and final decisions.
- Take an attitude of hoping for the best, but preparing for the worst. Avoid unrealistic optimism. Sometimes palliative approaches are delayed because family members cling to false hopes.
Role of the Critical Care Nurse

Nurses in critical care units experience special challenges in facilitating communication among physicians, family and other team members. In the fast-paced atmosphere of aggressive treatment, communication often is confused, misunderstood or lacking. In the highly stressful critical care environment, there is a special need for explaining and re-explaining many times to assure understanding (National Consensus Project for Quality Palliative Care, 2009; Truog et al, 2009).

Know and Adhere to Facility Policies

Familiarize yourself with all facility policies related to ADs and with all materials concerning ADs that are provided to patients upon admission. In addition, learn your facility’s policy and resources for resolving ethical conflicts.

The Joint Commission (TJC) requires accredited organizations to establish a specific systematic mechanism for addressing ethical issues. Usually facilities meet this requirement by creating an ethics committee. The PSDA requires that at the time of admission to a healthcare facility, patients must be informed of their rights. Once informed about their nature and rationale, the patient should be offered the opportunity to execute a living will. As part of the admission procedure, healthcare facilities are required to ascertain if their patients have executed an AD and/or appointed a proxy, DPAHC. However, the PSDA does not specify who should instruct the patient regarding Advance Directives. Therefore it is crucial for you to understand your responsibilities under the facility’s AD policy (CMS, 2011; TJC, 2010).
Responsibilities Under the Facility’s AD Policy

- If you are the admitting nurse, you may be responsible for verifying that the patient or family has provided copies of any executed ADs for inclusion in the medical record. Ideally the patient, family members and primary physician will have made decisions regarding ADs prior to admission.
- To help ensure that executed ADs are followed, the patient or family will need to provide copies to attending physicians, specialists and anyone else who might initiate care.
- As part of their overall care planning process, most hospitals have developed protocols defining how nurses are to identify and document the best way to contact the appointed proxy for healthcare decisions should the patient become incapacitated under the provisions of the PSDA. Know those protocols.
- It is important to note that while the PSDA requires that all Medicare patients receive information regarding Advance Directives, they are not required to make a living will or communicate their wishes regarding AD. Patients must not be coerced or forced to do so.

Discussing with Patients Their Concerns Related to ADs

- Follow the facility’s policies on nurses consulting with patients about this subject, and what other resources may be available or preferable given the hospital policy, nurses’ workload, and other relevant conditions.
- Referrals to social services, pastoral care, and/or a patient representative may be recommended and even preferred under hospital or unit policy.
Witnessing ADs

• You may be prohibited from witnessing the signing of a living will or DPAHC by facility policy and/or state law. For example, California law requires that ADs be witnessed only by “disinterested parties”. As a healthcare provider, you are clearly not a “disinterested party” to the specifications of a living will.
• Even though you may be prohibited from witnessing the signing of an AD, your nursing responsibilities may include assuring there is documentation of the rationale for executing the AD in the medical record, including an assessment of the patient’s decision-making capacity. In your nurse’s notes, document conversations or patient teaching with the patient’s proxy.

Access Your Support System

Caring for patients and their families as they make decisions about end-of-life care and experience the dying process stresses the nurse. Critical care nurses experience burnout and emotional exhaustion related to futile treatment at the end of life. Take care of yourself with your own stress relief measures.

Share your feelings and frustrations with your colleagues and other resource persons. Make proactive plans to find relief for your own stress and support your colleagues in their stress relief (National Consensus Project for Quality Palliative Care, 2009).
Personal Beliefs, Legal and Moral Obligations

You may feel uncomfortable if the stipulations of an AD are in conflict with your own moral or religious beliefs. Depending upon your own beliefs, you may feel that more or less should be done. Each person and each family in our very diverse society brings personal and cultural beliefs and values to the end-of-life decision-making process. Be sensitive to the religious and cultural differences among us, and avoid projecting your personal values and beliefs onto others and their decisions.

In some circumstances, you may disagree strongly with decisions made by your patients and their families. You may feel that you are ethically, or even legally, at risk if you and your co-workers withhold care in compliance with a living will, or if you are directed by a physician or family member to provide care in breach of the patient’s ADs. To date, court rulings support patients’ exercise of their right to self-determination. In fact, healthcare professionals may expose themselves to charges of assault and battery for providing treatment against the patient’s wishes.

If you have strong negative feelings regarding a particular patient’s end-of-life treatment decisions, communicate those feelings with your nurse manager and to any other designated entity according to specific hospital policy before the moment of action, or inaction, arrives. States which have adopted the Uniform Rights of the Terminally Ill Act require healthcare providers who do not want to comply with the patient’s decisions to act as promptly and practical and take all reasonable steps to arrange care by another physician or healthcare provider. Upon admission to the hospital, hospitals in states in which the Act applies provide patients with information in writing regarding the rights of the caregiver. By studying the patient admission documents in use in your facility, you will learn your rights in this area.

You may experience an ethical dilemma when a physician’s verbal or written orders are in conflict with what you understand to be the patient’s wishes as expressed in a living will, by a DPAHC or by family representatives. Prepare yourself for such situations before they happen by ascertaining exactly how such situations are handled at your facility. Acquaint yourself with pertinent policies and inquire about actual practice. Be on the alert for potential conflicts so that you can avail yourself of appropriate advice before you must act in a patient care situation (National Consensus Project for Quality Palliative Care, 2009).
Conclusion

Providing supportive care for patients at the end-of-life and helping their families and significant others during end-of-life decision making can challenge the most experienced healthcare professionals in many ways. Preparing for end-of-life challenges can be facilitated by clarifying your own personal values with regard to these sensitive issues and will usually help to focus on the patients needs, not your own emotions. Identify and access your own resources for stress relief. Update yourself periodically with information about your facility’s policies and procedures related to ADs. Use all of these measures to be certain that you are well prepared for any situation that can arise related to creating an implementing Advance Directives.
References


References (cont.)


Please Read

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