IMPROVING ADVANCE CARE PLANNING DOCUMENTATION

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Nursing 702

A manuscript submitted in partial fulfillment of
the requirements for the degree of

MASTER OF NURSING

WASHINGTON STATE UNIVERSITY
Intercollegiate College of Nursing

JULY 2009
To the Faculty of Washington State University:

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Abstract

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Although patients and providers feel advance directives are helpful to communicate end of life wishes, many patients do not have an advance directive. Some barriers to completion of advanced directives identified by patients can be overcome by providers who are willing to engage in end of life discussions with their patients and provide resources or assistance with completing the appropriate documentation. For providers who may be less informed about advance care planning or are intimidated by initiating discussions, this article may be especially useful. Information is provided about the different types of advance care planning documents available and their specific benefits. Some useful on-line resources are also provided including information on obtaining advance directive documents.
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Introduction

Attorney Luis Kutner first developed the concept of Advance Directives (ADs) and the living will in 1967. A living will was intended to assist individuals gain autonomy over the medical treatment received while one is incapacitated. It would specifically allow persons to refuse treatment that may prevent death. ADs are now legally valid throughout the United States although there is variation among different states (Sabatino, 2007).

The legal principles for which ADs exist arise from common laws that allow individuals who are mentally competent to have control over what happens to their body. These rights continue even when an individual becomes incapacitated or is dying. The Natural Death Acts are the specific laws that allow persons to refuse medical treatment when dying and allows individuals to have a “natural” death. Natural Death Acts allow the individual to receive and/or refrain from receiving care when the persons is incompetent to either give or refuse consent for treatments and therapies (Lens, 2002).

These laws also provide legal protection to providers in carrying out a patient’s AD. It also allows protection for not following an AD, however, it requires that the provider make a reasonable effort to transfer care to another provider who is willing to carry out the intentions of the patient’s AD. To support enforcement of carrying out an AD, a living will may contain statutory
language that allows for this, it is also referred to as a natural death act (Guido, 2009).

For patients who desire written advance care planning, there are different types of documents available. These include the choice of a living will or a designated healthcare proxy. There are also format options to choose of a more personalized nature. Some include material that is sensitive to age, literacy and ethnicity as well as documents that are based on patient values (Karel, Powell & Cantor, 2004; Sudore, Landefeld, Barnes, Lindquist, Williams, Brody, et al, 2007; Wiener, Ballard, Brenna, Battles, Martinez & Pao, 2008).

Though there are perceived benefits for having executed an AD, completion rates for the general population are estimated to be less than 20 percent (Jezewski, Meeker, Sessanna & Finnell, 2007).

This article addresses the underutilization of AD documents and the barriers to completing them. Information is provided about the different types of AD documents, resources for obtaining them, and strategies for providers to assist patients with their completion. This information may be helpful for nurse practitioners to become more familiar with ADs and improve communication about end of life preferences among patients, their families, and the providers who care for them.

Background/Problem

AD documents can provide patients, who have become unable to communicate their wishes, with the ability to have choice and control over
their healthcare if and when they experience extreme illness or are near death. Discussion about ADs can also provide patients the therapeutic opportunity to discuss their mortality and what it means to them. Despite some evidence that ADs are not always observed, many patients feel that utilizing an AD document would be helpful in communicating their end of life wishes and have specific opinions regarding interventions at the end of life (Clements, 2009; Hardin & Yusufaly, 2004; Wiener, et al, 2008). Generally, healthcare providers feel that having an AD is useful and believe they are followed most or all of the time (Bergman-Evans, Kuhnel, McNitt & Myers, 2008). However, despite both patient's and provider's perceived benefit for using ADs, they remain underutilized. This is evidenced by stagnant completion rates. Despite any attempted strategies to increase completion rates, they continue to remain low (Perkins, 2007).

Completion Barriers

There are several perceived barriers to AD completion. Some reasons cited by patients for not completing a written AD are: not thinking about it; difficulty with the paperwork; and waiting for their provider to begin the discussions about ADs (Golden, Corvea, Dang, Llorente & Silverman, 2009). For those patients who are thinking about advance care planning, the likely barrier is the lack of discussion between them and their provider. One recent study queried patients living with cystic fibrosis about end of life communication. The majority (65%) indicated a preference for who they
would like for a proxy and 58% had specific ideas about medical treatments they would be willing to receive if incapacitated. Only 30% reported having any form of completed written documentation. Patients who discussed ADs with a clinician had an increased likelihood of having completed a written AD. Seventy-nine percent reported being comfortable talking with their provider, however, only 13% had done so (Sawicki, Dill, Asher, Sellers & Robinson, 2008).

The Patient Self-Determination Act requires hospitals and other providers who receive Medicare reimbursement to inquire whether patients have an advance directive or would like to receive information about obtaining one at the time of their admission (Kring, 2007). Nonetheless, many providers do not fulfill this legal obligation (Clements, 2009; Mirza, Kad & Ellison, 2005; Sawicki, et al, 2008).

Provider's feel they do not have enough time to discuss ADs. Besides time constraints, some indicate that they are reluctant to initiate these conversations with their patients and feel they lack of aptitude to adequately discuss end of life topics (Wissow, et al, 2004).

Types of Advance Directives

An AD is a statement of preference regarding one's interest in receiving or declining life sustaining medical treatment while a person is in a state of incapacitation. This statement may be verbal or written. Thus it does not require preparation by an attorney or to even exist as a formal document,
though the majority of states require that a formal document that conforms to statutory language. A person can disclose his or her preference in a casual discussion with a friend or family member. A declared wish about not wanting to be kept alive on a ventilator may be considered a verbal AD in a handful of states. Utilizing a written formal document is more effective if there is any dispute among providers or family. Further, the legal enforcement of oral ADs may be more difficult than enforcing written ones and laws concerning verbal ADs differ between states (Mitty & Ramsey, 2008). For most written advance directives to become legally valid the patient's signature must be signed in front of two witnesses or a Notary Public can be utilized. However, each state has different requirements for signing validity (National Hospice and Palliative Care Organization, 2009).

There are two basic types of formal advance directive documents, a living will and a healthcare proxy. A living will, generally given statutory enforcement as a natural death act, is a declaration of a patient's desires for receiving or declining healthcare interventions during a state of incompetency and most often names a surrogate decision maker. Another type of advance directive is the designation of a healthcare proxy. This is a patient's intent to authorize another person to make healthcare decisions for the individual, when he or she is incompetent to make his or her own wishes known. A healthcare proxy is also known as a surrogate decision maker, healthcare agent, medical power of attorney or durable power of attorney for healthcare
(Mitty & Ramsey, 2008). Some states require that when appointing a healthcare proxy, the individual and proxy must have discussed the individual’s healthcare preferences (Guido, 2009). In situations where patients do not have a designated person in advance of incapacitation, the medical decision making often defaults to a family member as determined by state laws (Sabatino, 2007).

A Physician Orders for Life Sustaining Treatment (POLST) form is a portable Do Not Resuscitate (DNR) order and is not an advance directive, but a physician’s order (Wood, 2007). It provides direction about whether or not to perform immediate life sustaining interventions such as Cardiopulmonary Resuscitation (CPR), defibrillation and mechanical ventilation for emergency medical personnel. The POLST program was developed in Oregon. Other states have implemented this program, including California, New York, North Carolina, Tennessee, West Virginia, Washington and some parts of Wisconsin with other states currently involved in program development. Each state has their own version of the POLST document which meets the specific requirements of their own state laws (POLST, 2009).

In Washington State, the POLST form becomes a set of medical orders when signed by a physician, nurse practitioner, or physician assistant. Emergency Medical Technicians (EMTs), who are most often the first responders, are required to have orders for their medical actions; therefore it is necessary to have providers sign this document. In Washington State, the
POLST form specifically lists nurse practitioners and physician assistants as providers who can legally sign (WSMA, n.d.). Several other states utilizing the POLST have also acknowledged nurse practitioners as having authority to initiate these medical orders (POLST, 2009). In addition to instructing emergency care, the POLST provides directions about additional medical interventions such as artificial hydration and antibiotics. The POLST is primarily targeted for those who are terminally ill and medically frail.

Many living wills have similar language to the POLST form. The difference between a POLST form and a living will is the fact that the POLST form is a set of medical orders designed to be used in emergency situations. Various AD forms and additional resources are readily available to patients at hospitals and on-line through many healthcare and state organizations.

Living Will Formats

Intervention based living wills indicate preferences for specific interventions such as the desire for tube feedings to prolong life or mechanical ventilation for respiratory failure. This is not necessarily related to any particular health condition. Standard AD forms are primarily intervention based. These are less preferred by most patients and are less likely to be completed (Sudore, et al, 2007). Confusing medical terminology and concern that the general statement of “do not resuscitate” does not accurately capture one’s preferences are just two reasons why intervention based ADs are less preferred.
Scenario based language in a living will describes goals or treatment preferences under certain scenarios or about health conditions (Ditto, Danks, Smucker, Bookwala, Coppola, Dresser, et al., 2001). Some of these conditions could include dementia, severe stroke, severe heart failure, and terminal cancer. One example of this might be: “If you had severe dementia, would this be an acceptable state of health?” Scenario based ADs are often combined with intervention based ADs. It may contain language that describes specific treatment interventions desired for specific health states. Some options that may be considered could include preferences for emergent resuscitative treatment or for long term artificial support. For example, “If you had severe dementia, would you want to receive life prolonging treatments such as antibiotics for severe illness?”

Values statements or a values history document is designed to explore what one considers valuable regarding one’s life. These are supplements to an AD (Institute for Ethics, n.d.). This supplemental document can clarify goals regarding end of life preferences (Leland, 2001). Value statements can assist in determining importance of length of life compared to functional ability; the importance of having relief from pain and suffering, and the importance of being able to interact with one’s family or environment. Examples of these values statement are: 1) “Having pain relief is very important to me and I would be willing to interact less in my environment so I wouldn’t have to
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suffer"; and 2) "Independence is extremely important to me and I feel I could not tolerate my life if I was permanently confined to a bed".

Benefits and Limitations of ADs

Benefits of ADs other than the actual declared preferences should be considered, such as the psychological benefits. These benefits may be therapeutic to both the patient and their proxies. Most people designated as health care proxies are more comfortable making decisions when they have written instructions such as a living will (Hines, Glover, Babrow, Holley, Badzek & Moss, 2001). Surrogates who have known the patient for a long period of time, like a close family member, typically know the individual's preferences. A living will does not increase these surrogates’ ability to predict a patient’s preferences (Coppola, Ditto, Danks & Smucker, 2001). However, it can provide surrogates with an increased sense of confidence in carrying out their surrogate responsibilities. It may also alleviate distress and prevent any guilt that their direction to the healthcare providers really followed the patient’s wishes and not their own.

Primary care providers (PCPs) may be contacted in an emergency when family cannot be reached. PCPs that have a long standing relationship with a patient may be fairly accurate in determining a patient’s intent for certain life sustaining treatment preferences. This is increasingly true in extreme conditions. Coppola, et al (2001) found that in hypothetical illness scenarios, PCPs are as equally as accurate as a family member for predicting patient
preferences for certain healthcare conditions. Hospital based providers are less accurate in being able to predict a patient’s treatment preferences without using an AD. In comparing the predictive ability of using a scenario based AD with a values based AD, it was found that scenario based ADs improved the hospital based provider’s accuracy for many illness situations (Coppola, et al, 2001). In the absence of family and a PCP, an important benefit of a living will is to assist providers to whom the patient is unknown with delivering only the care desired by the individual.

Improving Completion Rates

An important barrier to completing AD documentation is the lack of advance care planning discussions between patients and their providers. Recent studies recommend that the best intervention to increase the completion rate of ADs is through direct provider to patient discussions (Jezewski, et al, 2007; Ramsaroop, Reid, & Aldeman, 2007). Additionally, patients would like their providers to initiate these conversations (Clements, 2009; Golden, et al, 2009). Providers who refrain from having these discussions for reasons of upsetting patients about topics of death should be reassured that this is not often the case, even for adolescents (Wiener, et al, 2008).

Nurse practitioners are often in the best position to inquire about end of life preferences, provide education, and when appropriate, encourage completion of documentation to help ensure that these wishes are known and
accessible when needed. This is especially true with well established patient-provider relationships. When these discussions occur in the primary care setting, patients are more likely to be in a stable health condition and in a state of mind to best determine and accurately articulate their health care preferences.

Patient satisfaction can increase when PCPs discuss ADs (Tierney, Dexter, Gramelspacher, Perkins, Zhou & Wolinsky, 2001). PCPs should consider development of a consistent dialogue about ADs that is informative and comfortable as well as having written ADs available in order to facilitate completion of ADs.

One method that may assist providers in initiating AD conversations is to add a screening question to a patient's health questionnaire. It can stimulate either patient interest in AD discussions or determine whether they would like assistance pursuing written documentation. Patients can be directed to peruse the many on-line AD resources available, many which are free (see Table 1). Additionally, there are several popular versions which may be purchased, such as Five Wishes which is available in multiple languages. For patients who are interested, but may have difficulty obtaining AD documentation, providers may consider having them available to distribute.

Improving completion of written documentation can be facilitated by use of ADs in alternative formats. For patients who have limited literacy, which include about half of all Americans (Kutner, Greenbery & Baer, 2005),
an AD designed at a lower literacy level is more likely to be completed. Utilizing media that gives special consideration to language barriers and persons with limited comprehension can help prevent the possibility of miscommunication (Sudore, et al, 2007). For elderly patients who may have difficulty with completing ADs, these types of ADs may also be preferable. Recent studies are now specifically investigating format preferences. Some of these include the use of graphics and improved design layout (Sudore, et al, 2007) as well as the use of an interactive computer program (Green & Levi, 2008).

In order to help ensure that a patient’s family is aware of their loved one’s advance care preferences, it may be valuable for patients and family members to engage in a formal discussion about end of life. This communication can help clarify goals and help prevent family conflict when the decisions are needed to be acted upon. It may be reassuring to the patient that their wishes will be known and honored as well as to the family or surrogate giving them confidence that they adequately understood them. This conversation can be conducted independently or in the presence of a professional facilitator. Without the use of a facilitator, there are materials available to help patients learn how to begin the dialogue of EOL discussions with their family. These discussions are difficult for some patients and the information may assist them to initiate EOL conversation (Karel, Powell & Cantor, 2004).
Once ADs have been discussed and documented, providers may wish to consider reassessing these preferences yearly and when there are changes in health status. It is recommended that a written AD be reviewed at least every five years as well as following any significant transitions such as illness, family additions, death of a loved one, change in marital status, and retirement (American Bar Association, 2009). Providers may wish to include this reassessment as part of an annual update of paperwork.

Patients should be educated about the importance of having this documentation available to their loved ones, hospitals they may use, and primary care providers. If a POLST form is completed, it should be available in a conspicuous location for EMT personnel or family who may be present in order to best honor their designated preferences. The individual should carry a copy of the form so that it is available if emergency care is needed while outside the home. In a study by Bergman-Evans, et al (2008), healthcare personnel reported that ADs were often not followed because the documentation was not available. Further, family and household members should be aware of wishes and location of documentation of these. Patients may consider utilizing an on-line registry. This can allow the documents to be easily accessed for any changes patient’s wish to make as well as ensuring access to healthcare providers when necessary.

Currently, residents of the states of Arizona, Montana, Nevada, Vermont, and Washington have access to state sponsored registries that are
free (refer to Table 1). Many other states are in the planning process of similar free registries (DLC, 2008).

Discussion

Nurse practitioners should not underestimate the value patients place on interacting with healthcare providers regarding end of life discussion and documentation. This may be due to the fact that some written AD materials are difficult for patients to understand. They may be seeking professional input in order to feel confident that their written instructions are reflective of their wishes. Additionally, they may feel more comfortable documenting their AD preferences when they feel supported by their provider. It may give patients an added sense of trust and advocacy when they are most vulnerable.

With the complexity of patient's health issues, and the limited time allotted in caring for patients in the primary care setting, it will be challenging for nurse practitioners to address advance care planning. It will require creativity and excellent time management. However, the energy and effort expended in this regard can bring tremendous value to patients and all who care for them.

For providers who may be less experienced or less confident in initiating and encouraging end of life discussions, it is important to become familiar with the multitude of AD resources that are available. Patients are looking to their providers to initiate these discussions. A conscientious and caring provider has the opportunity to make a significant difference in
increasing the completion rates for ADs and improving the quality of end of life care.

For patients who are seeking assistance in selecting the type of AD documents that may be most beneficial, there is much to consider. What is known is that having a healthcare proxy who is very familiar with the patient can provide the best advocacy. They should share any specific instructions through several discussions with their selected proxy and have these wishes discussed with family members, their providers, and legally documented in writing using a living will document that is combined with a designation of healthcare proxy form. The best format for these documents is one that considers the patient’s ability to comprehend the implications. It should meet their literacy needs and maintain the legal requirements of their state of residence.

In addition, patients should be encouraged to utilize a values history or other similar document that includes content which addresses patient goals. It can provide them with a sense of being known and is shown to provide their surrogates with confidence. It is also believed to give additional guidance to their healthcare providers so that they can better support them through a desired natural transition through end of life.
Table 1

On-line AD Resources
References


