End-of-Life Care: The Legal, Cultural, and Interdisciplinary Barriers Hindering the Effective Use of Advance Directives

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I. INTRODUCTION

With the advent of medical technology allowing individuals to live longer, the need for end-of-life planning is an important issue facing people in America. End-of-life planning is an intelligent and forward-thinking action to take in order to ensure the patient’s wishes are followed. However, many individuals are not actively pursuing advance directives, a legal process to aid in end-of-life care, for themselves and their family members. It is important when exploring end-of-life planning at an academic and societal level that the focus be rooted in three areas: the law, cultural factors and interdisciplinary considerations regarding physicians. These three areas are inextricably linked in understanding why end-of-life planning and the use of advance directives have not proven to be effective methods at helping minority populations. The lack of cultural considerations and concern regarding intersectional factors; that compose an individual patient and inform their decision making about end-of-life

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care, are not being addressed through the legal construct of an advance directive. In order to better assess the underlying reasons why cultural differences make a difference in the low utilization of advance directives, it is necessary to look at three key areas: (1) the legal foundation for the advance directive and the standards used today; (2) the role language plays in presenting barriers to advance directive use; and (3) the role providers play in integrating advance directive participation within their end-of-life discussions with their patients.

II. LEGAL OVERVIEW

Before discussing the role cultural factors and interdisciplinary considerations factor into end-of-life planning, it is necessary to touch upon the legal history and key areas of the law that contribute to the effectiveness of end-of-life planning for culturally and ethnically diverse individuals. An advance directive is a powerful tool that individuals can utilize to ensure that their families and doctors honor their rights when their health conditions render them unable to advocate for themselves.\(^1\) First, it is necessary to explore the way the federal government and the Supreme Court stands on this issue through the landmark case of *Cruzan v. Director, Missouri Dept. of Health* and the Patient Self Determination Act. Secondly, implementation of the federal standards to the state level will be explored

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1. 42 U.S.C.A. § 1395cc (2011) (contains written instruction of care for a patient when they are incapacitated, i.e. a living will, that is recognized under State Law).
by analyzing Illinois’s Living Will Act, Power of Attorney Act and Health Care Surrogate Act.

Ultimately, the push towards proactive end-of-life planning came with the landmark case of *Cruzan v. Director, Missouri Dept. of Health.* In *Cruzan*, the Supreme Court established that competent individuals have the right to plan for future incapacity and that the states have the discretion to balance the patient interests against the state interest. Shortly after the Court decided *Cruzan*, Congress passed the federal Patient Self Determination Act of 1990 ("Patient Self Determination Act"). The Patient Self Determination Act aimed to homogenize the way the states conducted end-of-life care planning and delineated the steps that providers need to take when assisting a patient with this process. The Patient Self Determination Act requires Medicaid and Medicare providers to include and abide by certain provisions in the advance directives that they help prepare for beneficiaries.

While the Patient Self Determination Act provided a basis for end-of life planning, the push towards proactive end-of-life planning came with the landmark case of *Cruzan v. Director, Missouri Dept. of Health.* In *Cruzan*, the Supreme Court established that competent individuals have the right to plan for future incapacity and that the states have the discretion to balance the patient interests against the state interest. Shortly after the Court decided *Cruzan*, Congress passed the federal Patient Self Determination Act of 1990 ("Patient Self Determination Act"). The Patient Self Determination Act aimed to homogenize the way the states conducted end-of-life care planning and delineated the steps that providers need to take when assisting a patient with this process. The Patient Self Determination Act requires Medicaid and Medicare providers to include and abide by certain provisions in the advance directives that they help prepare for beneficiaries.

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5. *Id.*
6. *Id.* (certain guidelines must be followed when providers inform patients that they have the right to make decisions and appoint an agent or surrogate in their advance directive).
planning that the states must follow, the states must individually address other legal issues, including the specifications for a living will, the requirements for appointing a power of attorney for health care, and the qualifications for health care surrogates.\(^7\) Under the Illinois Living Will Act (“Living Will Act”) a living will is defined as a “written declaration instructing his or her physician to withhold or withdraw death delaying procedures in the event of a terminal condition.”\(^8\) Execution of this will must include the following elements: (1) the patient looking to execute the will must be mentally competent and to have reached the age of majority, (2) the document must be signed by the patient, or another at his or her direction, and witnessed by two individuals of 18 years or older, and (3) the patient must notify her physician of the living will, which the physician will then include within the individual’s medical records.\(^9\) Generally, civil penalties apply to those who conceal, damage, or falsify a revocation to the living will without consent of the individual.\(^10\) If a patient dies due to another’s willful concealment or withholding of knowledge of a revocation the perpetrator will be convicted of involuntary manslaughter.\(^11\) Illinois state law provides further measures to identify and hold an individual

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9. Id. at §35/3(a)-(b), (d).
10. Id. at §35/8(a).
11. Id. at §35/8(b).
legally responsible for following through with the best wishes of the patient at the end of their life.

In addition to the Living Will Act, there are two acts that allow a patient to designate a person to care for their end-of-life decisions. The primary difference between the Illinois Power of Attorney Act ("Power of Attorney Act") and the Illinois Health Care Surrogate Act ("Health Care Surrogate Act") lies in the extent and scope of authority given to the individuals who assume the respective positions.\(^\text{12}\) Under the Power of Attorney Act, when a patient designates a person as his or her power of attorney, that person becomes that patient’s designated agent and has the authority to make all-encompassing medical decisions for the patient.\(^\text{13}\) A designated agent has the power to consent to treatment, and withdraw and admit the patient from the provider facility.\(^\text{14}\) Additionally, the agent has the same access as the patient, to the patient’s medical records authorized by Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), and has the ability to authorize organ donations and disposition of the individual’s remains.\(^\text{15}\) The power of attorney designation, unless specified, will continue for the duration of the individual’s lifetime.\(^\text{16}\)

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13. 755 ILCS § 45.
14. Id. at § 45/4-10(b).
15. Id.
16. Id.
Under the Health Care Surrogate Act, a surrogate is sought out only after the physician has identified that there is no existence of a living will, advance directive, or power of attorney.\textsuperscript{17} A health care surrogate is only applicable when the patient has a “qualifying condition”\textsuperscript{18} and does not have the ability to make decisions for herself concerning medical treatment.\textsuperscript{19} The Health Care Surrogate Act aims to ensure that the surrogate can follow through with any of the patient’s preferred decisions regarding sustaining life through extraordinary means without involving judicial action.\textsuperscript{20} However, since the patient does not expressly choose the health care surrogate,\textsuperscript{21} the surrogate must balance the burdens and benefits of life-sustaining treatment through close conformation to the individual’s personal perspectives on religion, morality, ethics, life and death.\textsuperscript{22}

In addition to state-specific forms designating a power of attorney and health care surrogates and creating a living will, the patient can also fill out other forms touching on specific instances of end-of-life care.\textsuperscript{23} Specifically, Illinois abides by a “Uniform Do-Not-Resuscitate (DNR)

\begin{enumerate}
\item Illinois Health Care Surrogate Act, 755 ILCS § 40 (2010).
\item Id. at § 40/10 (including terminal conditions, permanent unconsciousness and incurable or irreversible conditions).
\item Id. at § 40/5(b).
\item Id.
\item Id. at § 40/25(a) (priority in this order: guardian, spouse, adult son or daughter, parents, brother or sister, adult grandchild, close friend, and guardian of the estate).
\item Id. at § 40/20(b)(1).
\end{enumerate}
Advance Directive.” 24 All hospital and Emergency Medical Technician (EMT) personnel honor this boilerplate advance directive at all facilities as long as the form is complete and appears valid.25

III. OBSTACLES TO EFFECTIVE END-OF-LIFE PLANNING

End-of-life care is of great concern to the American health care industry because it is generally administered without clear guidelines for patients whose cultural traditions present a barrier to making health decisions for themselves.26 In part, because of culture-specific issues barring the use of advance directives, the nation as a whole has seen large numbers of patients avoid and neglect end-of-life care planning.27 Two different barriers to the effective use of advance directives in end-of-life planning are culturally insensitive language within the form itself, and the role providers play in presenting advance directives to patients from varying cultural backgrounds.

24. Id.
27. Kevin B. O’Reilly, 76% of Patients Neglect End-Of-Life Care Planning, AM. MED. ASSOC. NEWS (Feb. 27, 2012), http://www.ama-assn.org/amednews/2012/02/27/prsb0227.htm (roughly 8% of patients actively seek out advanced directives during medical appointments, although 80% believed having end-of-life plans was important).
A. Cross-Cultural Perspectives on Advance Directives

Title VI of the Civil Rights Act of 1964 states, “No person in the United States shall, on the ground of race, color, or national origin be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” The Patient Self Determination Act should ensure that no racial bias would stand in the way of obtaining advance directives and end-of-life care for minority populations. However, inherent cultural differences and responses to the universal legal standards embodied in the law of advance directives act as a barrier towards effective end-of-life planning in the United States. Culture is defined as “the values, beliefs, and behaviors that a people hold in common, transmit across generations, and use to interpret their experiences.” The terminology and objectives of the advance directive are supposedly universally understood: an advance directive is a listing of the patient’s wishes that should be followed after she has either died or become medically incapacitated and can no longer make

30. Turner, supra note 26, at 292-98.
decisions for herself.  

The structure of the language in advance directives is not culturally sensitive, and potentially leads to individuals deciding not fill them out. For example, the Illinois Declaration of a Living Will states:

I direct that such procedures which would only prolong the dying process to be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.

Navajo culture draws attention to word meaning and conversation. They believe that the ability to shape reality and control events can be done through the use of negative and positive language. Therefore, although federal and Illinois law support the aforementioned statement, a Navajo Indian would take issue with the fact that the language is negative information and could be deemed as harmful. A Navajo Indian patient would not be likely to prepare an advance directive.

Another example of the way cultural considerations prevent minority groups from filling out advance directive forms is seen this statement taken from the Living Will Act,

33. Id.
34. Turner, supra note 26, at 292.
35. Id.
36. Id.
37. Id.
In the absence of my ability to give directions regarding the use of such death delaying procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

This frank statement regarding the realities of death and attempts to make plans for end-of-life scenarios causes ethnic groups, such as Mexican American and Korean American patients, to shy away from these advance care planning methods because they do not feel that preparing one would bring them, or their family, any benefit for a situation that they believe is out of their hands.\textsuperscript{39}

To ignore an individual’s cultural background within the context of end-of-life care harms effective advance directive planning.\textsuperscript{40} The emphasis on culture is particularly important in this context because an individual identifies the most with cultural considerations in the last moments of her life.\textsuperscript{41} Therefore, lawmakers and medical providers must consider cultural factors when creating policies that determine an individual’s well-being at the end of their life.\textsuperscript{42}

\textsuperscript{39.} Turner, \textit{supra} note 26 at 293.
\textsuperscript{41.} \textit{Id.}
\textsuperscript{42.} \textit{Id.} at 206.
A closer look at the Power of Attorney Act demonstrates that the Illinois Generally Assembly did not consider culturally competent language when drafting these documents. The Power of Attorney Act states that “The purpose of this Power of Attorney is to give your designated ‘agent’ broad powers to make health care decisions for you, […] You may name successors but you may not name co-agents.” In the case of Japanese American patients, Japanese culture has the tradition of including the family in the “culture of making decisions” when it comes to terminal illness and end-of-life care. This same understanding is seen in Latino elderly, who prefer broad family decisions about how to move forward with end-of-life care. Therefore, to restrict all decision making authority to a singular person through a power of attorney would be contrary to the interests of the terminally ill patient.

In some instances, the legal language can work cohesively with cultural expectations because of broad and general wording. For example, the Health Care Surrogate Act states that “In determining the patient’s best interests, the surrogate shall weigh the burdens on and benefits to the patient of the treatment against the burdens and benefits of that treatment and shall take into account any other information, including the views of

44. Id.
45. Blank, supra note 40, at 204.
46. Id. at 205.
family and friends, that the surrogate decision believes the patient would have considered if able to act for herself or himself.” 47 Both Mexican Americans and African Americans share the belief that family dynamics significantly influence the choice of proxy for end-of-life decision-making.48 A closer look within these two cultural groups further demonstrates gendered constructs of expectation that is not considered on the advance directive forms. This includes the preference that men within the Mexican culture hold proxy status because of the belief that the women have other commitments in the home that hinder their ability to make rapid decisions for their loved ones concerning health care.49

The examination of Illinois’ advance directives reveals that more patients do not participate in end-of-life planning because they do not take into account the cultural and religious factors that play a role in end-of-life decision making.50 The universality of death as a human experience makes this event an intrinsic part of the beliefs of any culture.51 Therefore, the way a patient reacts to advance care planning can be influenced by intangible factors linked to cultural beliefs rooted in morality and superstition.52 Because of this, the language of the advance directive needs to be sensitive

49. Id.
50. Turner, supra note 26, at 298.
51. Perkins et. al., supra note 31, at 50.
52. Id. at 51-52.
to the cultural hesitance to discuss end-of-life planning. If the objective of the advance directive is to aid the person once sickness has progressed to the point of incompetence, then it is necessary that the language in the advance directive take into account this barrier. For example, the Living Will Act states, “If at any time I should have an incurable and irreversible injury, disease or illness judged to be a terminal condition [...] and [the attending physician] has determined that my death is imminent except for death delaying procedures[...].” The language presented here conjures powerful connotations of the inevitable nature of death. In African American culture, discussing treatments that an individual may want at death is adamantly avoided. The reasoning behind this position against discussing end-of-life planning is the belief that one should not speak concretely about uncertain future events. The belief that discussing these plans might bring one bodily harm; causes some Mexican American and African American individuals to wait until the day comes to make final decisions concerning end-of-life treatment. Moreover, many do not believe they are terminally ill, thus preferring intensive and potentially futile treatment.

54. Perkins et. al., supra note 31, at 52.
55. Id.
56. Id.
57. Smith et. al., Racial and Ethnic Differences in Advance Care Planning Among Patients with Cancer: Impact of Terminal Illness Acknowledgement, Religiousness, and
The use of advance directives for patients with different cultural backgrounds can lead to barriers and inequities of end-of-life care. Cultural standards regarding moral obligations also differ and care must be taken to avoid harm to one’s wishes. An example of unethical treatment that may be accepted in a patient’s cultural traditions is euthanasia. Euthanasia is a criminal act of homicide in the United States; however, it is a legally acceptable practice in the Netherlands, Belgium and Colombia. Indigenous people employed natural methods of euthanasia that coincided with their cultural and religious beliefs. The Caribs of Grenada practiced euthanasia because they believed that evil spirits possessed individuals who were terminally ill. Conversely, the Aborigines of Australia took part in this practice because they believed that people who were terminally ill were undergoing the process of transmutation, or subsequent reincarnation back into the world of nature. They supported the notion that an individual

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59. Id.
62. Id.
63. Id.
64. Id.
should not fear death but accept the will of the supernatural.\textsuperscript{65} Attempting to bridge the cultural gaps in advance directives requires an understanding that religious and cultural practices will vary by individual and ethnic group, and that patients’ wishes as informed by their culture, should be accommodated.\textsuperscript{66} However, patient autonomy does not solely define the standards of ethical medical care.\textsuperscript{67}

Physicians also need to ensure that they are following the ethical considerations of their profession. The ethical practice within the medical community hinges upon the Hippocratic Oath, pledged by every physician. The Hippocratic Oath\textsuperscript{68} states,

> I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God.

According to the American Medical Association’s policy on end-of-life care, physicians hold no ethical obligation to provide care that they believe will not have a reasonable chance of benefitting the patient.\textsuperscript{69} Overall, physicians must be committed to sustaining the life and relieving the

\textsuperscript{65} Id.
\textsuperscript{66} Turner, supra note 26, at 298-99.
\textsuperscript{67} Id.
\textsuperscript{69} AM. MED. ASSOC., supra note 60.
suffering of the patient. They are also obligated to provide comfort and care to the patient at the end of their life, while taking into consideration the best treatment for the patient’s condition. Patient autonomy should be kept as a priority when assessing end-of-life decisions in the pre-planning and advancing stages of illness and death. However, medical provider obligations to their patient should also coincide with the standards of their profession, even when dealing with complex, morally conflicting, emotionally charged and time-sensitive situations.

The need to incorporate greater awareness of a patient’s cultural considerations at the terminally ill stage can be accommodated; however, accommodation must be done in a way that also adheres to the obligations of the medical providers caring for those patients. Adjusting the language stated in the advance directive forms is just one way to surmount the cultural barriers that deter minority populations from participating in advance directives. The next step towards the greater effectiveness of advance directives would be to explore the role that providers play in culturally competent care during the end-of-life planning process.

70. Id.
71. Id.
72. Turner, supra note 26, at 292-98.
73. Id. at 299.
B. The Role Physicians Play in Expanding Participation in Advance Directives

An advance directive, alone, is not the cure-all solution for addressing the cultural disparities that exist in end-of-life planning. A physician’s implementation of advance directives into the physical patient examination is necessary to ensure that the advance directive will lead to a positive health outcome for the individual. The process for integrating advance directives into the physician-patient conversation has not undergone any significant improvements because physicians are taught to save end-of-life care dialogues for the end of the medical examination and to bring up these issues more blatantly only when they are dealing with a critically ill patient.74

In order for physicians to navigate cultural considerations in end-of-life planning with their patients, they should employ these three guidelines: (1) prioritize end-of-life planning, (2) initiate and integrate the discussion of end-of-life planning into their patient’s physical exams through the use of advance directives, and (3) continuously work to promote end-of-life planning.75 First, it is necessary that the impetus towards advance directives be from the physician or primary care provider.76 Many cultures,

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75. Perkins et. al., supra note 31, at 56.
76. Id.
such as Hispanics and European Americans, have a strong belief that the health care system will abide by their wishes.\textsuperscript{77} Therefore, these cultural groups would likely be persuaded to use an advance directive if it was coming from a medical provider.\textsuperscript{78}

Secondly, physicians act as the gatekeepers of using the advance directives as legal documents, and they should take the time to collaborate with their patients and attempt to listen and define the factors that will contribute to their patients’ wishes.\textsuperscript{79} A common occurrence is that the form is given to the patient prior to the appointment but never discussed during the appointment.\textsuperscript{80} The advance directive form itself is not easily accessible, or easy to read and understand.\textsuperscript{81} Many individuals hold cultural bias that would prevent them from taking an advance directive seriously without further explanation.\textsuperscript{82} A patient’s understanding of an advance directive and its legal implications may be hindered by environmental obstacles or social dynamics, therefore it is necessary for a physician to review the document with the patient one-on-one and provide additional information regarding their concerns.\textsuperscript{83} An individual’s needs and desires for her future are constantly changing; however, an advance

\textsuperscript{77} Id.  
\textsuperscript{78} Id.  
\textsuperscript{79} Id.  
\textsuperscript{80} Id.  
\textsuperscript{81} Id.  
\textsuperscript{82} Id. at 52.  
\textsuperscript{83} Id. at 56.
directive is a tangible document that is not changeable unless the physician and patient take the time to make those changes.\(^{84}\)

The Physician Orders for Life-Sustaining Treatment ("POLST") form presents a new opportunity to remedy the gaps in advance directives because of differing cultural standards. However, instead of being more culturally sensitive, the objective of this form is to improve treatment by converting the preferences of a patient to medical actions that remain consistent throughout the patient’s health care systems.\(^ {85}\) The POLST contains medical language and is directed towards incorporating explicit, patient-directed instructions for health care providers.\(^ {86}\) The form works in conjunction with any advance directives that the patient already has in place and will not replace an advance directive’s conference of power of attorney status.\(^ {87}\) Since these forms are medically relevant and outline specific actions that can be taken at the end of an individual’s life, it is even more important that physicians take the time to understand what their patients want at the end of their lives.\(^ {88}\) The inclusion of POLST forms in end-of-life planning signifies that the physicians are now a responsible and

\(^{84}\) Id.


\(^{86}\) Id. (including treatment orders for resuscitation, medical interventions, artificial nutrition and antibiotics).

\(^{87}\) Id.

\(^{88}\) Perkins et. al., supra note 31, at 56.
intrinsically linked contributor to an individual’s end-of-life plans.\textsuperscript{89}

IV. CONCLUSION

The use of an advance directive without a primary provider’s support, guidance, and human connection is an ineffective and flawed tool. If the lawmakers and physicians can collaborate on advance directives, then advance directives might have a chance to be used widely by populations throughout this nation. By having the lawmakers reformat the structure of the advance directive’s language use and encouraging physicians to increase their engagement and commitment to the advance directive and end-of-life planning, then there might be a chance of breaking down the legal, social and cultural barriers that have stood in the way of minority populations accessing and producing well thought out, descriptive end-of-life plans. However, to marginalize culturally competent considerations in an attempt to provide a universal answer to end-of-life problems might further alienate minority populations from taking part in advance directive planning measures altogether.\textsuperscript{90}

\begin{itemize}
\item \textsuperscript{90} Blank, supra note 40, at 211.
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