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ADVANCE MEDICAL DIRECTIVES IN THE ERA OF HEALTH CARE REFORM: WHO DECIDES?

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GUEST CONTRIBUTOR

The alleged over-utilization of healthcare services at the end of life poses a wide range of ethical, empirical, and fiscal questions that have taken on greater urgency with the enactment of the Patient Protection and Affordable Care Act (ACA). Realized or not, the ACA's goal of "bending the cost curve"—that is, slowing the growth rate of healthcare spending—has inevitable consequences for the use of all forms of expensive medical interventions.[1] Likewise, well-founded or not, the controversy stirred by ACA opponents' allegations of "death panels" and "rationing" complicates what ought to be a broader societal discussion of how medical interventions are used to extend life, and in what context, and by whom, those decisions should be made.[2] Advance medical directives (AMDs)—whether based on living wills (LWs), the appointment of healthcare proxies or agents (HCAs),[3] or the emerging "paradigm" of Physician's Orders for Life-Sustaining Treatment (POLST)[4]—have long been advocated as a means to address these dilemmas.[5] But after more than three decades of experience with legislation and court decisions governing AMDs, it is appropriate to ask: Is this their proper purpose? And are they up to the task?

The hope that AMDs will rationalize end-of-life decision making, and perhaps help bend that cost curve, seems grounded more in optimism than in experience. Thirty years of research on advance directives reveals several obstacles to their effectiveness: most people do not execute AMDs; the prescribed legal forms (particularly LWs) are hard to understand and provide vague and unhelpful guidance; healthcare providers are often not aware an AMD exists for a particular patient; the "legal transaction" model underlying state laws on AMDs is ill-suited to the clinical setting and imposes needless execution requirements; and even HCAs are often unclear what to decide when their principal becomes incapacitated.[6] But little consensus exists on how to address these problems. Leon Kass and Eric Cohen criticize what they term "the gospel of the living will," not only pointing out these well-documented deficiencies in AMDs, but also questioning the presumption that ever-greater reliance on patient "autonomy" is the solution to the challenges of caring for those who have lost the capacity to decide for themselves.[7] To address the perceived deficiencies in LWs, other experts have proposed—and much legislation now reflects—a "menu" approach, in which patients state preferences regarding specific forms of treatment;[8] the POLST paradigm is built on this model.[9] This approach, in turn, has been criticized as "reactionary" and liable to frustrate the effectiveness of the advance directive as a tool to preserve the *prospective* decisional autonomy of a *patient* with present decision-making capacity.[10] It seems that all parties to this debate agree in principle that advance care *planning* is a laudable objective; they differ, however, on the utility of advance care *directives* in reaching that goal.

By considering the history of AMDs and the ethical issues posed by their use (or misuse), this article aims to provide clinicians and other healthcare providers (HCPs) with a framework for incorporating the use of AMDs that genuinely reflect the dignity and values of their patients into their practices more effectively. I contend that AMDs should not be oversold as a means to address broader concerns regarding the possible mis-utilization of medical care at the end of life;[11] indeed, the more this is done, the more likely the backlash that AMDs are intended to serve interests other than those of the dignity and values of individual patients. Rather than focusing on increasing the ubiquity (and legal enforceability) of AMDs, I suggest that we should focus first on the process of advance care planning in the clinical setting, and *then* assess what forms of AMDs may enhance that process. A more modest understanding of what AMDs can and cannot achieve may foster a more organic, patient-centered approach to these problems throughout medicine, thus reducing the conflicting demands that have fed this controversy over the past three decades, and are particularly acute today.

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from the director's desk

BY PAIGE COMSTOCK CUNNINGHAM, JD, MA
EXECUTIVE DIRECTOR

At The Center for Bioethics & Human Dignity (CBHD), part of our core mission is to stay on the cutting edge of bioethical issues, watching for emerging trends, both those that are encouraging and those that trouble us. But, that does not mean that CBHD is neglecting the more familiar issues such as beginning- and end-of-life concerns. We are noticing an uptick in questions about physician-assisted suicide, euthanasia, healthcare decisions for elderly parents, and advance planning directives. From time to time, it is good to get back to the basics.

Although many of the ethical issues at the beginning and end of life are fairly well settled, their application is highly personal, and their relevance may not be obvious until a life situation arises. And when that time does come, abstract principles or values can acquire an emotionally tinged urgency. I would suggest that there are two aspects to responding to these bioethical concerns: thinking them through carefully and reflectively in advance, and acting in accordance with your acknowledged values and principles in the midst of the crisis. Both aspects are best worked out in conversation and consultation, not isolation. Two personal examples may illustrate my point.

My husband Jay and I recently updated our estate plan, including a durable power of attorney for healthcare. In discussing questions posed by our attorney, Jay and I reviewed our principles and values and how that affected our decisions. All of our children—now adults--were home for Thanksgiving. During a low-key moment, my husband Jay and I told them about our plans, and answered their questions.

Last year, my mother-in-law's health declined due to congestive heart failure and kidney failure. At one point, I had to sit down with her and go through end-of-life planning documents before she could leave nursing care and return to assisted living. My goal was to make sure she understood each provision, and to ascertain her wishes regarding nutrition and hydration, organ donation, CPR, and so forth. Jay and I wanted to be sure we could act in accordance with her wishes.

As her condition worsened, we had to make decisions about re-hospitalization, in-home hospice care, and withdrawal of breathing support via nasal cannula. We were no longer contemplating abstract principles and values, but were in the midst of making decisions that could affect a family member's life. We consulted with her personal physician, specialists, home healthcare agencies, an expert on POLST, the hospice nurse, and the chaplain. At one point, I called two doctors with bioethics expertise—friends of CBHD—to ask if we were missing anything in deciding to remove the cannula. Conversations and consultations were integral to our decision making.

As I have said many times, everyone will one make at least one bioethical decision in their lifetime. There is no way to know when that will be, and a crisis is not an optimal time for beginning to think ethically. Ethical principles cannot be grasped in sound bite portions. Moral conscience—virtuous character—needs to be formed gradually, and strengthened regularly, so that we will have a reliable foundation for, as Dennis Hollinger puts it, "choosing the good." Then, if and when a bioethical dilemma arises, we can have greater confidence that we are making a wise, morally good choice.

As part of our ongoing contribution to the conversation about basic issues at the end of life, the Center thinks it is worthwhile to focus on the familiar, for new knowledge, and from a new perspective. In this issue, Edward Grant does just that. In his first contribution to Dignitas, Grant updates Advance Medical Directives (AMD) in light of the developments in the past decade in advance care planning, through the perspective of law. Often central to end-of-life decision-making, the attorney's role can be neglected or overlooked. Yet advance planning often begins and ends in the attorney's office. This is not ideal. The conversation should be interprofessional, as Grant points out: "Wise attorneys will advise clients to consult a physician with any questions regarding the medical impact of decisions and treatment preferences stated in an AMD."

The various disciplines—theology, philosophy, law, and medicine—all have something to contribute to helping us choose the good. At CBHD we are committed to fostering an approach that welcomes all of them in our bioethical conversations, even for the most basic of bioethical concerns.

The Center for Bioethics & Human Dignity (CBHD) is a Christian bioethics research center at Trinity International University.

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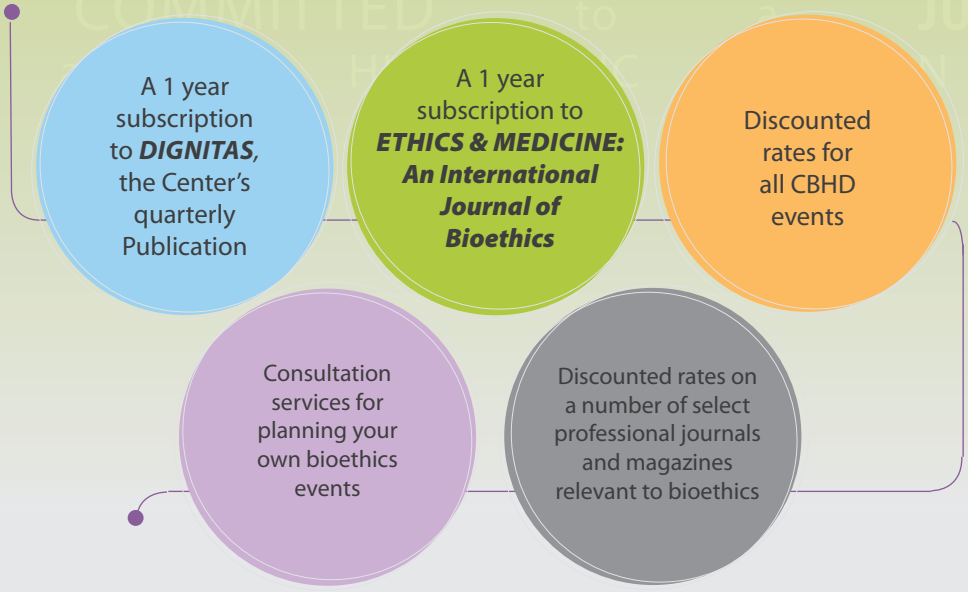

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The Development of AMDs: A Brief History

Living Wills: AMDs have been part of clinical practice for close to 40 years. California passed the first living will law, the Natural Death Act, in 1976, the same year that the New Jersey Supreme Court issued its decision in the case of Karen Quinlan, authorizing the withdrawal of a mechanical ventilator thought necessary to sustain her life.[12] The California law established the template for the first generation of LW laws: a standard, one-way directive (called a "Directive to Physicians") to refuse life-sustaining treatment in the event of terminal illness and loss of decision-making capacity.[13] The law's constrictive definition of life-sustaining treatment (LST) limited use of the directive to circumstances where death was imminent regardless of whether the LST was continued or not; this restricted the utility of the law and other first generation advance directive statutes.[14]

Common Law and Constitutional Law: More importantly from a legal perspective, early LWs also risked creating the impression that they provided the sole basis for decisions to withdraw LST. Court decisions in the 1980s clarified the issue, acknowledging that the common law protects the rights of patients to make medical treatment decisions and to have their wishes honored if they become incapacitated, with or without an AMD.[15] The United States Supreme Court, in the 1990 *Cruzan* decision, recognized the refusal of LST as a "liberty interest" protected under the Fourteenth Amendment to the Constitution—but a liberty interest subject to the State's interest in protecting life, which could be asserted by requiring clear and convincing evidence of a patient's prior wishes.[16] An AMD could certainly meet that evidentiary standard, but in practice courts often accepted far more informal prior oral statements as sufficient.[17] Most state advance directive laws now clarify that they do not preempt or impair existing rights and responsibilities under the common law, the Constitution, or other statutes regarding medical treatment decisions.[18]

Healthcare Powers of Attorney: By the time of the *Cruzan* decision, many states had recognized the deficiencies of the one-way LW provisions and enacted laws permitting individuals to execute a "durable power of attorney for health care," appointing a healthcare proxy or agent to make decisions for them if they became incapacitated.[19] The advantages of having an HCA are clear: the agent can interact with the treatment team to assess the specifics of the patient's condition and convey the patient's wishes with greater detail than can be conveyed through a one-size-fits-all LW. Some ethical issues remain, however: chiefly, is the agent's task simply to be a conduit for a patient's stated wishes, or also to express independent judgment about what would be in the patient's current best interests based on the particulars of the clinical situation? Though HCA laws do not constrain the decisions of agents in this regard, clinicians who interact with HCAs should be sensitive to this concern, just as they would be in the more common circumstance of interacting with a family member not formally appointed as an HCA who nonetheless acts *de facto* in that role.

> ***Yet, a comprehensive legislative scheme is no guarantee against intractable controversies at the bedside ... [Florida's] laws failed to prevent the bitter litigation over the treatment of Terri Schindler Schiavo.***

In 1991, New Jersey became the first state to adopt legislation merging the concepts of LW and HCA. Other states quickly followed.[20] Currently, all states and the District of Columbia have advance directive laws that, if not explicitly merging the concepts of LW and HCA, at least provide for both the appointment of an HCA and the execution of a narrative statement (and, in some states, a checklist) of treatment preferences.[21] Beyond this, the details of state legislation vary considerably, and attempts at uniformity have enjoyed at best a mixed rate of success.[22] Some states explicitly retain the LW concept by providing a standard statement or checklist of preferences along with the narrative option. For example, Connecticut law integrates provisions for a LW and appointment of an HCA, but each provision is optional; a patient does not have to do both. The LW portion in Connecticut specifies three forms of LST, with the option to reject or request each one: cardio-pulmonary respiration, artificial respiration, and nutrition and hydration by tube.[23] Massachusetts, on the other hand, has no LW provision, although appointment of an HCA may be accompanied by a narrative statement of preferences.[24] Meanwhile, several states retain the requirement that the advance directive follow a statutorily-prescribed form.[25] A minority of states permit execution of an oral advance directive, subject to varying requirements regarding witnesses and the medical condition of the patient.[26] States also differ in their treatment of specific forms of LST, particularly "artificial" nutrition and hydration, or tube feeding. Idaho, for example, states a default rule that tube feeding cannot be withdrawn if this would cause the death of the patient, but permits a patient to execute a directive to the contrary.[27] Other states, such as Colorado, provide two options: a patient can refuse all forms of LST, or refuse all LST except tube feeding.[28] Mississippi's law includes an optional set of "instructions for health care," as well as an option to choose medical treatment to prolong life "as long as possible *within the limits of generally-accepted health-care standards.*"[29] The highlighted language implicitly addresses the ethical problems posed in attempting to follow an advance directive to "do everything," without qualification, to sustain life. Other states have comparable provisions,[30] and virtually all states grant clinicians the right to refuse to

withdraw treatment based on conscience or other objections.[31] Yet, a comprehensive legislative scheme is no guarantee against intractable controversies at the bedside. Florida has long had one of the most comprehensive legislative schemes for AMDs and proxy decision-making, including virtually all the features discussed above.[32] Ironically, those laws failed to prevent the bitter litigation over the treatment of Terri Schindler Schiavo.[33]

ABBREVIATIONS:

- **AMD** (Advance Medical Directives);
- **HCA** (Healthcare Agent or Proxy);
- **LST** (Life-Sustaining Treatment);
- **LW** (Living Will);
- **POLST** (Physician Order for Life-Sustaining Treatment);
- **PSDA** (Patient Self-Determination Act)

Impact of AMD Laws: Despite this blanket of state laws, surveys consistently show that only a minority of patients who lack decision-making capacity have executed an AMD or appointed an HCA. Even where a patient has done so, obstacles remain: the written directive may not address the precise clinical dilemma at hand, the HCA may not be certain how to act, or the fact that an HCA or AMD exists may not be known to the treatment team. And in some cases, doctors who are aware of an HCA may even ignore it because they feel that more can be done to benefit the patient and prolong life.

Federal and state legislators have attempted for many years to bridge this gap. The Patient Self-Determination Act (PSDA),[34] enacted in 1990, required all Medicare and Medicaid provider organizations (hospitals, nursing homes, home health agencies, etc.) to provide written information to patients upon admission regarding their rights under state law to execute an AMD, to maintain written policies regarding AMDs, and to document in a patient's medical record if an AMD exists. The law also mandated states to provide a written description of their laws for providers to give to patients and called for the Department of Health and Human Services to undertake a public education campaign on AMDs. There is little evidence that the PSDA significantly increased the use of AMDs, however;[35] the required notification was subsumed in the volume of other paperwork typically accompanying a hospital admission, and the requirements upon governments were apparently met largely by doing the bureaucratic minimum.

More significant has been the enactment of laws in more than 40 states and the District of Columbia establishing a "default" list of surrogate decision-makers in the event of patient incapacity.[36] The laws vary considerably, with some (such as the District of Columbia) providing a rigid, hierarchical list, and others allowing greater flexibility. While the laws are intended to fill the gap when no AMD is available, they actually provide an additional incentive to create an AMD as well: the statutory list of surrogates may not reflect an individual's true wishes regarding who should make decisions for them. Clinicians can play an important role if, as part of their conversations with patients regarding advance care planning, they inform them that failure to appoint an HCA might mean the law will appoint one for them—perhaps a person who is not familiar with the patient's values and preferences.

More about advance care planning follows. But among the biggest issues facing physicians who wish to better serve their patients in this area are time and money. The initial House of Representatives version of the ACA included (in section 1233) a proposal to reimburse physicians for time spent with patients to discuss advance-care planning; it made such reimbursement contingent on physicians following a detailed "script" of the information that should be provided to patients. Critics of the ACA ominously castigated section 1233 as creating "death panels."[37] Even some who eschewed this rhetoric noted the potentially coercive aspect of the "script," which was apparently designed to compel the patient to consider the full range of potential medical treatment decisions and thus persuade the patient to make some form of advance directive.[38] The reimbursement provision was not included in the final version of the ACA, and attempts to resurrect a form of physician reimbursement for such conversations through regulation were eventually withdrawn by the Obama Administration.[39] It appears so far that this latest effort at the Federal level to create incentives for encouraging patients to execute AMDs will likely be no more effective than the PSDA of a quarter-century ago.

Beyond Traditional Advance Directives: The POLST Paradigm

The lack of adequate advance care planning, despite universal legislation on the subject, has been labeled an economic and public health "crisis" by some commentators,[40] and a predictable consequence of that very same legislative agenda by others.[41] One cannot doubt the persistence of those who seek to "lock in" a patient's wishes so that decisions about withdrawing life-sustaining treatment can be made more readily. (One recent proposal suggests further research into whether a "default" choice for comfort care over life-extending care might align AMDs better with a patient's true wishes and reduce the unnecessary use of medical resources.[42])

The latest effort to achieve this goal, the "Physician Order for Life-Sustaining Treatment" (POLST), has quietly gained traction in a large number of States, albeit under various names and with various forms of legislative support.[43]

The goal of POLST is straightforward and ambitious: to convert a patient's stated treatment preferences into an "immediately actionable medical order," memorialized in a standard, brightly-colored form that becomes part of the medical record for the patient.[44] POLST is designed to overcome at least two perceived gaps in existing laws on AMDs—immediacy and enforceability. The assumption driving POLST is that clinicians can, and indeed must, act promptly to comply with these "physician's orders" that are part of the patient's chart (or, in the developing future, electronic medical record). To this end, the standard POLST Form is simple and direct. It is a one-page, "multiple-choice" approach with three basic options: to accept or reject cardio-pulmonary resuscitation (or "Code"); to choose "comfort measures only," "limited additional interventions," or "full treatment"; and to request or refuse artificially administered nutrition and antibiotics.[45] Additional orders may be added to the standard form.

Much of the impetus for POLST lies in resolving the potential conflict for emergency medical providers who respond to calls involving a patient who has an AMD declining the use of CPR. In those circumstances, the values of immediacy and enforceability are paramount, so that emergency responders, in fulfilling their general obligation to employ CPR, do not override a patient's expressed wishes. But the aims of POLST are broader.[46] First developed in the 1990s at the Oregon Health & Sciences University (OHSU), the "POLST Paradigm" remains effectively under OHSU's purview. OHSU's POLST Program certifies as "endorsed" POLST initiatives State and local programs that meet defined standards for supervision, education and training, and ongoing evaluation, as well adopting a compliant POLST form. As of June 2013, 14 States had "endorsed" POLST programs, and 29 were classified as "developing."

POLST's proponents emphasize that completion of the form should be the end-point of a process of advance care planning that begins in the clinical setting, ideally any time that a patient is expected to live a year or less. POLST criteria stipulate that patient participation must be voluntary, even under provisions that require patients to be informed of the option to participate. POLST forms are also to be reviewed and updated if there is a substantial change in a patient's health status, if a patient's treatment preferences change, or if the patient is transferred from one treatment setting or care level to another.[47] While compatible with existing AMD schemes, POLST aims to shift the locus of advance care planning to the clinical setting and to ensure that the outcome is clearly recorded in a manner that HCPs can understand and follow. Optional POLST registries, available in a handful of States, allow patients to ensure that their POLST form is recorded electronically and thus available if the printed form cannot be located by healthcare providers.[48]

Whether the POLST Paradigm will succeed in making advance care planning

more common and patient wishes more closely adhered to where other initiatives have failed remains an open question. Much depends on whether close consultation with a physician before a form is executed, which is an assumption of the Paradigm, occurs effectively in the clinical setting. It may be naive to assume, for example, that the completion of POLST forms will be any more consultative or informative (from the patient's perspective) than the oft-criticized process for obtaining informed consent. The five principal criticisms directed at living wills by Fagerlin and Schneider suggest five pertinent questions for the POLST Paradigm: **(1)** Will enough people decide to execute the forms, and will their reasons for declining to do so be respected? **(2)** Will the creation of POLST forms comply with standards for informed consent, including being current and relevant to the treatment decisions in question? **(3)** Does the brief POLST document genuinely reflect accurate and effective treatment preferences? **(4)** Will POLST forms be available when treatment decisions must be made, as they are designed to be? And, **(5)** will POLST forms guide or override the input of a designated HCA regarding treatment decisions?

Working with Advance Directives: Clinical Considerations

As the foregoing discussion indicates, clinicians face a bewildering array of patient needs, societal expectations, and legal standards in the area of advance care planning. Few dispute that modern medicine has fallen short in bridging the gap between the vast array of treatments and technology that can be used to preserve life and the limited knowledge most patients (and families) possess about the efficaciousness of such treatments and whether they would be consonant with a patient's values and desires. For all the good intentions behind them, state statutes regarding AMDs offer limited help in bridging this gap, and may in fact have been counterproductive.[49] It comes as no surprise, therefore, that years of legislative enactments have done little more than codify the pre-existing, fundamental principle that patients possess the rights to state their preferences for medical treatment and to have those preferences honored.

But reinforcement of that principle is not a bad place to begin the discussion of how clinicians can better guide their patients in the process of advance care planning. The temptation, fed by years of legislation and celebrated court cases, is to see end-of-life care as a legal dilemma, as opposed to a challenge rooted primarily in the ethics of medicine. The widespread image of medicine thwarting the (expressed or inchoate) desire of patients to be free of LST ignores the complexities of clinical practice as well as the tentative nature of many expressions of patient preference. On the other hand, such images often fuel the demand for further laws on AMDs when, in fact, long-established principles of the common law provide ample space for HCPs and patients to engage in advance planning discussions that will result, as one proponent says of AMDs, in "sufficient guidance to those responsible for the patient's care."[50] In short, legal officiousness should not interfere with, and surely will not improve, the practice of good, patient-centered medicine as life draws to a close.

> ***"... clinicians face a bewildering array of patient needs, societal expectations, and legal standards in the area of advance care planning.***

Guarding against such officiousness requires familiarity with the law and particularly with the specific forms of advance directives, including those associated with the POLST paradigm, in the jurisdictions where a clinician practices. Should a physician anticipate that a patient's illness may result in incapacity to make treatment decisions, the physician ought to broach the subject of advance care planning, especially to determine whom the patient would want to make treatment decisions if incapacity occurs. From this could follow discussion of specific treatment options, entry of DNR orders, and related decisions. Without providing legal advice, physicians and other HCPs can then inform patients that legal avenues exist to put down their preferences in writing, under laws that will help those preferences to be enforced. If a patient is reluctant to execute an AMD under state law, the basis for that reluctance can be explored, but the ultimate decision is the patient's. The physician should assure such patients that they will act, even absent an AMD, to follow the patients' expressed wishes to the greatest extent possible and consistent with sound medical practice.

Commentators have debated whether ethical principles governing informed consent, particularly regarding specific treatment options, should be followed in the process of executing AMDs.[51] One modern principle of informed consent, however, should be non-negotiable: just as informed consent to a particular medical procedure is a process, not an event, ascertaining a patient's wishes regarding appointment of a HCA or other AMD should not be an abrupt or reflexive undertaking. In particular, when advising clients for whom terminal illness and/or incapacity is not merely a speculative event, physicians should reassure those persons that the choice between treatment designed to extend life and palliative care to provide comfort is not mutually exclusive (allowing, of course, for any physical burdens or pain associated with continued LST). Physicians can advise patients that there is a continuum of care that can (and will) be adjusted to meet the patient's goals for treatment.

The Distinct Roles of Physicians & Attorneys

Clinicians should not attempt to be lawyers, but they need to be familiar with the basic requirements of their own

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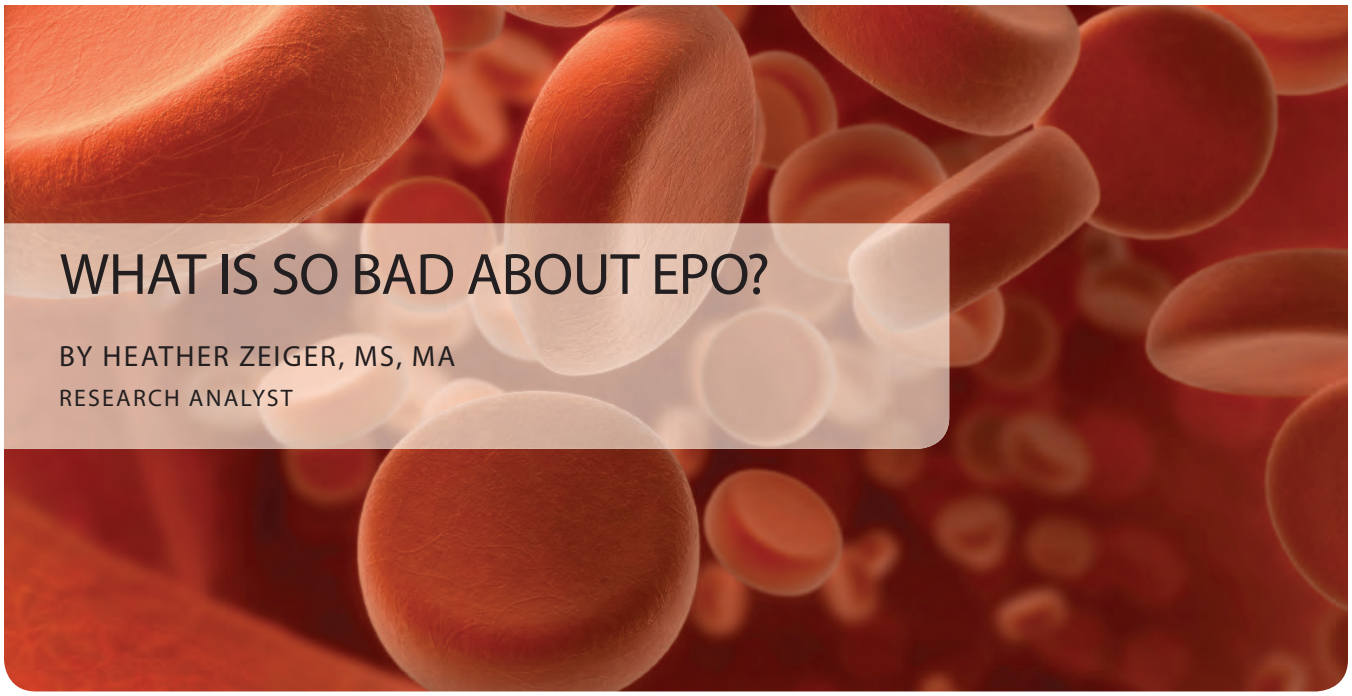


WHAT IS SO BAD ABOUT EPO?

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

The 1990s was an exciting decade for professional sports. Mark McGuire and Sammy Sosa each hit over 65 home runs in a single season, only to be topped by Barry Bonds a couple of years later. A cyclist named Lance Armstrong came on the scene, beat cancer, and won the Tour de France in 1999 (and then several more times in the 2000s). The same timeframe that saw these accomplishments, however, also saw the beginning of what some have dubbed the "steroid era." The use of performance enhancing drugs (PEDs) picked up drastically in the 1990s, while testing for their use was behind-the-times. Today, random testing policies have decreased the incidence of PED use compared to the 1990s, but as the recent BioGenesis scandal and Lance Armstrong's admission to using PEDs in his competitions from 1999 onward demonstrate, PEDs are still very much in the public eye.

Most people associate PEDs with anabolic steroids, which are used to increase muscle mass. But there is another kind of PED that increases the body's endurance. Endurance has to do with how efficiently the blood can supply oxygen to the muscles. If you want to maintain a certain pace for a long period of time, you need to train your body to supply oxygen to your muscles efficiently. But, no matter how hard or long you train, there is a limit to how much oxygen your blood can carry at one time. If an endurance athlete could do something to change this upper limit, he would have a significant advantage over his opponents.

What Is EPO?

Blood has two main components: plasma and red blood cells. Red blood cells transport oxygen from the lungs to the parts of the body that consume oxygen, such as muscles or the brain. During exercise, muscles become oxygen depleted. The capacity to replenish that oxygen efficiently makes all the difference in endurance sports, like cycling, running, and cross-country skiing. The more red blood cells a person has, the more oxygen can be supplied per unit of blood. A typical red blood cell count (hematocrit level) for athletes is between 40-50%.

The body naturally makes a hormone called erythropoietin (EPO), which regulates red blood cell formation.[1] This hormone, predominantly made in the kidneys, responds to the concentration of oxygen in the blood. It is activated, for instance, when one goes from lower elevations to higher elevations; at high elevations, there is less oxygen in the air, meaning less oxygen in the lungs. EPO signals increased red blood cell production so there will be more oxygen carriers to re-supply the muscles.

In the 1980s scientists made a synthetic version of EPO to treat anemia, which was approved for clinical use in the U.S. in 1989.[2] Prior to the production of synthetic EPO, people on dialysis as well as cancer patients undergoing chemotherapy had to get blood transfusions to resupply their red blood cell levels; now, with the help of synthetic EPO, their bodies can make their own red blood cells.

As with many enhancement technologies, however, what started as a therapeutic technique became a way for an athlete to gain a competitive advantage. Self-injection with EPO became one of several techniques – along with training at high altitudes and receiving blood transfusions – used by athletes to increase their blood oxygen levels for competitive advantage in endurance sports.

Of these three techniques, only training at high altitudes, or simulating high altitudes with a hyperbaric chamber,

is permitted. High-altitude training changes the athlete's environment, but does not bypass any of the body's natural processes in producing red blood cells. The problem with this technique is that it provides only a limited benefit to athletes because of the body's natural limitations, and if there is a delay between altitude training and competition (due to travel or recovery), then the advantage further diminishes.

Accordingly, some athletes have turned to blood transfusions as a way to increase red blood cell count artificially. Some remove their own blood after altitude training to ensure that their red blood cell count is high, store the blood, and re-insert it right before competition. This technique often involves treating the blood so that the concentration of red blood cells is higher than normal. Blood transfusions are banned in most athletic competitions, but this ban has been difficult to enforce because there is no way to detect a blood transfusion unless the athlete uses someone else's blood.[3] The drawback to this technique (beyond its being banned) is the difficulty of storing and transporting the blood samples. They must be kept at a certain temperature, and the transfusions must be done at just the right time.

Synthetic EPO provides a greater advantage to athletes and is much easier to use than the other two techniques. According to some studies, synthetic EPO can provide up to a ten percent athletic advantage allowing the athlete to maintain a certain effort level over longer distances. This ten percent advantage adds up over the course of an endurance race. This is also enough of an advantage that athletes who want to play clean will likely have difficulties keeping pace. EPO use in cycling likely came into widespread use in the early 1990s when world-class cyclists noticed a drastic change in the competition's pace and endurance demands.[4] This is where Lance Armstrong comes in.

Why Did Lance Armstrong Test Negative?

In response to allegations of EPO abuse, Armstrong maintained that he tested negative, but later admitted that he had in fact used the drug. Synthetic EPO has been notoriously difficult to detect; athletes have found ways around tests that look for increased hematocrit levels. It was not until recently that tests have been able to distinguish between synthetic and natural EPO, and false negatives remained possible even after this development. By 2005 the tests had been significantly refined, and testers found that Armstrong's stored blood samples – which had previously tested negative for synthetic EPO – now tested positive.

Ethical Considerations

It can be difficult to draw ethical lines in the case of EPO doping, but understanding the science behind it helps to clarify some aspects of the issue. One argument on behalf of EPO use maintains that the body naturally makes EPO, and using synthetic EPO amounts to the same thing as training at high altitudes, which is permitted. Shouldn't the use of synthetic EPO, then, be permitted? Upon closer consideration, however, the proposed analogies with natural, permissible enhancement do not hold up. Synthetic EPO bypasses the body's natural processes and causes the body to go beyond what it is designed to do. It brings about such substantial physiological changes that elite athletes like Greg LeMond could no longer compete against EPO users,[5] suggesting that synthetic EPO fundamentally changes the competitors—and the competition.

Sports are intended to be a competition among human beings. To fundamentally change the body or bodily systems such that they operate beyond the parameters of their design diminishes the dignity of the human being and promotes an instrumental conception of the body as a tool that may be used and manipulated in pursuit of one's goals without regard to its intrinsic value. While breaking the rules is an important ethical consideration, a more fundamental concern is how the use of performance enhancers is part of a larger cultural trend towards commodification of the body and, ultimately, our dehumanization.

1 S. Elliot, "Erythropoiesis-Stimulating Agents and Other Methods to Enhance Blood-Oxygen Transport," *British Journal of Pharmacology* 154 (June 2008): 529-541.

2 Ewen Callaway, "Sports Doping: Racing Just to Keep Up," *Nature* 475 (July 2011): 283-285.

3 Testers can look for elevated hematocrit levels, but this is easily by-passed using saline solution.

4 Michael Shermer, "The Doping Dilemma," *Scientific American* 298, no. 4 (April 2008). Shermer interviewed LeMond, who had won the Tour de France in 1986, 1989, and 1990. LeMond was set to compete again in 1991. He felt that he was in top physical condition, but contends that something was different about the competitors in the 1991 race. Riders who had not been able to keep pace with him in the past, were passing him without problems. LeMond believes 1991 was the year synthetic EPO was first put into wider use in cycling.

5 Ibid.

QUESTIONS?

Would you like to offer comments or responses to articles and commentaries that appear in *Dignitas*? As we strive to publish material that highlights cutting-edge bioethical reflection from a distinctly Christian perspective, we acknowledge that in many areas there are genuine disagreements about bioethical conclusions. To demonstrate that bioethics is a conversation, we invite you to send your thoughtful reflections to us at info@cbhd.org with a reference to the original piece that appeared in *Dignitas*. Our hope is to inspire charitable dialogue between our readers and those who contribute material to this publication.

CONTINUED, MEDICAL DIRECTIVES FROM PAGE 7

state's laws regarding AMDs. In those states that permit execution of an oral AMD, physicians should provide that option (with knowledge of any requirements for witnessing, etc.) in the discussion of advance care planning. Clinicians also need to be aware of any legal requirements for certifying that a patient has lost decision-making capacity, thus triggering the authority of a HCA to make treatment decisions. Most state laws require certification by a second physician of the loss of capacity; some even require the involvement of a psychiatrist, psychologist, or other specialist with expertise in making such determinations. Finally, physicians should be aware of their rights and obligations to refuse to participate in the withdrawal or provision of medical treatment on grounds that such actions are ethically inappropriate.

clients to consult a physician with any questions regarding the medical impact of decisions and treatment preferences stated in an AMD and, if the client chooses to do so, forego final execution of such documents until that consultation has taken place. Similarly, physicians, HCPs, and healthcare institutions ought to be aware that patients may have executed an AMD with their lawyers and inquire whether such documents exist. Both physicians and attorneys should be aware that the more remote a statement of treatment preferences is, the less reliable it may be as an accurate predictor of what the patient would want in the present. Just as "old" testamentary wills should be accounted for and revisited, so too with "old" AMDs.

For attorneys in particular, it is not sufficient to be knowledgeable regarding specific state legislation on AMDs.[52] To

> ***Decades of experience demonstrate that AMDs are no panacea for the ethical dilemmas posed by end-of-life decision-making.***

Just as clinicians should not play lawyer, attorneys should not be placed in the position of speculating regarding the potential outcome of decisions set forth in a statutorily-prescribed AMD form. This brings up an unfortunate reality regarding AMDs: many people will first engage in discussion of such documents, and thus begin the process of advance care planning, when preparing their wills and other estate-related documents. In other words, in the office of their attorney, not their doctor. Lawyers (unlike, typically, physicians) are reimbursed through client fee for engaging in these discussions and preparing the necessary documents, and so have an incentive—and likely an ethical obligation—to advise their clients on the law governing AMDs. These discussions and decisions may take place years or decades before the anticipated onset of terminal illness (consider the young couple planning their estate after birth of a first child). Wise attorneys will advise meet the goals of advance care *planning*, any statutorily-prescribed form of AMD (including one with checklists for various treatment options) should be stringently examined before execution to determine if it meets the standards of disclosure sufficient for a client/patient to understand the nature of what the directive purports to decide. Ethically-adequate informed consent requires capacity, autonomy (freedom from coercion, duress, or manipulation), the disclosure of all relevant information (admittedly difficult when giving or declining consent to future treatment), and comprehension.[53] The debate on the *extent* and *detail* to which these principles should be applied to the formulation of advance directives may not yet be resolved, but there should be no dispute that a fundamental level of capacity, autonomy, disclosure, and comprehension should be assured before an AMD is executed.[54] Conversely, simply because an AMD has been executed does not necessarily mean that the patient received an adequate disclosure of information or comprehended what information he or she received.[55]

Finally, physicians and attorneys should both be aware that a validly-executed AMD is of no use if it is not available when the patient/client becomes incapacitated. The existence of an AMD may be noted in a medical chart even without following the full POLST paradigm, and an attorney should advise clients that, unlike a testamentary will, an AMD must be quickly accessible as well as securely filed.

Conclusion: Kass and Cohen aptly express the skeptical view toward AMDs, which runs counter to the more prevalent, favorable view of such instruments:

> If living wills promote a deeper understanding of what it means to age well and care well, then we are all for them. If they help preserve even a dose of loving humanity in the face of the "machinery of the modern hospital," then we endorse them. But the evidence suggests that living wills have largely failed to meet these noble ends, and that no legal instrument can liberate us from the human dilemmas of learning how to put ourselves in the hands of caregivers, and how to care for those who put their trust in us.[56]

Decades of experience demonstrate that AMDs are no panacea for the ethical dilemmas posed by end-of-life decision-making. Where available and reliable, they should be given their proper legal effect; to do otherwise is to erode the dignity of the patient. Yet, their inherent limitations should be more widely acknowledged, and, most important, the execution of an AMD should not be a substitute for proper advance care planning that arises primarily from the relationship between the patient and the physician or other HCP. In the long run, changing the focus in advance care planning from a "legal transaction" approach governed by a web of complex state statutes to one grounded

in the physician-patient relationship, communication, and consideration of the full context of the patient's condition—not merely the fact of terminal or debilitating illness—should be the goal. Approaches such as those advocated by the "Five Wishes" campaign offer an alternative to the "legal transaction" paradigm.[57] Those engaged in the quotidian task of advising and counseling their patients and clients have a pivotal role to play in lowering expectations regarding the efficacy of advance directives in solving broader healthcare issues, while ensuring that the directives executed by those patients and clients are reliable and effective statements of their genuine wishes for end of life care.

1 Steven A. Schroeder, "Personal Reflections on the High Cost of American Medical Care: Many Causes but Few Politically Sustainable Solutions," *Archives of Internal Medicine* 171, no. 8 (April 25, 2011): 722.

2 Mary E. Tinetti, "The Retreat from Advanced Care Planning," *Journal of the American Medical Association* 307, no. 9 (March 7, 2012): 915.

3 Charles P. Sabatino, "Advance Directives and Advance Care Planning: Legal and Policy Issues," U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy (October 2007), http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.pdf

4 Thaddeus Mason Pope and Melinda Hexum, "Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment," *Journal of Clinical Ethics* 23, no. 4 (2012): 353.

5 Dan K. Morhaim and Keshia M. Pollack, "End-of-Life Care Issues: A Personal, Economic, Public Policy and Public Health Crisis," *American Journal of Public Health* 103, no. 8 (June 2013).

6 Sabatino, "Advance Directives," 18-19; Lesley S. Castillo et al., "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care," *Annals of Internal Medicine* 154 (January 18, 2011): 121.

7 Eric Cohen and Leon R. Kass, "Cast Me Not Off in Old Age," *Commentary* 121, no. 1 (January 2006): 34-36.

8 Linda Emanuel et al., "Advance Directives for Medical Care: A Case for Greater Use," *New England Journal of Medicine* 324, no. 13 (March 28, 1991): 889; Linda Emanuel and Ezekiel Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document," *Journal of the American Medical Association* 261, no. 22 (June 9, 1989): 3288.

9 Pope and Hexum, "Legal Briefing," 353.

10 Robert S. Olick, *Taking Advance Directives Seriously* (Washington D.C.: Georgetown University Press, 2004), 80-82, 98-114.

11 Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (March-April, 2004): 30.

12 In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976).

13 See Alan D. Lieberson, *Advance Medical Directives* (Deerfield, IL: Clark Boardman Callaghan, 1992), 44-53.

14 Lieberson, *Advance Medical Directives*, 46.

15 See, e.g., In re Storar, 52 N.Y. 2d 363 (1981); In re O'Connor, 72 N.Y.2d 517 (1988); Estate of Longeway, 133 Ill2d 33 (1989).

16 *Cruzan v. Director,* Missouri Department of Health, 497 U.S. 261 (1990).

17 In *Cruzan*, for example, the case was eventually remanded to a Missouri probate court, which accepted as clear and convincing evidence of Nancy Cruzan's wishes the testimony of friends regarding a casual conversation about the use of LST on disabled children they cared for as teacher's aides. *Cruzan v. Mouton*, Estate No. CV384-9P (Circuit Ct., Jasper County, Mo., Probate Div.) (December 14, 1990). For discussion, see Edward R. Grant and Cathleen A. Cleaver, "A Line Less Reasonable: *Cruzan* and the Looming Debate over Active Euthanasia," *Maryland Journal of Contemporary Legal Issues* 2, no. 99, (1991) 147-153.

18 Sabatino, "Advance Directives," 2-3.

19 Lieberson, *Advance Medical Directives*, 278-322.

20 Sabatino, "Advance Directives," 12-13.

21 The National Hospice and Palliative Care Organization maintains an electronic library of all state advance directive forms as a resource for patients, families, and caregivers. http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289 (accessed September 3, 2013).

22 An example is the Uniform Health-Care Decisions Act (UHCDA), promulgated in 1993 by the National Conference of Commissioners on Uniform State Laws (ULC), a nonpartisan organization that promulgates proposed model legislation on a wide variety of legal issues. The ULC had previously issued the Uniform Rights of the Terminally Ill Act (1985), an effort to harmonize existing LW legislation. The problem, as noted by one of the authors of the UHCDA, is that states had already enacted their own LW and other advance directive legislation, and had little incentive to harmonize their laws with those of other states. David M. English, "The Uniform Health-Care Decisions Act and Its Progress in the States," *Probate and Property*, (May/June, 2001), http://www.americanbar.org/publications/probate_property_magazine_home/rppt_publications_magazine_2001_01mj_01mjenglish.html (accessed September 3, 2013).

23 Conn. Gen. Stat. §§ 19a-570. 575-577.

24 Mass. Gen. Law 201D §§ 1, 4.

25 See, e.g., Ore. Rev. Stat § 127.515(3).

26 Castillo, "Lost in Translation," 121, 123-124; See, e.g., Va. Code § 54.1-2983.

27 Id. Code § 39-4510.

28 Co. Rev. Stat. §§ 15-18-101, 104.

29 Miss. Code Ann. §§ 41-41-209.

30 The Virginia statute, for example, specifically provides "[n]othing in this article shall be construed to require a physician to prescribe or render health care to a patient that the physician determines to be medically or ethically inappropriate." Va. Code § 54.1-2990. A physician who objects to a request for particular treatment must inform the patient or appointed HCA of the objection and, if it cannot be resolved, make "reasonable effort" to transfer the patient to a physician who will comply. *Ibid*. See also Md. Code Health Gen. § 5-611; Fla. Stat. § 765.1108.

31 Castillo, "Lost in Translation," 125.

32 Fla. Stat. Ann. §§ 765.301 - 765.309.

33 The Ethics Program at the University of Miami maintains a useful compendium of materials regarding the Schiavo case, accessible at http://www.miami.edu/index.php/ethics/projects/schiavo (accessed September 5, 2013). The Supreme Court of Florida also maintains a website with links to all of its opinions in the matter, accessible at http://www.floridasupremecourt.org/pub_info/schiavo/index.shtml (accessed September 5, 2013).

34 42 U.S.C. § 1395cc(f)(1), (2).

35 Fagerlin and Schneider, "Enough," 32.

36 Sabatino, "Advance Directives," 11; American Bar Association, Commission on Law and Aging, "Default Surrogate Consent Statutes," (November 2009), http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/famcon_2009.authcheckdam.pdf (accessed September 3, 2013).

37 The charge was at least a malapropism, perhaps borne of confusion between section 1233's provisions for advance care planning and other provisions of the ACA, which survived to final enactment, creating the Independent Payment Advisory Board (IPAB). IPAB, a 15-member commission appointed by the President in consultation with Congressional leadership, is mandated to achieve cost savings in the Medicare program should the rate of growth in Medicare spending exceed specified limits. Despite provisions in the ACA stating that spending cuts should not affect Medicare coverage or the quality of care, critics have alleged that IPAB's decisions will result in rationing of health care. See David B. Rivkin, Jr., and Elizabeth P. Foley, "An ObamaCare Board Answerable to No One," *Wall Street Journal*, June 20, 2013, A21; Howard Dean, "The Affordable Care Act's Rate-Setting Won't Work," *Wall Street Journal*, July 29, 2013, A13; Peter R. Orszag, "The Critics Are Wrong about IPAB," *The Health Care Blog*, July 31, 2013, http://thehealthcareblog.com/blog/2013/07/31/the-critics-are-wrong-about-ipab/ (accessed September 3, 2013).

38 See Charles Lane, "Undue Influence," *Washington Post*, Aug. 8, 2009, http://articles.washingtonpost.com/2009-08-08/opinions/36869317_1_advance-directives-end-of-life-new-patients (accessed September 3, 2013).

39 Tinetti, "The Retreat from Advanced Care Planning," 2.

40 Morhaim and Pollock, "End-of-Life Care Issues," 5.

41 Fagerlin and Schneider, "Enough," 11.

42 Scott D. Halpern et al., "Default Options In Advance Care Directives Influence How Patients Set Goals for End-Of-Life Care," *Health Affairs* 32, (Feb. 2013): 408.

43 Pope and Hexum, "Legal Briefing," 343.

44 Susan E. Hickman et al., "The POLST (Physician Order for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation," *Journal of Law, Medicine & Ethics* 36, no. 1 (2008) 119.

45 This is based on the POLST form adopted by the California Emergency Medical Services Authority. http://www.emsa.ca.gov/pubs/pdf/

ApprovedPOLSTForm.pdf

46 Most states addressed this conflict in the 1990s through legislation or regulatory protocols permitted execution of and adherence to out-of-hospital do not resuscitate orders. Sabatino, "Advance Directives," 10.

47 Pope and Hexum, "Legal Briefing," 361.

48 *Ibid*., 363.

49 Bernard Lo and Robert Steinbrook contend that the legal formalities associated with AMDs place burdens on patients and physicians that complicate the process of advance care planning. See B. Lo and R. Steinbrook, "Resuscitating Advance Directives," *Archive of Internal Medicine* 164, no. 14 (July 26, 2004): 1501, 1502-04. See also Castillo, "Lost in Translation," 121-126.

50 Olick, *Taking Advance Directives Seriously*, 81.

51 Ibid., 104-108; Cf. Emanuel & Emanuel, "The Medical Directive," 3288-3293.

52 Attorneys in particular should be fully-versed in the common-law and related judicial pronouncements in their states (and in those in which their clients reside) as they may affect the ability to draft enforceable advance directives outside the statutorily-prescribed AMD forms.

53 Edmund D. Pellegrino and Daniel P. Sulmasy, "Medical Ethics," Section 2.3 in *Oxford Textbook of Medicine*, 4th ed., ed. David A. Warrell et al. (New York: Oxford University Press, 2003).

54 Robert Olick, a critic of applying informed consent standards designed for contemporaneous medical treatment decisions to the execution of AMDs, nonetheless acknowledges "the informed consent model is an important yardstick for much-needed efforts to improve the use of advance directives and to make advance care planning a standard component of the physician-patient relationship." Olick, *Taking Advance Directives Seriously*, 107.

55 Olick, for example, concedes that a "nonautonomous" directive may be overridden in favor of an assessment of a patient's current best interests. *Ibid*., 80-82, 113.

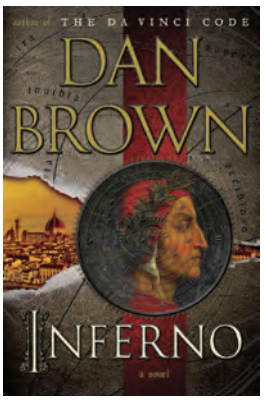
56 Eric Cohen and Leon Kass, "Old Age," *Commentary* 121, no. 4 (April 2006): 16.

57 The Five Wishes campaign is the product of Aging with Dignity, a non-profit founded by a former legal counsel to Mother Teresa of Calcutta. www.agingwithdignity.org

The promise and perils of advances in technology, science, and medicine have long been fodder for creative works in literature and cinema. Consequently, a variety of resources exist exploring the realm of medical humanities as well as those providing in-depth analysis of a given cultural medium or particular artifact. This column seeks to offer a more expansive listing of contemporary expressions of bioethical issues in the popular media (fiction, film, and television)—with minimal commentary—to encompass a wider spectrum of popular culture. It will be of value to educators and others for conversations in the classroom, over a cup of coffee, at a book club, or around the dinner table. Readers are cautioned that these resources represent a wide spectrum of genres and content, and thus may not be appropriate for all audiences. For more comprehensive databases of the various cultural media, please visit our website at cbhd.org/resources/reviews. If you have a suggestion for us to include in the future, send us a note at msleasman@cbhd.org.

BIO-FICTION

Dan Brown, ***Inferno*** (Doubleday, 2013). *Bioterrorism, Genetic Engineering/Gene Therapy, Population Control, Public Health, Transhumanism.*



In this latest installment, esteemed Harvard professor Robert Langdon finds himself in a life and death mystery in the streets of Florence to track down a rogue geneticist bent on releasing a bioterror attack as his final answer to the impending "population bomb," and inaugurate a transhuman future.

Veronica Roth, ***Divergent*** (Katherine Tegen Books, 2011). *Neuroethics.*

In this opening volume of the Divergent trilogy, Beatrice/Tris Prior faces a crucial decision during the annual right of passage. The choosing ceremony of a post-apocalyptic Chicago presents teens with a societal choice to live with one of five tribal factions that uphold a single virtue of humanity. Will she choose the selfless faction Abnegation of her family, or the brave protectors of society, the Dauntless? The choosing ceremony leads to an unexpected revelation. Beatrice/Tris is found to be divergent. But what does this mean? And, why is she able to control the neurostimulation of simulations and the fear landscape?

BIOETHICS AT THE BOX OFFICE

Bourne Legacy (2012, PG-13 for violence and action sequences). *Genetic Engineering/Gene Therapy, Human Enhancement, Military Ethics, Research Ethics.*

Man of Steel (2013, PG-13 for intense sequences of sci-fi violence, action and destruction, and for some language). *Designer Babies, Genetic Engineering, Reproductive Technology Ethics.*

The Intouchables (2011, R for language and some drug use). *Disability Ethics, Ethics of Care, Human Dignity.*

Robot & Frank (2012, PG-13 for some language). *Aging, Artificial Intelligence, Human-Machine Relations, Personhood, Robotics.*

TOP BIOETHICS NEWS STORIES: SEPTEMBER – NOVEMBER 2013

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

"NIH Program Explores the Use of Genomic Sequencing in Newborn Healthcare" *National Institutes of Health*, September 4, 2013

> Can sequencing of newborns' genomes provide useful medical information beyond what current newborn screening already provides? Pilot projects to examine this important question are being funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the National Human Genome Research Institute (NHGRI), both parts of the National Institutes of Health. (http://tinyurl.com/mwnc6yk)

In the U.S., newborns are typically screened for certain diseases such as phenylketonuria or cystic fibrosis. Genetic sequencing is only used to confirm screening results. The NIH is now considering using genetic sequencing as standard procedure for newborn care. However, with genetic sequencing come questions of privacy, consent, and the potential for genetic discrimination.

"Golden Rice Not So Golden for Tufts" by Martin Enserink, *Science Insider*, September 18, 2013

> A study in which Chinese children were fed a small amount of genetically modified rice violated university and U.S. federal rules on human research, according to a statement issued yesterday [September 17] by Tufts University in Boston, whose scientists led the study. Tufts has barred the principal investigator, Guangwen Tang, from doing human research for 2 years and will require her to undergo training in research on human subjects. (http://tinyurl.com/m3yzv72)

After a year-long investigation, Tufts University and outside investigators released a report on a controversial trial involving children from China and "golden rice." Golden rice is genetically modified to contain beta carotene, which increases vitamin A in the body. The study was to see if golden rice would counter vitamin A deficiencies in Chinese children. While the study goals were noble, the way that Tang and her team obtained consent from those involved in the study was deemed inappropriate.

"Stem Cells Made with Near-Perfect Efficiency" by Monya Baker, *Nature*, September 18, 2013

> Researchers have for the first time converted cultured skin cells into stem cells with near-perfect efficiency. By removing a single protein, called Mbd3, a team at the Weizmann Institute of Science in Rehovot, Israel, was able to increase the conversion rate to almost 100% — ten times that normally achieved. The discovery could clear the way for scientists to produce large volumes of stem cells on demand, hastening the development of new treatments. (http://tinyurl.com/m5vo7s3)

Shinya Yamanaka and John Gurdon shared the Nobel Prize in Physiology and Medicine for determining a process that converts a person's skin cells into induced pluripotent stem cells. However, this process was fairly inefficient. The results yielded a small percentage of induced pluripotent stem cells mixed in with skin cells. Scientists found that if they turn off a protein that effectively tells cells to stop being pluripotent, they can convert skin cells to induced pluripotent stem cells with approximately 100% efficiency.

"Health Exchanges Open for Business—with Glitches" by Christopher Weaver, Timothy W. Martin, and Louise Radnofsky, *The Wall Street Journal*, October 1, 2013

> The health-insurance marketplaces at the center of President Barack Obama's health law saw a surge of consumer interest Tuesday that surprised even many of the law's backers. But the debut proved patchy, with few applicants actually able to buy coverage on clogged websites that were bedeviled with technological problems. (http://tinyurl.com/knpkpjg)

Among the top bioethics news items for this quarter, the highest profile news item was the launch of the government's healthcare exchange web site. Its anticlimactic launch continues to make headlines due to glitches, controversy, and misunderstandings over who is eligible for subsidized coverage. Currently, the Obama administration is considering a bill that will allow people to stay on their current insurance plan for another year.

"Silk Road Closure Will Be 'Devastating' for Australians Trying to Buy Nembutal" by Australian Associated Press, *The Guardian*, October 4, 2013.

> The closure by US authorities of the black market Silk Road website will have a devastating effect on some elderly Australians, says the euthanasia advocate Dr Philip Nitschke. They were using the site to source reliable quantities of the "premier" end-of-life drug Nembutal, Nitschke, director of Exit International, said on Friday. (http://tinyurl.com/mpzkz85)

The Silk Road made headlines for eluding the authorities and for re-launching after the owner was arrested. The Silk Road was a repository for black market drugs, hit men, and other nefarious items. Importantly, this was where many people wanting to end their life would

obtain black market drugs such as Nembutal with complete anonymity.

"IVF Babies 'Are a Third More Likely to Develop Childhood Cancer'" by Nick McDermott, *The Daily Mail*, October 4, 2013

> Scientists said those born after fertility treatments were 33 per cent more likely to have childhood cancer. They were 65 per cent more likely to develop leukaemia and 88 per cent more likely to develop cancers of the brain and central nervous system. The study suggests fertility treatment may change the way certain genes function when they are passed from parent to child in a process known as 'genomic imprinting'. These faults in genes are linked to childhood cancers, the Danish researchers said. (http://tinyurl.com/nkbnep4)

"No Excess Cancer in IVF Babies" by Chris Kaiser, *Med Page Today*, November 6, 2013

> Overall, assisted reproduction was not associated with an increased risk of leukemia, neuroblastoma, retinoblastoma, central nervous system tumors, or renal or germ-cell tumors, according to the study published online Nov. 6 in the New England Journal of Medicine. (http://tinyurl.com/kg9v25y)

A Danish study on the link between childhood cancer and assisted reproductive technology found that children born after fertility treatments were 33% more likely to get cancer, while a large-scale British study showed little-to-no correlation between children born after fertility treatments and incidence of childhood cancer.

"FDA Considers Three-Parent IVF" by Jef Akst, *The Scientist*, October 17, 2013

> To prevent the passage of mitochondrial disorders from mother to child, researchers have devised a clever solution: take the nucleus of a woman carrying harmful mutations in her mitochondrial DNA and transfer it to an enucleated egg of another woman without such defects. The hybrid egg, which carries the nuclear DNA of the mother-to-be and healthy mitochondria from the egg donor, can then be fertilized in vitro with sperm from the would-be father, and the resulting embryos implanted into mom. (http://tinyurl.com/kgdfpm5)

Despite numerous ethical and safety considerations, three-parent IVF has been approved in Britain and, as of October, the FDA is considering whether to approve it for the U.S. Mitochondrial disease is passed down from the mother to her children because all mitochondrial DNA is passed down through the mother. This technique, while called "three-parent" IVF, involves producing a child whose DNA would be predominately comprised of the intended mother and father with a small percentage of the child's DNA from the mitochondria of an egg donor.

"In Syria, Doctors Risk Life and Juggle Ethics" by Sheryl Gay Stolberg and Anne Bernard, *The New York Times*, October 21, 2013

> . . . Syria's civil war has been especially dangerous for health professionals; a United Nations report issued last month described the "deliberate targeting of hospitals, medical personnel and transports" as "one of the most alarming features of the Syrian conflict." By varying estimates, more than 100 doctors have been killed and as many as 600 have been imprisoned. (http://tinyurl.com/lnlhcwm)

The World Health Organization reports that Syria's health system is in complete disarray. Many of the hospitals have been damaged or are no longer functioning. People require basic health needs including vaccinations and insulin. Additionally, doctors must treat people who have been injured from chemical warfare. The humanitarian group, Doctors without Borders, has had to navigate disclosing sensitive information to authorities.

"WHO Responding to Health Needs Caused by Typhoon Haiyan ("Yolanda")" News Release, *World Health Organization*, November 11, 2013

> The typhoon – locally known as Yolanda – ravaged the central part of the archipelago Friday morning [November 8] with winds reaching speeds of more than 250 km per hour causing storm surges of up to 5 metres. Many people living in these affected areas were injured and the devastating effects of this typhoon left already vulnerable health facilities damaged or completely destroyed. As a result of the breadth and severity of the storm, health services in the worst affected areas no longer exist or are severely stretched, with medical supplies in very short supply. (http://tinyurl.com/lolmzwa)

An important area of bioethics is the special circumstances surrounding natural disasters. In these cases, triage and resource management become key factors in determining the best way to provide medical attention to those in need. This November, the Philippines was devastated by a massive typhoon, which killed thousands of people and destroyed entire towns.

"Condemned Man's Request to Donate Organs Raises Troubling Ethical, Medical Questions in Ohio" by Julie Carr Smyth and Amanda Lee Myers *Associated Press*, November 14, 2013

> An eleventh-hour request by an Ohio death row inmate to donate his organs is raising troubling moral and medical questions among transplant experts and ethicists. (http://tinyurl.com/mt33pld)

Ronald Phillips is a convicted murderer in Ohio who wants to donate a kidney to his mother and after his execution, donate his heart to his sister. It is not unheard of for an inmate to donate a non-vital organ, such as a kidney or bone marrow. However, ethicists are concerned over the precedent it would set if inmates are allowed to donate vital organs, and they question whether someone on death row can freely give consent.

EVENTS

Academy of Fellows Consultation

CBHD hosted the third consultation for our Academy of Fellows. This year's topic "Justice and Bioethics: Towards a Christian Understanding" brought together biblical scholars and theologians to dialogue with our Fellows to explore the unique perspectives of justice that emerge from Old and New Testament studies and the theological traditions. Speakers included: Willem VanGemeren, PhD; Constable Campbell, PhD; and Vince Bacote, PhD; as well as presentations by CBHD fellows Dennis Hollinger, PhD and Bart Cusveller, PhD. The event was live-streamed and will be available online in the near future.

Her Dignity Network Webinar

In early November, the Center hosted our first webinar featuring an interview with CBHD Fellow Mary Adam, MD. The online event was hosted by Jennifer McVey and Paige Cunningham. Dr. Adam answered questions on the topic of "Reducing Maternal Mortality While Increasing Infant Survival: A Case Study from Kenya," based on her work with Equipping Africa as part of a maternal and newborn community health project in Nairobi, Kenya. The webinar and additional information about Equipping Africa are available on **HerDignity.net.**

MEDIA RESOURCES

CBHD.org on Twitter: @bioethicscenter

Bioethics.com on Twitter: @bioethicsdotcom

The Bioethics Podcast at thebioethicspodcast.com

Facebook Cause at causes.com/cbhd

Facebook Page at facebook.com/bioethicscenter

Linked-In Group at linkd.in/thecbhd

YouTube at youtube.com/bioethicscenter

The Christian BioWiki christianbiowiki.org

STAFF

PAIGE CUNNINGHAM, JD

- Attended the Christian Legal Society National Conference in October.
- Along with Jennifer McVey, spoke to the combined women's groups of The Orchard church, on the theme of "Beyond Perfect: Lessons from the Tower of Babel."

MICHAEL SLEASMAN, PHD

- Interviewed for Moody Radio *Midday Connections*' "Bring to Mind" podcast in September revisiting the Christian life of the mind and engaging technology. The episode aired in October, marking the first anniversary episode from the inaugural episode featuring Michael in October 2012.
- Attended the American Society for Bioethics and Humanities annual meeting in October.

JENNIFER MCVEY, MDIV

- In early November spoke with Paige at The Orchard Church's women's group on the topic of Beyond Perfect.

HEATHER ZEIGER, MS, MA

- Since late August, Heather has been contributing a new series of essays to our Bioethics.com news blog. These essays unpack some of the scientific and medical background, as well as the ethical issues involved in understanding recent articles in the news. Topics have included molecular robots, stem cell hamburgers, efficient iPS cells, genetics, and mitochondrial replacement and reproductive technology.
- Published "Playing God? The 3-D Printing Revolution Is Here. Should We Be Concerned about How Far It Will Go?" in the November/December 2013 issue of *Relevant*. The piece featured interviews with Michael Sleasman and Nigel

ON THE CBHD BOOKSHELF

ARTICLES OF NOTE: **For those interested in knowing what books and articles the Center staff have been reading and thought worth highlighting. **Note that the resource includes material by members of the Center's Academy of Fellows.**

Asch, David, Sean Nicholson, and Marko Vujcic. "Are We in a Medical Education Bubble Market?" *New England Journal of Medicine* 369, no. 21 (2013):1973-1975.

Bernat, James. "Life or Death for the Dead-Donor Rule?" *New England Journal of Medicine* 369, no. 14 (2013): 1289-1291.

Bettigole, Cheryl. "The Thousand-Dollar Pap Smear." *New England Journal of Medicine* 369, no.16 (2013): 1486-1487.

Bohannon, John. "Who's Afraid of Peer Review?" *Science* 342, no. 6154 (2013): 60-65.

Dudzinksi, Denise, Rosamond Rhodes, and Autumn Fiester. "Pedagogical Goals for Academic Bioethics Programs." *Cambridge Quarterly of Healthcare Ethics* 22, no. 3 (2013): 284-296.

Feudtner, Chris, Mark Schreiner, and John Lantos. "Risks (and Benefits) in Comparative Effectiveness Research Trials." *New England Journal of Medicine* 369, no. 10 (2013): 892-894.

Hamburger, Philip. "The Censorship You've Never Heard Of." *Commentary* 136, no. 1 (2013): 21-26.

Herzfeld, Noreen. "Outsourced Memory: Computers and Conversation." *Perspectives on Science and Christian Faith* 65, no. 3 (2013): 179-186.

Hütter, Reinhard. "Polytechnic Utiliversity." *First Things* 237 (November 2013): 47-52.

Kipnis, Kenneth. "Disasters, Catastrophes, and Worse." *Cambridge Quarterly of Healthcare Ethics* 22, no. 3 (2013): 297-307.

Khushf, George. "A Framework for Understanding Medical Epistemologies." *Journal of Medicine and Philosophy* 38, no. 5 (2013): 461-486.

Ladin, Keren, and Douglas Hanto. "Rationing Lung Transplants – Procedural Fairness in Allocation and Appeals." *New England Journal of Medicine* 369, no. 7 (2013): 599-601.

**Meilaender, Gilbert. "Works and Righteousness." *First Things* 237 (November 2013): 41-46.

Paasche-Orlow, et al. "Readability of Consent Form Templates: A Second Look." *IRB: Ethics & Human Research* 35, no. 4 (2013):12-19.

COMING SOON: 2013 ANNUAL REPORT