Advance Healthcare Directives: Communicating and Implementing End of Life Medical Treatment Wishes

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ABSTRACT

Court decisions have established an individual's Constitutional right of privacy to choose or decline end-stage medical treatment. Further, courts have acknowledged that surrogates may make such decisions for an individual who has become legally incompetent provided the surrogates, appointed by the individual patients, can establish the intent of such individuals by subjective oral evidence (Cruzan, 1990). All states have legislatively established criteria for written Advance Healthcare Directives (AHDs) to evidence an individual's desires regarding end-stage medical treatment, which can be legally enforced. Since there has been some confusion by healthcare providers in interpreting the AHDs, this paper evaluates the ambiguity of the special language of AHDs and suggests best practices, provisions, and examples to clarify the intent of individual patients and provide healthcare professionals nationwide access to AHDs.

Keywords: Healthcare Directives, Legislation, Law, Patients, Physicians, end of life, Quinlan, Schiavo, Cruzan.

INTRODUCTION

The case law involving Karen Ann Quinlan, Terri Schiavo and Nancy Cruzan underscore the need for written documentation which clearly expresses the intent of individuals in determining their end-stage medical treatment. This written documentation takes the form of Advance Healthcare Directives (AHDs) and should be prepared as part of estate planning for financial assets and dependents or in the case of those without significant financial assets, as a matter of lifelong planning.

In 1990, Congress passed the Patient Self-Determination Act. In general, this legislation required hospitals, nursing homes and health providers to provide information to adult patients about AHDs. It should be noted that the legislation did not apply to physicians (The Patient Self Determination Act of 1990).

AHDs are currently recognized in some form in all states. They are written documents in which a patient designates a healthcare agent, representative, or surrogate to make healthcare decisions on patient's behalf when the patient is unable to understand the consequences of their condition and treatment and/or communicate with healthcare professionals relating to their treatment. The AHD must be made in writing and signed by the patient while the patient is legally competent. The AHD provides guidance to the representative as to the patient's wishes.

AHDs typically direct the healthcare agent to either provide or withhold specified treatments in the event the patient has an "end-stage medical condition" or "other extreme irreversible medical condition". These directions also apply in the event the patient is "permanently unconscious" such as in an "irreversible coma or an irreversible vegetative state with no realistic hope of significant recovery". In addition, AHDs provide that suffering from severe and irreversible brain damage or brain disease with no realistic hope of significant recovery should be treated as an 'end-stage medical condition" or "permanent state of unconsciousness" (Costello, Puller, Cooney, Kottkamp & Markley, 2013).

The difficulty which healthcare professionals have is determining exactly what constitutes an "end-stage condition" as identified in the AHD. There appears to be a language barrier in that physicians and medical personnel can have difficulty interpreting legal terms, and lawyers can have difficulty interpreting medical terms. Current studies report that there is confusion among providers as to utilizing medical procedures in the setting of "critical illness". The studies also indicated that in the setting of critical illness, patients are at risk to be over and under treated (Ahlswede & Breslin, 2015).

Since medical personnel have acknowledged difficulty in determining conditions that are "permanent" and "irreversible", it can be inferred that the ordinary individuals that sign such AHDs are also unclear as to the directions they are given regarding their own life and death situations. Lack of clarity can be one of the causes for the absence of an AHDs when patients are in a hospital situation as studies have shown (Shapiro, 2015). The issue which should be addressed by both legal advisors and physicians is how to best communicate the wishes of the patients to their medical providers (Hardin & Yusufaly, 2004).

Recently the utilization of Physician Orders for Life-Sustaining Treatment (POLST) has helped translate patients' goals for end of life care. Although the use of POLST is beyond the scope of this presentation, the use of a POLST should be part of the arsenal of tools used by physicians and lawyers in clarifying and serving the wishes of patients (Bomba, Kemp & Black, 2012).

BACKGROUND

The judicial background for this paper is found in the following cases and contains the underlying factual situations, legal authority, and judicial action. Since the first case was heard by the Supreme Court on December 9, 1989, the right to die has become a focus of other cases and statutory law. The following three cases discuss high profile legal actions and form the basis for actions that subsequently occurred.

In the matter of Karen Quinlan, an alleged incompetent

The idea of Healthcare Directives for end of life situations first came to the public consciousness in the case of Karen Ann Quinlan. After taking certain drugs and alcohol while on a crash diet, Karen Ann Quinlan fell into a coma. She suffered irreversible brain damage after experiencing respiratory failure. She was admitted to a hospital and placed on a feeding tube and a ventilator to assist in breathing (McFadden, 1985).

The New Jersey Supreme Court acknowledged a constitutionally protected "right of privacy" and that Karen, if she became cognitive, had the right to refuse medical treatment, specifically use of the ventilator (In the matter of Karen Quinlan, an alleged incompetent, 1976). In its opinion, the Court noted:

> "We glean from the record that … physicians … refuse to treat the curable as if they were dying; or ought to die, and that they have sometimes refused to treat the hopeless and dying as if there were curable" (In the matter of Karen Quinlan, an alleged incompetent, 1976).
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> "… many have refused to inflict an undesired prolongation of the process of dying on a patient in irreversible condition when it is clear that such 'therapy" offers neither human nor humane benefit" (In the matter of Karen Quinlan, an alleged incompetent, 1976).

Quinlan's father, Joseph Quinlin, requested that he be appointed guardian of Karen and that she be disconnected from her ventilator. The trial court appointed Joseph Quinlan as guardian of Karen's property but appointed an independent guardian over her person. The independent guardian argued against disconnecting her ventilator contending that such action would be homicide.

The court noted that Joseph Quinlin was Roman Catholic and consulted with the hospital Chaplain and sought the position of the Roman Catholic Church. Interestingly, the Court's opinion referenced and quoted the reasoning of Pope Pius XII in his address to anesthesiologists on November 24, 1957, which stated that a physician had no right, independent of the patient, to use extraordinary means to prolong life and that the physician can act only if the patient explicitly or implicitly, directly or indirectly, gives him permission (In the matter of Karen Quinlan, an alleged incompetent, 1976).

In a declaratory judgment, the New Jersey Supreme Court reversed the trial court and appointed Joseph Quinlan and guardian of the property and person of Karen Ann Quinlan (In the matter of Karen Quinlan, an alleged incompetent, 1976). As legal guardian, Joseph Quinlan directed that Karen be removed from the ventilator. After being removed from the ventilator, Karen continued to breathe on her own. She remained in a vegetative state and passed away 9 years later from respiratory failure (In the matter of Karen Quinlan, an alleged incompetent, 1976).

Schiavo and Schindler v. Schiavo

Terri Schiavo collapsed at her home, and oxygen was cut off to her brain resulting in severe brain damage. She required feeding tubes connected to her stomach to sustain life (Lynne, 2005). After some time, Terri's husband, Michael Schiavo, sought court relief to remove the feeding tubes. He testified that he and Terri discussed life support when her grandmother was in a nursing home and Terri said "I don't want to live like that." Terri's parents, who objected to removal of the feeding tubes, said the Terri consistently showed a strong will to live. Further, Terri's girlfriend testified that she spoke with Terri after watching movies about Karen Ann Quinlan and Terri said she did not agree with the decision to remove Quinlan from the respirator (Lynne, 2005). Judge George Greer of the Florida 6th Circuit Court ruled that Schiavo would not be kept alive by artificial means and directed removal of the feeding tubes (In re Guardianship of Schiavo, 2001). Schiavo's parents appealed and Judge Frank Quesada of the Civil Court ordered reinsertion of feeding tubes (Schindler & Schindler, 2005b).

Numerous decisions, reversals, appeals, hearings, and arguments occurred before the Florida Courts continued the case. The notoriety and importance of the case caused the passage of "Terri's Law" by the Florida Legislature, which empowered then governor, Jeb Bush, unreviewable discretion to "stay" the withholding of artificially provided nutrition and hydration from Terri Schiavo. Governor Bush ordered reinsertion of the feeding tubes (Florida Bill 35e).

Appeals to the Florida Supreme Court resulted in "Terri's Law" being declared unconstitutional and the governor's order to reinsert the feeding tubes was declared void.[13] This prompted the U. S. Senate and House of Representatives to emergency sessions and in two days enacted "U.S. Senate Compromise Bill 686, known as the "Palm Sunday Compromise", which specifically gave jurisdiction of the case to the Florida Federal Courts rather than the State Courts. President George Bush returned from vacation to Washington specifically to sign the bill (Act for the Relief of the Parents of Theresa Marie Schiavo, 2005).

However, all this legal activity only delayed removal of the feeding tubes. The 11th Circuit Court of Appeals denied the appeal of Terri Schiavo's parents (Schiavo, 2005) and the U.S. Supreme Court declined to hear their appeal, bringing an end to the litigation (Schiavo, Schindler & Schindler, 2005). Consequently, the feeding tubes were removed and Terri Schiavo died on March 31, 2005.

Cruzan v. Director, Mo. Dept. of Health

In the U. S. Supreme Court case of *Cruzan v. Director, Missouri Department of Health*, 497 U.S.261 (1990), the Court dealt with the issue of the evidence required before a state permits a patient to be removed from life support (Cruzan, 1990).

The Court stated that medical care decisions must be guided by the individual patient's interests and values permitting persons to determine their own medical treatment (Cruzan, 1990). The Court determined that the right of self-determination is not lost because an individual cannot sense a violation of it. The Court further stated that such right could be exercised by a surrogate decision maker using a "subjective" standard (Cruzan, 1990).

The Court recognized that medical care must be guided by an individual patient's interests and values and that an individual's rights do not diminish simply because they have become incapable of participating in treatment decisions (Cruzan, 1990). Further, the Court also recognized that States have a legitimate interest in the prolongation of the life of the individual patient and an interest in the sanctity of life itself (Cruzan, 1990). In this case, the Supreme Court upheld the State of Missouri's requirement of "clear and convincing" evidence of a patient's wishes for removal of life support (Cruzan, 1990).

Literature Review

Studies that have been conducted have provided evidence that an AHD will benefit patients including reducing the likelihood of dying in the hospital and receiving care that is consistent with their wishes (Yadav, 2017) Literature in this area has indicated that AHDs have had little effect in many areas of the patient outcomes. Studies that have been conducted focusing on the relationship of patients with AHDs and the decision-making resulting for that patient have focused on patients with AHDs in place (Shapiro, 2015). For patients with an AHD the care the patient receives is more likely to be consistent with the wished they have for that care and end-of-life decisions (Yadav, 2017). The patients who do not have AHDs do not have documented wishes. This results in the inability of studies to determine how their wishes impacted the care and outcomes. Consequently a study cannot track these patients without AHDs because of the lack of a baseline desire (Gillick, 2010).

AHDs are permitted by statute in all states in the United States, and can be divided into two general categories: (A) Designations of a healthcare agent to make healthcare decisions on a patient's behalf; and (B) Instructional, which provide guidance on what a patient wants in the event of certain conditions. (Herzberg & Zuckerman, 2016) A study conducted in intensive care units on a population of 2,216 patients during the study period indicated that a minority of the patients had an advanced directive of some form. (Shapiro, 2015) More troubling results of the study included the following:

> "Few of the reported directives ever appear in the patient's hospital chart; it is not clear that many exist. Despite continued prodding of family members to bring in copies, by the end of the patient's ICU stay, only one in ten has documentation in the medical record of written treatment preferences and/or legally designated surrogate medical decision maker" (Shapiro, 2015).

Hospitals and nursing facilities are required to ask about a patient's AHD status, and if they do not have an AHD in place, they offer the opportunity to prepare one, generally from a form provided. (Herzberg & Zuckerman, 2016) Based upon the study conducted, these requests are not impacting a majority of the patients (Shapiro, 2015). It is then up to individuals and their advisors, relatives, attorneys, accountants, etc., to be guided to have a AHD that provides them the opportunity to provide direction to a healthcare provider in the event they become incapacitated and are unable to legally sign an AHD (Herzberg & Zuckerman, 2016). In an analysis of studies published from 2011 to 2016, it was estimated that only one in three US adults has completed any type of AHD (Yadav, 2017). There were several reasons suggested for this result:

- The feeling among healthcare providers that AHDs do not meet the expectations for having them and may have caused healthcare providers to not promote them;
- Multiple legal requirements are required for the completion of an AHD leading to reduced use. The example provided was the requirement of two witnesses in many states; and
- There may be misconceptions regarding portable physicians' orders providing out of –hospital medical personnel with legal authority regarding unwanted life-

saving and a complete AHD with more specific wishes for healthcare agents and healthcare professionals (Yadav, 2017).

RECOMMENDATIONS

Based upon a review of the case law, statutory law, and literature in the area, a series of steps should be considered that may avoid problems for those involved. These groups consist of those involved in the process that can benefit from the existence of an AHD and the effort to increase the creation and usage of these documents should focus here (Yadav, 2017). The areas that should be addressed separately by groups of individuals and organizations involved in the process, due to the uniqueness of each individual, group of individuals, or organization involved. The utilization of AHD may also be increased through these series of recommendations coupled with Medicare's change in reimbursements to provide physicians with reimbursement for advanced healthcare planning effective January 1, 2016 (Yadav, 2017).,

The suggested approaches for individuals, groups of individuals, and organizations are broken down into the following categories:

- Healthcare agents, healthcare professionals, and patients.
- Individual and patient education and planning.
- Relatives and healthcare agents.
- Healthcare providers.

Healthcare Agents, Healthcare Professionals, and Patients

It is clear from the review of case law, statutory law, and the literature that the communication between patients, their healthcare agents, and healthcare professionals must be improved. The AHDs should include the generally provided items relevant to end of life decision making, with more specific questions and notations made in determining the goals of each individual patient.

It has been suggested that AHD's include the following questions, which should be evaluated with the following answers: (A) I want to continue living like this; (B) I'm not sure; and (C) I don't want to live like this.

Question 1: If I cannot understand what I read or cannot carry on a conversation due to dementia or brain injury.
Question 2: If I need to stay in a nursing home for the rest of my life.
Question 3: If I need somebody to take care of me (bathing, feeding, using the bathroom and getting dressed) for the rest of my life.
Question 4: If I can't go outside the rest of my life (Ahlswede, 2015).

There are many other questions which may be important and relevant to the patient and their family, including any potential pain and suffering endured by the patient as a result of their condition, and the intrusion and discomfort of the potential treatment. These questions and the patient's answers would be very helpful to healthcare providers in evaluating the desires of the patient in making the decision to withhold or withdraw specific treatment. Healthcare professionals and legal counsel should try to address these issues for the benefit of their patient/client. The patient and their healthcare agent should meet with their physician and lawyer to discuss these issues. This will result in an AHD which truly reflects the thoughts and ideas of the patient, and provides the healthcare professional and healthcare agent with the guidance they need to meet the needs and desires of the individual patient.

An AHD that clearly reflects the understanding and will of a patient is useless if a healthcare professional does not know it exists. As the literature review revealed, many patients not only don't provide the AHD, the directives do not consistently appear in the patients' medical records. Although the Patient Self-Determination Act provides that medical facilities must ask a patient and advise them about AHDs, in emergency and time-critical situations, particularly where people travel from state to state, healthcare professionals may not be aware an AHD exists.

In many states, an AHD registry exists on-line, or legislation to establish a state registry is currently under consideration. A National Registry which encompasses the registry of each state would provide protection to those patients who had executed an AHD. Since the selection of healthcare agents as well as the desires of an individual patient may change over time, it would be the individual patient's responsibility to make sure the National Registry is up to date and reflects the patient's most current desires (Grant, 2011).

Individual and Patient Education and Planning

Education of the patient, their healthcare agent on the AHD and how to react in a time of need is very important to the successful implementation of a patient's wishes. Individuals should take the time to educate themselves on life sustaining and end-of-life medical care, such as resuscitation, ventilators, and feeding tubes. This will help the individual understand the comfort measures that are available, such as pain control, and other palliative measures. Once the individual understands these areas they are in a better position to understand what their options are, and what their choices mean. Once an individual becomes a patient, they may not have the capacity to make the necessary decisions or the capacity to understand the results of a decision. It is the full understanding of each decision to be made that makes an AHD the vehicle to provide end of life decision guidance in accordance with the individual's wishes. The following points are central to the successful preparation and fulfillment of the wishes of the individual:

- Complete an AHD, with the assistance from their physician or healthcare provider or if they may compete one independently. They need to be clear in stating their wishes.
- Choose a healthcare agent whom they are confident will speak for them and uphold their stated wishes. This agent should be in receipt of a copy of their AHD, and be able to retrieve a copy quickly if a situation warrants.
- Individuals should share a copy of their AHD with their physician, medical specialty providers, and attorney. If they change providers, they should be sure to share a copy with them as well. There are some smartphone apps that allow an AHD to be stored online for ease of retrieval in the case it is needed.
- Individuals should discuss, and if necessary, explain their wishes to relatives and friends to whom they may also provide a copy of their AHD. This is a very personal choice, so they should only discuss as little or as much they feel appropriate. The relatives and friends may be more comfortable in understanding the choices when the thought process that led to the choices is explained.
- When possible, take a copy of the AHD when the individual is to receive care from a medical facility or nursing home.
- Update the AHD annually. Wishes may change over time as well as surrogates; that is not uncommon. It is very important to make certain an updated AHD is redistributed to

those outlined earlier.

Relatives and Healthcare Agents

As a relative of someone that a relative or healthcare agent may either be taking care of, or may be taken care of in the event of an emergency, planning is essential for a smooth transition from relative to caretaker. It is difficult to ask a person what their wishes are during end of life care, due to the sensitive nature of the question, but the question needs to be asked. Without clear direction, a relative or possibly an appointed healthcare agent will be making decisions for someone without knowing what they truly desire. The following questions can help provide direction:

- Ask the person if they have a written AHD. If they do, request a copy. If they do not, facilitate an open conversation on the importance of having one in the case that the patient can no longer speak for themselves. Stress that as the relative or healthcare agent the patient's wishes and autonomy will be respected and that the relative or healthcare agent wants to ensure that their written wishes will speak for themselves in the case where the patient no longer can.
- Try to obtain as much information as possible about the patient's wishes for particular treatments, or lack thereof. The decision-making process may take time, and it is ok if all decisions are not made on the day that the conversation begins.
- Mention that there is a mutual interest in having an AHD, and if the relative or healthcare agent does not have one, address that issue so the other person is comfortable. That is often a safe way to begin a conversation on this topic.
- Ask a physician for assistance with the conversation. Healthcare providers are often well versed in discussing this topic with their patients. Be there for the conversation if invited by the individual, and ask questions to promote clarity of understanding. Remember that the individual is the only one who can speak with their healthcare provider on matters involving their health, absent the AHD being provided to the healthcare professional.
- Let the patient know that you will be there for them during the process of care. Be open to hearing about their feelings, preferences, and values. Understand that these may change over time, and be respectful of such changes.

Healthcare Providers

To assure this right, state legislatures have enacted legislation pertaining to an individual's rights in signing AHDs. Under Pennsylvania statutes competence is the condition in which an individual who is provided with the appropriate medical information and communication supports and is documented by a healthcare provider to do the following listed items. It also recognizes that an individual may be found competent to make some healthcare decisions but also be incompetent to make others.

1. Understand the potential material benefits, risks, and alternatives involved in a specific healthcare decision.
2. Make the healthcare decision on their own behalf.
3. Communicate that decision to any other person. (20 Pa.C.S.A. § 5422)

A healthcare provider should be proactive in their approach to patient care in this area. Patients must recognize that the healthcare provider may also have a right not follow such a directive if they have cause for doing such. In that case, the healthcare provider may also have the responsibility to transfer the patient to another facility or to another healthcare provider. The following are approaches that can assist the healthcare provider in the planning for an AHD and in following the requests of the patient:

- Take a proactive approach to suggesting that all adult patients have an AHD. Provide a template copy that would meet the requirements of state law to every person who wants to have one and who does not have access to legal counsel, making certain that their template conforms to the current statutory law and case law.
- Be open to assisting patients, relatives, and healthcare agents in understanding AHD-related terminology and the various processes of care, including the palliative options.
- When presented with a new or updated AHD, review the patient's updated wishes, and check for understanding of what is stated. Encourage questions from the patient.
- Maintain a paper or scanned copy of the patient's most recent AHD containing the signature in a location of easy retrieval in case the document is needed. Technology today allows healthcare providers to maintain an electronic copy in the patients' medical files if they choose.
- If the patient is in end-stage medical condition or in other extreme irreversible medical condition, be compassionate yet cleary communicate their medical condition to the patient. Do not minimize the seriousness of their condition and give the information needed to allow the patient's wishes to be followed.

CONCLUSION

Although case law provides for oral evidence to substantiate a patient's wishes for end-stage healthcare decisions, in order to provide assurance that a patient's wishes will be followed, an AHD should be made in writing. A healthcare agent should also be designated to act as representative of a patient if they lack the competence to understand the material benefits, risks and alternatives of a specific healthcare decision or if the patient becomes unable to make the healthcare decision or communicate to the healthcare provider.

The AHD should provide a specific description of the desires of the patient, and these desires should be discussed with the patient's physician and designated healthcare agent. Further, the signed copy of the AHD should be delivered to the personal physician, healthcare agent, and recorded in a registry to ascertain the patient's wishes in the event the patient's personal physician or healthcare agent are not available to represent the patient who is need of medical treatment while in an end-stage condition.

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