Understanding Living Wills and DNR Orders

ABSTRACT

A living will is a document intended to convey a patient's preferences regarding end-of-life healthcare decisions when the patient cannot express them personally to a physician or other healthcare provider. A living will directs healthcare providers or a patient's authorized representative about the types of medical care the patient wishes to have provided or to forgo at the end of life, consistent with the patient's values and autonomy. A do-not-resuscitate (DNR) order is a medical order issued by a physician or other practitioner authorized to issue medical orders that directs clinicians not to provide cardiopulmonary resuscitation in the event of cardiac or respiratory arrest. A DNR order, by itself, does not address the withdrawal or withholding of any medical care other than resuscitation. Despite the prevalence of living wills and DNR orders, PA-PSRS reports received between June 2004 and September 2008 have revealed that healthcare providers, as well as patients and families, may not understand the differences between living wills and DNR orders. Misinterpretation of living wills and DNR orders may inadvertently result in the provision of unwanted care or the withdrawal or withholding of otherwise appropriate interventions. Accurate interpretation and implementation of these documents, in addition to effective planning and communication, is essential to ensure that a patient's end-of-life preferences for medical care are honored. (Pa Patient Saf Advis 2008 Dec;5[4]:111-7.)

The term "advance healthcare directive" refers to a number of different documents intended to convey a patient's preferences about healthcare.[1] Some advance healthcare directives are intended to appoint a person to make decisions on the patient's behalf when the patient is unable to do so; some authorize another individual to admit the patient to a nursing home or other type of healthcare facility under certain circumstances; and some give specific instructions about what kind of and under what circumstances medical care is to be provided or withheld. A living will is a type of advance healthcare directive, specifying the life-sustaining treatments a patient wishes to *receive or forgo* when the patient is no longer capable of making decisions for him- or herself *and* has an end-stage medical condition *or* is permanently unconscious.[1] A patient may revoke a living will at any time, even at the end of life. In order to implement the terms of a living will in a clinical setting, a physician must determine that the patient is no longer competent and certify in writing that the patient is in an end-stage medical condition or is permanently unconscious.[1]

A do-not-resuscitate (DNR) order is a medical order to withhold cardiopulmonary resuscitation (CPR) in the event of cardiac or respiratory arrest. Typically, a DNR order is entered into a patient's medical record after a discussion between the physician and the patient and/or a patient's authorized representative.[2] A DNR order may be entered into a patient's medical record in the absence of a living will.

In addition to preserving a patient's autonomy, one of the underlying purposes of living wills and DNR orders is to give healthcare providers direction regarding a patient's preferences for end-of-life care and interventions. However, as reflected in PA-PSRS reports, there is confusion about how to interpret and implement these documents. From June 2004 to September 2008, PA-PSRS received more than 200 reports involving living wills and DNR orders. An understanding of the implications of living wills and DNR orders, as well as the understanding that these documents are not interchangeable, is important in providing appropriate and respectful clinical care. This article will discuss living wills and DNR orders as defined in the Commonwealth of Pennsylvania. Strategies are presented to assist clinical staff, patients, and families to understand what these documents mean to help ensure that a patient's wishes are communicated and appropriately carried out.

Background

Living Wills

In the Commonwealth of Pennsylvania, patient self-determination is governed by the Living Will Act, which provides a statutory framework for healthcare decision making.[1,3] The Living Will Act establishes that only competent adults or emancipated minors are able to make a living will. Pennsylvania law requires that the document be entered into the patient's medical record, but entry into the medical record does not make a living will operational. A living will becomes operational only when a physician determines that the patient is incompetent *and* certifies in writing that the patient has an end-stage medical condition *or* is permanently unconscious.[1] (See "Glossary of Selected Terms.")

Certification of an end-stage medical condition can pose problems when the patient has an illness involving slow deterioration, such as with Alzheimer's disease. Determinations of competency can be very difficult and present a challenge to the determining physician as well as other healthcare practitioners involved in the patient's care. Competency is not static, and a patient's decision-making capability may fluctuate. A patient may become confused when experiencing a high fever but be lucid when the fever has resolved. In addition, a patient may be

Glossary of Selected Terms

Incompetency is a condition in which an individual—despite receiving appropriate medical information, communication support, and technical assistance—is documented by a healthcare provider to be unable to

- understand the potential material benefits and risks involved in and alternatives to a specific proposed healthcare decision;
- make that healthcare decision on his or her own behalf; or
- communicate that healthcare decision to another person.

End-stage medical condition is an incurable and irreversible medical condition in an advanced state caused by injury, disease, or physical illness that will, in the opinion of the attending physician to a reasonable degree of medical certainty, result in death, despite the introduction or continuation of treatment.

Permanently unconscious is a medical condition that has been diagnosed, in accordance with currently accepted medical standards and with reasonable medical certainty, as a total and irreversible loss of consciousness and capacity for interaction with the environment. The term includes an irreversible vegetative state or irreversible coma.

Life-sustaining treatment is a medical procedure or intervention that, when administered to a patient or principal who has an end-stage medical condition or is permanently unconscious, will only serve to prolong the process of dying or maintain the person in a state of permanent unconsciousness.

Source: 20 Pa. Cons. Stat. § 5442 (2008).

found incompetent to make some healthcare decisions, but competent to make others.[4] For example, a patient may be competent to consent to a chest x-ray but incompetent to agree to complicated surgery. Incompetence does not mean that the patient made a choice that others would not make, such as when a competent patient chooses to forgo recommended treatment.

Studies have demonstrated the lack of understanding about the meaning of terms found in living wills. A survey examined whether cohorts consisting of patients, their physicians, and family members understood the meaning of terms used in living wills. The cohort groups had high concordance (83%) regarding understanding of the term "the use of life support to keep patients alive." However, 71% of patients, 42% of family members, and 27% of physicians responded that a living will could be used to guide treatment decisions in non-end-of-life clinical situations, reflecting a lack of understanding about when a living will becomes operative.[5] Another study demonstrated that patients with living wills poorly understood the meaning of "life-sustaining therapies" and the implications of their advance directives. Of 755 patients admitted to a community teaching hospital during the study period, 264 study participants were surveyed regarding their understanding of CPR. Of these, 82 (31%) had living wills. Most (76%) created their living will with a lawyer or family member, and 7% involved a physician. After the patients were provided an explanation of the meaning of CPR, 37% of patients with living wills indicated they actually did not want CPR. Their living wills did not accurately reflect their treatment preferences.[6]

A DNR order is a medical order issued by a physician or other authorized practitioner that directs healthcare providers not to administer CPR in the event of cardiac or respiratory arrest. A DNR order may be written in the absence of a living will or the conditions that would make a living will operative. A living will may contain a provision indicating that a patient does not desire CPR. However, if a patient's preference to forgo CPR is expressed only in a living will, CPR will be withheld only when a physician has determined that the patient is not competent and has certified in writing that the patient has an end-stage medical condition or is permanently unconscious.[1] Without such physician determination and certification or without a DNR order, the patient's expressed preference for withholding CPR is not sufficient.[2] In order for a patient's preferences to be carried out, patients, families, and healthcare providers must understand the distinction between the circumstances under which a living will and a DNR order are applicable.

A DNR order is not subject to the preconditions imposed by the Living Will Act. A DNR order becomes operative only in the narrow context of cardiac or respiratory arrest regardless of the precipitating clinical event and *does not* preclude otherwise appropriate treatments or life-sustaining interventions.[2,7] Misinterpretation of DNR orders was demonstrated by a survey conducted in an outpatient cancer center, which showed that only 34% of the patients correctly understood the meaning of a DNR order; 66% of the patients did not realize that a DNR order would result in not being resuscitated even if the cause of the cardiac or respiratory arrest was potentially reversible.[8]

Patient Safety Risks Related to Living Wills and DNR Orders

The potential for misunderstanding the meaning and implications of a living will and DNR orders by healthcare providers, patients, and families may lead to withholding of desired interventions or administering unwanted interventions. Communication failures between providers, patients, and facilities may lead to the same results. These patient safety risks have been reported through PA-PSRS.

Unwanted Treatment

In the absence of a DNR order, CPR will be administered, if medically justified, unless a living will has become operative. A patient may undergo unwanted treatment (i.e., CPR) if he or she does not appreciate the important differences between a living will and a DNR order when expressing, in a living will, the wish not to undergo CPR. In addition, the risk of a patient receiving unwanted care or not receiving desired and appropriate care arises when healthcare providers do not interpret or implement a living will appropriately. Dobbins has shown that the existence of a living will may not affect healthcare decision making. A retrospective review was conducted of the records of 160 elderly patients who died in a community hospital to determine the effect of living wills on healthcare decisions. The findings demonstrated that a living will did not influence healthcare provider decisions about the use of life-sustaining treatment and the initiation of comfort care plans or the decision to treat the patient in the intensive care unit (ICU). The documents did influence healthcare providers to write DNR orders more often.[9]

From June 2004 to September 2008, 37 of the PA-PSRS reports related to living wills or DNR orders have involved patients receiving potentially unwanted interventions. Examples are as follows:

A patient was admitted through the [emergency department (ED)] after suffering a femoral fracture from a fall at home. The patient underwent an open reduction of the fracture and was transferred to the ICU postoperatively due to numerous preexisting comorbidities. The patient developed hypotension and tachycardia. A hospitalist was summoned to the bedside, and medications were administered. The patient then developed ventricular tachycardia. The patient did have DNR order but an attempt was made to resuscitate the patient. The resuscitation attempt was unsuccessful.

A patient was admitted through the ED with increased lung congestion and vomiting blood. Resuscitation status was not addressed on admission. The patient was diagnosed with acute respiratory distress due to pneumonia. No chest x-ray had been ordered. The patient was being assisted with breakfast and suddenly became unresponsive and stopped breathing. A resuscitation team was called. The patient had living will in the chart indicating no resuscitation. The hospitalist spoke with the attending physician, who stated the patient's wishes were . . . DNR; however, the order was never given. The resuscitation was stopped, and the patient expired.

A patient with numerous comorbidities had a DNR order in the chart; when the patient's vital signs changed, the patient was resuscitated despite the DNR order.

Misperceptions of the Meaning of Living Will and DNR

Researchers have raised concerns that DNR orders and living wills may be misunderstood by healthcare providers. A case series of patients with a living will presenting for treatment and their hospital course illustrated these concerns. In one case, the primary care physician (PCP) advised the emergency physician (EP) that a patient presenting with chest pain did not need to be admitted because the patient had a living will. The PCP interpreted the living will as imparting a DNR status. The EP disagreed with the PCP's interpretation, and the disagreement resulted in a delay in treatment. In another case, a nurse delayed notifying the attending physician of a change in the patient's clinical status. The nurse mistakenly interpreted the patient's living will as meaning a code status of DNR. In a third case, the EP and PCP misinterpreted a living will, believing it to be operative. This resulted in less aggressive treatment of a myocardial infarction.[10] The case series author stated that "just because a living will exists, its existence does not cause it to become activated. Also, it must be re-iterated that a DNR does not equal 'do not treat.'"[10]

A recent study has shown that a misunderstanding of the meaning of a living will may unnecessarily put patients at risk when patients present for emergency care. A survey administered to physicians, nurses, and first responders at a 350-bed acute care and level II trauma center presented a fictitious living will and prompted respondents to assign a code status (DNR or full code) and define the level of care associated with the DNR code status. Seventy-nine percent of respondents assigned a DNR code status, and 70% construed DNR to mean "comfort care/end-of-life care."[11] Other studies support that DNR orders may be applied to broader treatment decisions and that interventions such as hospitalization, blood transfusion, central line placement, and intubation may be withheld based on the existence of a DNR order, even when a patient has not requested that these treatments be withheld.[12,13,14]

From June 2004 to September 2008, 93 of PA-PSRS reports regarding living wills or DNR orders indicated that a DNR order may have been misinterpreted as

Key Points

- A living will applies *only* if the patient is incompetent *and* has an end-stage medical condition *or* is permanently unconscious.
- A living will does not apply to questions of day-to-day care, placement or treatment options, and other non-end-of-life circumstances.
- A do-not-resuscitate (DNR) order is a medical order issued by a physician or other authorized practitioner that directs clinicians *not* to provide cardiopulmonary resuscitation in the event of cardiac or respiratory arrest.
- A DNR order, by itself, does not include the withdrawal or withholding of any medical care other than resuscitation.

a directive to withdraw or withhold care, suggesting staff may not have understood the narrow scope of a DNR order. It is important to note that the reports do not convey the clinical context of the decision to withdraw or withhold care, which may have been based on other factors unrelated to the DNR order. Examples include the following:

A patient was transferred from the ICU to the telemetry unit. No monitors were available. . . . Staff phoned the doctor to see if they could discontinue the monitor on [another] patient who was DNR to use on this patient.

A patient was intubated and restrained due to the patient pulling on lines. . . . The patient was unable to be weaned from ventilator. Family and physician discussion revealed code status had been changed from full code to DNR. Restraints were removed, and the patient was extubated and expired.

A patient presented to the ED in cardiac arrest. After admission, the patient developed a fever. Blood cultures were positive for methicillin-resistant Staphylococcus aureus*. The patient expired after the family made the patient a DNR and did a terminal wean [from the ventilator].*

Shortly after admission, the patient went into respiratory arrest. The patient was intubated, and restraints were applied to prevent the patient from removing the endotracheal tube. The patient then requested DNR status, restraints and endotracheal tube were removed, and the patient expired.

A patient was on a Levophed® drip. When the drip began running out, no Levophed was available to mix another dose. The patient was a DNR, and Levophed was discontinued.

Miscommunication

PA-PSRS reports show that there is a potential for a breakdown in communication between healthcare providers and between healthcare providers, patients, and families. Seventy-one reports submitted through PA-PSRS from June 2004 to September 2008 related to living wills or DNR orders indicated some form of communication breakdown. The majority of reports involved a lack of understanding of the meaning of the documents by families, lack of communication of the presence of a DNR order among healthcare providers, misidentification of patients, and failure to identify patients with DNR orders. All these issues may lead to a patient's preferences not being carried out. Examples of these issues reported through PA-PSRS include the following:

A patient was admitted through the ED from a long-term care facility (LTCF). The patient's [living will] was not sent with information from the LTCF. Shortly after admission, the patient had a respiratory arrest. A code was called, and the patient was successfully resuscitated. The family was called to notify of code. [The family] advised staff that the patient had [a living will] and was a DNR.

The physician ordered a DNR status; subsequently, the physician noted a DNR sticker was not placed on patient's chart. No report was given to the nurse from the previous shift regarding code status, and no DNR armband was placed on the patient.

Patient was admitted from another facility as level 2 DNR. Family member states family discussed level of intensity with doctor and requested change to level 1 (DNR). Per family, doctor agreed that it was appropriate and told them that he would take care of it. The patient coded with family present. The family requested a code. The staff initiated resuscitation but then noted level 2 status and code stopped. A nurse spoke to the family, who stated the code status had been changed. The code team was recalled and resumed resuscitation. The patient was resuscitated successfully.

A patient was wearing a purple wristband (DNR) indicating code status. The band was removed, and an appropriate band for "do not use extremity" applied.

A DNR order was entered for a patient. The unit secretary prepared a DNR band and gave it to the nurse's aide to apply to the patient. The nurse's aide then passed it on to a second nurses' aide, who applied the band to the wrong patient.

Patient had a blue armband indicating DNR order. No DNR order was found on the patient's chart. [The discrepancy was] discussed with the patient, and the patient wanted full code status. The blue armband was removed.

Risk Reduction Strategies

As the above PA-PSRS reports indicate, living wills and DNR orders may be misunderstood by healthcare providers, families, and patients. Communication breakdowns, including the lack of appropriate documentation and patient misidentification, also present patient safety risks. Several strategies may be used to reduce this risk. (For additional resources, see "Companion Online Information.")

Improving Communication

The implementation of a DNR order may preclude a number of procedures, including chest compressions, cardiac defibrillation, medications, and endotracheal intubation.[2] A DNR order may apply to any combination of these interventions, potentially leading to confusion. For example, a patient may want to be intubated but may not wish to receive any other treatment. DNR protocols have been developed that integrate these procedures; however, these protocols may differ among facilities in terminology, scope, and content. For example, PA-PSRS reports from different facilities throughout the state include the following terms: DNR A through D, DNR levels I through V, modified DNR II, and DNR/DNI.

In addition to inconsistent terminology, in Pennsylvania, a DNR order is not portable after the patient is discharged or transferred to another facility. The Physician Orders for Life-Sustaining Treatment (POLST)

Companion Online Information

Caring Connections

- Caring Connections, a program of the National Hospice and Palliative Care Organization, provides a variety of information about advance directives for patients and families. Available from Internet: http://www.caringinfo.org/Home.htm.

Pennsylvania Department of Aging

- The department provides a brochure, which includes an advance directive statutory form. See "Advance Directives for Health Care, Living Wills and Powers of Attorney in Pennsylvania." Available from Internet: http://www.aging.state.pa.us/aging/lib/aging/Advance_Directives_brochure1.pdf.

Pennsylvania Medical Society

- The Pennsylvania Medical Society provides an online summary of the Living Will Act. Available from Internet: http://www.pamedsoc.org/mainmenucategories/Government/LawsAffectingPhysicians/AdvanceDirectives/Act169facts.aspx.

The Hospital & Healthsystem Association of Pennsylvania (HAP)

- HAP provides an informational brochure on advance directives. See "Decide for Yourself: A Guide to Advance Healthcare Directives." Available from Internet: http://www.haponline.org/downloads/decideen.pdf.

Hamot Medical Center

- Ferdinando L. Mirarchi, DO, medical director, emergency medicine, Hamot Medical Center, presented an informational lecture on living wills and DNR orders at the University at Buffalo on September 10, 2008. See "To Live or Let Die! Living Wills and DNR Orders." Available from Internet: http://www.hamot.org/livingwillvideo/.

form has been recommended in other states as one mechanism for issuing a single medical order that reflects a patient's end-of-life preferences expressed through a living will and is transferrable across care settings to help ensure the patient's wishes are honored throughout the healthcare system.[2,15,16] (The POLST form has *not* been adopted in Pennsylvania, however, and current healthcare regulations preclude physicians from issuing medical orders that transfer from one facility to another in most cases. The Pennsylvania Department of Health currently has a task force reviewing the advisability of adopting a POLST-like medical order statewide.)

Healthcare providers can use a number of strategies to facilitate communication with patients and families regarding end-of-life treatment preferences. The following have been identified as key elements of a successful advance directive program and may be applied to the process of obtaining a DNR order.[2,16]

- Develop an individualized plan of care through a process of interaction with the patient that is specific to the patient's values and goals, including consideration of the patient's relationships, culture, and medical condition.
- Engage individuals who are close to the patient so that they understand and support the plan. Discuss with the patient and surrogate how much leeway the surrogate has in decision making.
- Document the plan, including identification of the designated surrogate in the event the patient is deemed no longer competent or able to communicate, in the form of an actionable directive that addresses wishes for treatment with specific medical orders reflecting the patient's current treatment preferences.
- Plan for a proactive but appropriately staged and timed discussion about healthcare decisions. The discussion must be revisited when the patient's prognosis becomes known or changes. Healthy adults can benefit from advance care planning to prepare for sudden, severe illness or injury. For individuals with advanced chronic disease and frailty, include a discussion regarding changing treatment goals as the patient's prognosis changes. Plans should be updated over time and available when needed.
- Ensure that patients, families, and/or surrogates understand the terminology contained in a living will and/or DNR order, as appropriate.

Healthcare providers can improve their own understanding and their communication with each other about a patient's wishes as expressed in a living will, the DNR order, or both, by implementing the following strategies:

- Establish ongoing education about living wills and DNR orders for residents, attending physicians, and nursing staff.[2]
- Ensure that residents, attending physicians, and nursing staff understand when a living will becomes operative.[10,16]
- Ensure that residents, attending physicians, and nursing staff understand that the existence of a living will does not imply that a patient has a DNR order.[10]
- Ensure that residents, attending physicians, and nursing staff recognize that a DNR order applies only to cardiopulmonary arrest and has no effect on any other treatment decision. In other words, a DNR order does not mean "do not treat."[10]
- Encourage physicians to obtain skills training in communication about end-of-life decision making.[2]

- Establish policies that require a discussion and documentation of any exception to a DNR order during the perioperative period, such as suspension of a DNR order during surgery.[2]
- Ensure that the existence of a living will is established on admission and documented in the patient's medical record.[2]
- If the facility uses color-coded wristbands to communicate DNR status to clinicians, ensure that policies address who is responsible for applying and removing DNR color-coded wristbands and how DNR wristband information is documented and communicated.[17]

Conclusion

A living will is an important mechanism for providing guidance and direction to healthcare providers regarding a patient's end-of-life preferences. A DNR order is one way a physician or other authorized practitioner can direct clinicians to respect a patient's wishes about receiving CPR in the event of cardiac or respiratory arrest. However, there is no substitute for collective, informed decision making and clinical judgment, requiring open communication between patients, families, and physicians. In order to communicate effectively, all parties involved must understand the meaning and implications of living wills and DNR orders. Living wills and DNR orders are intended to honor a patient's end-of-life preferences. Through planning, education, and effective communication, healthcare providers can assist patients in realizing their end-of-life treatment goals.

Notes

1. Living Will Act, enacted as part of Act 169 of 2006, 20 Pa. Cons. Stat. § 5441 *et seq.* (2008).
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15. Dunn PM, Tolle SW, Moss AH, et al. The POLST paradigm: respecting the wishes of patients and families. *Ann Long-Term Care* 2007 Sep;15(9):33-40.
16. Hickman SE, Hammes BJ, Moss AH, et al. Hope for the future: achieving the original intent of advance directives. *Hastings Cent Rep* 2005 Nov-Dec; Spec No:S26-30.
17. Pennsylvania Patient Safety Reporting System. Update on use of color-coded wristbands. PA PSRS Patient Saf Advis [online]. 2006 Aug 9 [cited 2008 Oct 5]. Available from Internet: http://www.psa.state.pa.us/psa/lib/psa/advisories/v3_s1_sup_advisory_8-9-06.pdf.

(See Self-Assessment Questions on next page.)

Self-Assessment Questions

The following questions about this article may be useful for internal education and assessment. You may use the following examples or come up with your own.

1. A patient safety risk related to the misinterpretation of a do-not-resuscitate (DNR) order by healthcare providers is the withholding or withdrawing of otherwise appropriate clinical interventions.
   a. True
   b. False
2. A living will becomes applicable when all of the following conditions occur EXCEPT:
   a. A copy is provided to the attending physician.
   b. The patient is determined to be incompetent by the attending physician.
   c. The patient is determined to have an end-stage medical condition or to be permanently unconscious.
   d. The determination of all applicable conditions is confirmed with a second opinion.
3. Living wills may be applicable to questions about day-to-day care, placement or treatment options, or other healthcare decisions involving patients who lack capacity in non-end-of-life circumstances.
   a. True
   b. False
4. An elderly patient with a medical history of stroke, myocardial infarction, and congestive heart failure is admitted after a fall at home. The patient is diagnosed with a hip fracture. The patient has a living will indicating she does not wish to undergo cardiopulmonary resuscitation (CPR), which is placed in her medical record. Before surgery to repair her fractured hip, the patient reminds her physician that she does not wish to undergo CPR. After a discussion about the implications of the DNR order, the physician enters a DNR order in the patient's medical record. On her second postoperative day, the patient's condition deteriorates and she suffers a cardiopulmonary arrest.

   Which of the following is an accurate statement about the appropriateness of CPR for this patient?
   a. CPR may be withheld in the presence of the DNR order only if the patient was determined to be incompetent.
   b. CPR may be withheld based on the living will since the patient suffered a cardiopulmonary arrest.
   c. A healthcare provider may not withhold CPR based on the DNR order without the existence of the living will.
   d. The healthcare provider may withhold CPR based on the DNR order without the provisions expressed in the patient's living will becoming applicable.
5. All of the following are strategies that would help reduce the risk of misinterpretation and/or miscommunication of a living will or DNR order EXCEPT:
   a. Determine on admission whether a patient has a living will, and ensure that it is appropriately documented in the patient's medical record.
   b. Recognize that obtaining skills training in communication about end-of-life decision making is best delegated to the hospital ethics committee.
   c. Ensure that residents, attending physicians, and nursing staff recognize that a DNR order applies only to cardiopulmonary arrest and has no effect on any other treatment decision.
   d. Ensure that patients, families, and/or surrogates understand the terminology contained in a living will and/or DNR order.

PENNSYLVANIA PATIENT SAFETY ADVISORY

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