



Physical Death Is Certain and Permanent: A Review of the POLST Paradigm

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Physical death of all human beings is both certain and permanent. We know this to be true. What is not always known is how we will die, where we will die, who will be with us, if we will be in pain, if we have made our end-of-life treatment wishes known to our physician and family, or if we will be aware that death is near. But we will all surely experience death.

We also know that death looks very different now than it did 60 years ago. Medical technology has exploded since the first respiratory ventilator in 1929, the first kidney dialysis machine in 1943, and the first human organ transplant (kidney) in 1954. The technology expansion has also produced great advances in pharmaceuticals and innovative diagnostic and surgical procedures. Modern medicine can now sustain biological life long after the quality and meaningful interactions that give purpose to being human are gone. However, though the technology and innovative advances in medicine are morally neutral, it is the how, why, and for what purpose we use these technologies and medical advances that attribute moral dimensions to them. If we use all of our medical resources to stave off biological death when death is imminent, we are not being good stewards of those resources. We also risk using the individual as a means to an end, rendering the application of such medical resources as immoral.

This article will explore issues related to healthcare and how we die in America, as well as a Christian response to end-of-life treatment decisions, primarily through the use of advance directive documents. Clinical examples will explain the moral application of medical technology, end-of-life care, and the role of advance directives for healthcare in such situations.

How We Die in America

When asked where a person would wish to die, most people say they would like to be home with family. Regardless of preferences, however, most Americans die in hospitals or long term care facilities. Indeed, according to the Centers for Disease Control and Prevention, 70% of Americans say they would prefer to die at home, but only 25% actually die at home.¹ The reasons for this disparity are complicated and multi-faceted. One factor includes the lack of discussions with family members about end-of-life (EOL) treatment options and preferences as an illness progresses. Another major factor is that physicians and other healthcare providers may not be asking questions or offering assistance to their patients who have serious illnesses that will likely progress to death. Our culture is generally not comfortable talking about death—and this is true of both providers and patients. Providers say they are not trained to have discussions about death and also they do not want to “take away hope” from their patients by talking about the likelihood of death due to illness and disease.

Case 1: One of my closest friends was diagnosed with breast cancer that had progressed very rapidly over 4 years. She had chemotherapy and radiation treatments, but despite these treatments her cancer spread to her lungs and liver. I would take her out for coffee each week, and as she grew sicker I would go to her home and sit with her and talk as she was able. She knew I was an Advance Practice Nurse (APN) and clinical ethicist and that much of my work was helping patients and family members during end-of-life decisions.

About 6 weeks before she died, I asked her if her doctors had discussed her prognosis and what her death might look like. Surprised, she said, “They have never brought that topic up, and if they don’t, I am not going to.” She was eventually admitted to the hospital for the last time and transferred to an inpatient hospice two days before she died.

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It should not be the sole burden of the patient to initiate important conversations with their doctor about EOL care. Rather, it is the obligation of physicians and providers to begin such conversations when the individual is diagnosed with serious illness that may eventually contribute to death. EOL treatment conversations should include comfort care and specifically palliative care options (making people comfortable through medications or devices); medications and their side effects that will be offered in their treatment (chemotherapy, radiation therapy, medications to assist with any side effects of treatment); supportive care such as social workers, clergy, psychiatric assistance, and physical therapy; and what aggressive treatments would be preferred if needed at EOL, such as ventilators, feeding tubes, and dialysis.

EOL care has been discussed for many years, but has taken on a much greater significance since the 2014 Institute of Medicine (IOM) report, *Dying in America*. In 2011, the IOM released an earlier report on pain management and the inadequacy of healthcare providers in taking care of patient pain.² This led to a major overhaul in the clinical arena regarding how providers assess and treat pain effectively. The *Dying in America* report notes:

For patients and their families, . . . no care decisions are more profound. For the millions of Americans who work with or within the health care sector—clinicians, clergy, other direct care providers, and support staff—the stake is a matter of professional commitment and responsibility. Health system managers, payers, and policy makers also have a professional stake in the provision of end-of-life care that is not only high quality but also affordable and sustainable.³

This report has had profound effects within the healthcare community. We now think about EOL conversations and treatment preferences as one among the other standards of care we are obligated to provide. A medical standard of care is generally noted as a customary practice or clinical care guideline that should be delivered to all persons with a specific illness or condition. Applied to EOL care, the standard of care for individuals with a life-limiting illness or condition includes conversations and information about EOL patient-care preferences. No longer should such conversations be disparaged as a form of “death panel” conspiracy. Even the Centers for Medicare & Medicaid Services (CMS) recognize EOL standards of care are important, as they will begin to reimburse physicians in 2016 for time spent having specific EOL discussions with those patients and families faced with such decisions.

The Process of Medical Decision-Making and the Importance of Advance Directives

Medical decision-making and consent is of great importance in our healthcare experiences. Autonomy has long been an established principle in healthcare and healthcare ethics. A person has the right to make his or her own decisions related to their health and the healthcare they will consent to or refuse. Alternately, paternalism is an approach to healthcare ethics that medical decisions are best made by the physician or provider. Paternalism remains an important principle in healthcare—that is to say, individuals usually seek the opinion of a physician when they have a need to do so. However, it is the autonomous individual who decides if they will follow the physician’s recommendation, seek alternative options, or refuse treatment altogether.

In medicine, autonomy is generally accepted as the right of every person to make their own medical decisions, provided they are of legal age, have the capacity to understand the risks and benefits of a specific recommended treatment, and have been informed of treatment alternatives. All other persons must rely on an alternative healthcare decision-maker, often called a surrogate, proxy, or guardian, depending on the situation. Ideally, the alternative healthcare decision-maker will have a history with this individual, will be aware of their values and beliefs, and will have had conversations about this individual’s healthcare desires, including possible EOL treatment decisions. However, experience and research indicate that, absent the ability of the person to make their own medical decisions, the alternate decision-maker often is not aware of patient treatment preferences, including EOL care.⁴ This can become quite uncomfortable for the patient, their decision-maker, and the healthcare team when medical decisions are needed.

When a person lacks decisional capacity to make his or her own healthcare decisions, a proxy decision-maker must be named. Formal advance directives (AD) for healthcare commonly facilitate this. ADs have been in use in various forms for over 45 years. The most common forms include the Living Will (LW), the Durable Power of Attorney for Healthcare (DPAH), and the more recent Physician Orders for Life-Sustaining Treatment (POLST).

Historically, ADs were a result of “patient and consumer rights movements of the 1960s and 1970s when, in response to the successes of intensive care, the United States Supreme Court established that patients have a constitutional right to refuse life-sustaining treatment.”⁵ The LW allows a person to make known in writing their

preferences for medical treatment in the event that they are terminally ill and expected to live 6 months or less (as assessed by their physician). DPAH, by contrast, allows a person to name a proxy healthcare decision-maker should they become unable to make their own medical decisions. This form also allows the person to write general treatment preferences. ADs generally require the individual's signature with at least one witness to the signature, and do not require a lawyer or notary to execute. All 50 states (and Washington, DC) have both LW and DPAH forms which are honored from state to state. If a person does not have an AD, many states have a formal legal process for naming a surrogate decision-maker, with a priority list for how this surrogate is to be named. With all AD forms, the person and their family, friends, named proxy, and healthcare providers should discuss the wishes of the person and share important information. The most opportune time to discuss AD preferences is when you are healthy and not having any emergent health issues.

Prevalence of lost decision-making capacity is high among persons at the end of life. A recent study of 1,536 persons who were hospitalized near the end of their life showed that 70.3% lacked decision-making capacity. Of these, only 67.5% had an AD of some kind.⁶ Should a person lack capacity to make medical care decisions and not have any AD or person from the surrogate list (often a friend or family member) that can assist with medical decisions, a guardian is then appointed through the legal system. Generally speaking, all persons over the age of 18 should have a DPAH.

Case 2: 25-year-old Susan suffered a severe brain injury after a car accident and was admitted to the neurosurgical unit in critical care. She was taken to surgery where it was discovered that she had a very large bleed within critical areas of her brain. Her surgeons spoke to her husband and parents afterwards and discussed her grim prognosis and that it was not expected that she would ever regain consciousness. Susan had filled out a DPAH form naming her husband as her legal decision-maker. She and her husband had both filled out their AD forms after the death of one of their close friends and discussed their treatment preferences. This helped him and their family make treatment decisions during this very difficult time.

History of POLST Paradigm

As noted above, persons in the United States have a right to refuse life-sustaining treatment. This right may be exercised by the individual patient or, if they lack capacity to do so, may be exercised by their proxy or surrogate

decision maker (via AD or guardian). A person's desire to refuse or accept life-sustaining treatment becomes very important should they have a life-limiting disease.

A more recent form of AD that is specifically for persons who have a life-limiting disease and/or a combination of life-limiting and other forms of illness is the POLST form. The National POLST Paradigm originated in Oregon in 1991 as a result of research that found current AD forms "were inadequate for the patients with serious illness or frailty—who frequently require emergency medical care."⁷ POLST is a written treatment order that is

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honored across all healthcare settings, including Emergency Medical System (EMS) personnel and First Responder personnel in emergency situations. Most states have a POLST program or are in the midst of developing such programs.

A POLST form is not intended to replace other forms of ADs, but is primarily intended for persons of any age with a serious life-limiting illness and provides medical orders for current treatment as voiced by the person or their legal decision-maker. It is important to note that POLST is meant to be used for the *current* medical situation, which may often include EOL treatment preferences (See Appendix for example of POLST form).

Christian Fears and End-of-Life Decision-Making

As Christians, we are to take care of our body and spirit as precious gifts from God, our Creator. We may take care of our body by healthy eating and getting exercise, sufficient rest, and medical checkups. We take care of ourselves so that we may live out our purpose as God has intended for us—to worship and to do God's work ("For we are God's handiwork, created in Christ Jesus to do good works, which God prepared in advance for us to do" – Ephesians 2:10 NIV).

Maintaining health also includes seeking assistance from wise counselors, such as physicians, to help guide us when we are sick. Guidance with all healthcare decisions is a deliberate and important process between a person and their physician/provider. ADs, which may include EOL treatment preferences, may be some of the most important decisions in our life and the lives of our

family members. Yet many Christians fear that any kind of AD could be misused or corrupted in a way that may dishonor God.

There may be a fear that having an AD might border on a belief in or acceptance of euthanasia, or the deliberate ending of a life by another person using medical means. There may also be confusion between an AD and some state level Death with Dignity statutes, which allow a physician, at the request of a patient diagnosed as terminal, to prescribe a lethal amount of medication that the patient may self-ingest with the intent to cause death.

An additional fear may be that deciding treatment preferences in advance of illness might demonstrate a lack of trust in God to take care of us according to His will when we are ill. As Christians, we believe that all life is sacred and ordained by God, and some may think that making a decision to forego life-sustaining medical treatment at the end of life shows a lack of concern for the sanctity of our own life.

These concerns, and others like them, can be illustrated by a discussion I recently heard on a Christian radio program. One of the commentators described an experience with a physician in the hospital where his father had been admitted. His father had a serious illness and was confined to bed most of the time. The family cared for their father and prayed each day that he would not suffer. On admission to the hospital for an acute illness, the radio commentator was named the decision-maker as his father did not have decisional capacity. The treating physician, as part of the admission assessment, asked the commentator and his family about the Do-Not-Attempt-Resuscitation (DNR) status of the father. This upset the commentator very much and he went on to describe on air how hospitals have adopted “a culture of death” by asking about possible EOL decisions. Perhaps this is also a fear among Christians in general that our secular society and healthcare systems no longer honor the sanctity of life. However, in my 32 years working in various healthcare settings, I have always found our care providers and clinical teams to work in a culture of life and healing rather than in a culture of harm and death. As Christians, we should honor life, but also not fear physical death and not be so quick to judge questions about EOL treatment preferences.

Catholic Responses to POLST

As might be expected, Christian responses to the POLST paradigm have varied. Within Catholic responses in particular a central criticism of the POLST form is the fear of a slippery slope, such that an individual does not necessarily need to be in the terminal state of health to have

POLST honored by emergency responders, physicians, and healthcare providers, and that perhaps the slope would muddy Catholic teachings that distinguish “between rightful and wrongful refusal decisions by using the terms ‘ordinary’ (proportionate) and ‘extraordinary’ (disproportionate) means of medical care.”⁸ Catholic teaching holds that one must “accept ordinary/proportionate means of medical treatment, and may forgo extraordinary/disproportionate means,” and as Christian Brugger et al. argue “The POLST model and POLST forms make no distinction between ordinary and extraordinary means.”⁹ The argument is that, by not having such a stipulation directly on the POLST form, there is an inherent and fundamental conflict with the form that cannot be reconciled. In addition, the section of the POLST form related to artificial nutrition (under which a choice may be made by a person to receive or refuse artificial nutrition) may encourage Catholic patients or require Catholic hospitals to make a choice counter to Catholic teaching (per Pope John Paul II in 2004 that artificial hydration and nutrition is morally obligatory until it becomes a disproportionate or burdensome treatment for the person).¹⁰

There are Catholic theologians who do not oppose the POLST paradigm. For example, the Illinois Catholic Bishops and the Illinois Catholic Health Association support the use of a POLST form, stating, “Seriously ill Catholics are encouraged to participate actively in decisions about their own healthcare decisions. An individualized, well-crafted Illinois POLST form can provide clear and specific clinical direction based on prior conversations in cases of an emergency where circumstances make conversations impossible.”¹¹

Criticism of POLST among both Catholics and Protestants is not directed so as to suggest that EOL treatment decisions are unimportant or that such discussions should not be thoughtful and perhaps ongoing between the person, the physician, and their family, but rather that POLST is simply not specific enough for real-time clinical situations, and there is a fear that the form presents a bias toward non-treatment.

When Cure is No Longer the Goal of Care, We Must Always Care

A common reason that physicians call me from the Intensive Care Unit (ICU) for an ethics consult is so I may talk with the family members about their desire for medical treatments that are no longer indicated because the patient is in the active dying process.

Case 3: Laura, a 70-years-old, was admitted to the ICU from the Emergency Department (ED) for weakness and

mental status changes. She had three adult children who were with her in the ED and, since she did not have an AD, and she was not able to make her own decisions at this time, her children acted on her behalf as her legal surrogate decision maker for healthcare decisions. She had been admitted 4 times in the last 6 months for complications of her chronic obstructive pulmonary disease as well as advanced abdominal cancer. She required intubation and

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mechanical ventilation in the ED and was sent to the ICU. Though her family took her home from the hospital two months ago with home hospice care, they since changed their mind and now wanted full aggressive ICU care for her, including surgery, blood transfusions, diagnostic tests and even dialysis, should her kidneys fail. Oncology was consulted and had no further cancer therapies to offer and recommended palliative hospice care. Laura was very sick and unconscious and had needed ongoing blood transfusions because she was losing blood from her cancerous abdomen. The ICU team had discussed limitation of further blood transfusions as well as her current status for full resuscitative measures. The team told the family that there was nothing more medically that could be done for Laura and they were committed to keeping her comfortable and allowing a natural death. Her three children continued to tell the ICU team that they had faith in God, their mother was a Christian, and they were waiting for a healing miracle from God.

“Waiting for a miracle from God” is a common phrase I hear at the bedside. Family members wish for treatments that are no longer clinically indicated because they are afraid of losing their loved one to the permanence of death. I often hear family members say that the patient’s life is “in God’s hands” and that God will take their loved one when He is ready. However, just in case, family members continue to want everything possible done to extend biological life. Another common thread I hear from family members is that “God still has plans for my mother—she is a fighter and I will not give up on her.” It is good to call upon God’s grace in times of need, but God does not need our medicine or technology in order to provide healing miracles. As Christians, we believe that God has the ability to heal our diseases, and we pray that healing be His will for us and those around us who are sick. God hears our prayers and understands our pain. However, the miracle with which God blesses

us may not be healing or recovery. When family members explain that they want full aggressive care continued in the face of impending death because they are waiting for a healing miracle, I suggest that perhaps the miracle has already occurred, that God has given this day to the patient and family to pray and worship together before God calls their spirit home with Him, as we believe. As Christians, we know that physical death is no longer our enemy; as Romans 14:8 states, “If we live, we live to the Lord; and if we die, we die to the Lord. So, whether we live or die, we belong to the Lord.”

Physicians are not obligated to continue or provide specific treatments if such treatments are not within the standard of care for a specific issue or if it will not provide any medical benefit. Alternately, we as healthcare consumers do not have a right to demand treatments that are not standard of care or clinically indicated. We do have the right to be taken care of appropriately at the end of our life, and our physicians have the obligation to care for us and to palliate our symptoms. Such care is designed to give support to people in the final phase of a terminal illness and focus on comfort and quality of life, with the goal for patients to be comfortable, free of pain, and able to live each day as fully as possible. This is the description of hospice care, but the mere word itself in clinical situations is often translated by patients and family members as “giving up.” However, quite to the contrary, palliative care and hospice services with their supportive care and pain management may actually improve quality of life as well as extend life in many cases.¹²

A Challenge for the Church

As a Christian within a secular society—and as a clinical ethicist in a secular healthcare system—I am extremely mindful of our human community. I am also very aware of God’s calling and His desire for us to honor the sanctity of life, to respect His sovereignty, and to be respectful stewards of all our resources. Being good stewards includes how we spend our time and money for God’s purposes as well as for our family, community, neighbors, and ourselves. I would argue that being a good steward of our community resources includes being good stewards of our healthcare resources. For healthy individuals, the “collective” cost of care to society (our community, at large) is not very much. However, for individuals with several chronic diseases, debilitation, and frailty, the costs can be extremely high. How might our community meet all the expectations individuals may have regarding medical treatments, especially at EOL, when collective resources are limited and finite?

CMS estimates that over “25 percent of all Medicare spending goes toward the five percent of beneficiaries who die each year.”¹³ Part of this stems from the increasing percentage of patients using the aggressive treatments of the ICU within the last two to three months of life (up to 33 percent in 2006) with no significant medical improvements and in which death resulted in all cases. “The interventions that do little to stave off death, particularly interventions whose burdens are large compared to their benefits,” should have very limited use.¹⁴

Conversations about EOL and how we can respond to death and dying should be part of our church ministries. I have attended many Christian churches in my lifetime and have been blessed immensely by my faith community. Our services often include prayer for those who are sick or in need of help as well as a call for salvation decisions that we may receive the Holy Spirit and receive spiritual eternal life. I would like to challenge our churches to not only speak to our spiritual life but also our physical life. Our churches can be a wonderful platform to have discussions about what decisions may need to be made at the end of our physical life before health crises occur. We find comfort when we are sick and our pastor makes a phone call to us or a hospital visit to pray with us. Our churches minister to us when we are sick and infirmed at the end of our life as well as provide comfort to our family and assistance with bereavement plans once death has occurred. But in my experience, we do not talk about EOL care preferences or what God’s word might have to say about this at church while we are well. Our churches should talk about how healthcare can be a culture of life, not a culture of death, and can educate us on what is going on in healthcare related to care choices and decisions.

It is true that modern medicine affords us many amazing and lifesaving treatments and allows us to enjoy our life with our family and friends as well as tend to our spiritual purpose. But modern medicine may also prolong pain and suffering through artificial means when we might otherwise have died naturally. Through it all, God’s church feeds our spirit, guides our journey through life, and blesses us as we care for those who are most vulnerable. Our churches offer comfort when we are sick and to our family and loved ones when we die. It is also true that physical death will come to each of us. Yet, our churches do not discuss *how* we will die. It is *how* we die and *what we discuss* about death and dying that I challenge our churches to have a greater voice. Dispelling myths and discussing fears regarding individual preferences for healthcare at the end of life is important, and our churches need to actively participate in this process. Discussing treatment choices and the use of

advance care planning tools, such as POLST, should have a place in our faith communities and activities. Making our treatment preferences known to our family through discussions and the use of an AD does not show dishonor to God, rather, it is an act of faith that our lives really are in His hands.

- 1 Associated Press, “CDC Survey Finds Most Americans Prefer to Die at Home,” *Journal of Emergency Medical Services*, February 28, 2013, <http://www.jems.com/articles/2013/02/cdc-survey-finds-most-americans-prefer-d.html> (accessed October 23, 2015).
- 2 Institute of Medicine, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research* (Washington, DC: National Academies Press, 2011).
- 3 Committee on Approaching Death: Addressing Key End-of-Life Issues, Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington, DC: National Academies Press, 2014), 21.
- 4 Kenneth Covinsky et al., “Communication and Decision-Making in Seriously Ill Patients: Findings of the SUPPORT Project,” *Journal of the American Geriatrics Society* 48, no. S1 (2000): S187–S193, doi: 10.1111/j.1532-5415.2000.tb03131.x.
- 5 Karen Detering and Maria Silveira, “Advance Care Planning and Advance Directives,” *UpToDate*, April 2015, <http://www.uptodate.com/contents/advance-care-planning-and-advance-directives> (accessed October 23, 2015).
- 6 Maria Silveira, Scott Y.H. Kim, and Kenneth M. Langa, “Advance Directives and Outcomes of Surrogate Decision Making before Death,” *The New England Journal of Medicine* 362, no. 13 (2010):1211–1218.
- 7 National POLST, “History,” <http://www.polst.org/about-the-national-polst-paradigm/history/> (accessed October 20, 2015).
- 8 Christian Brugger et al., “The POLST Paradigm and Form: Facts and Analysis,” *The Linacre Quarterly* 80, no. 2 (2013): 113.
- 9 Ibid.
- 10 Ibid.
- 11 Illinois Catholic Healthcare Association, “POLST FAQ,” *POLST Illinois*, September 12, 2013, <http://www.polstil.org/wp-content/uploads/2013/10/IHCA-POLST-Illinois-FAQs-20130912.docx> (accessed October 1, 2015).
- 12 For more information regarding hospice care, visit: National Hospice and Palliative Care Organization, “Hospice Care,” July 23, 2015, <http://www.nhpco.org/about/hospice-care> (accessed October 20, 2015; site now discontinued).
- 13 Helen Adamopoulos, “The Cost and Quality Conundrum of American End-of-Life Care,” *The Medicare NewsGroup*, June 3, 2013, <http://www.medicarenewsgroup.com/context/understanding-medicare-blog/understanding-medicare-blog/2013/06/03/the-cost-and-quality-conundrum-of-american-end-of-life-care> (accessed October 21, 2015).
- 14 Lisa Anderson-Shaw, William Meadow, Hilary S. Leeds, and John J. Lantos, “The Fiction of Futility: What to Do with Policy?” *HEC Forum* 17, no. 4 (2005): 294.