Futile-Care Theory in Practice

A Look at the Law in Texas

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Abstract. Examination of the bioethical concept of futile-care theory reveals its deleterious effects on patients when put into practice. Futile-care policies and laws unilaterally locate health care decision making in persons and committees other than the patient and his surrogate(s). Although not voluntarily ceded by the patient, this authority is assumed by third parties whose interests and goals do not contribute to the material and spiritual flourishing of the individual patient. A prime example is the Texas medical futility law, which blatantly disregards the natural right of patients to decide the course of their own health care. Christians are called on to oppose this unprecedented assault on human dignity, freedom, and life itself. *National Catholic Bioethics Quarterly* 14.4 (Winter 2014): 619–624.

Throughout most of Western history, medical ethics has been based on Judeo-Christian principles, which enshrine sanctity of life as paramount. Preservation of life has been the unquestioned guide for medical treatment. The patient's inherent worth has been recognized and respected regardless of physical or mental condition, age, or functional status. Medical diagnosis and the means necessary to restore health and preserve life are determined by a thorough history, physical examination, and appropriate tests. A plan of care is tailored, then, to the needs of the individual patient.

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An authentic doctor–patient relationship is collaborative, consisting of shared decision making. This ideal model serves their mutual dignity and respects the sanctity of life. Unilateral decision making by physicians or other impersonal third parties does not. The Charter for Health Care Workers is clear about this and emphasizes that "to intervene medically, the health care worker should have the express or tacit consent of the patient. … Without such authorization he gives himself an arbitrary power."[1] Cited in an endnote is the Pontifical Council *Cor Unum*'s "Questions of Ethics regarding the Fatally Ill and the Dying": "The patient cannot be the object of decisions which he will not make, or, if he is not able to do so, which he could not approve. The 'person,' principally responsible for his own life, should be the center of any assisting intervention: others are there to help him, not to replace him."[2]

Bioethics, which emerged in the 1960s, has evolved beyond Judeo-Christian values to embrace postmodern secular and utilitarian philosophies.[3] Treatment decisions often are guided by third-party assessments of the patient's quality of life based on his mental or physical condition, age, functional abilities, and potential societal contributions. These utilitarian calculations contradict the "inalienable right to life of every innocent human individual," which the *Catechism of the Catholic Church* reminds us is a "constitutive element of a civil society and its legislation" (n. 2273).

Futile Care: A Bioethical Theory

Bioethicists, with some notable exceptions, have pushed futile-care theory for over twenty years. The theory proposes, *When a patient reaches a certain stage of illness, injury, disability or age, life-sustaining treatment, including food and fluids, may be withheld or withdrawn on the basis of the physician's perception of the patient's quality of life, regardless of the patient's or family's wishes.* Many hospitals have adopted such futile-care policies.[4]

The shift from the "sanctity of life" to the "quality of life" as the core principle of medical ethics has been gradual and nuanced, under the veil of "dignity." Too few seem aware of it. Medical futility decisions assault human dignity. Patients are commodified as objects that lack value. Through the lens of futile-care theory, it is

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[1] Pontifical Council for Pastoral Assistance to Health Care Workers, *Charter for Health Care Workers* (Vatican City: Libreria Editrice Vaticana, 1995), n. 72.

[2] Pontifical Council *Cor Unum*, "Questions of Ethics regarding the Fatally Ill and the Dying" (June 27, 1981), cited in note 156 of the Charter; the *Cor Unum* document has been reprinted in *Conserving Human Life*, ed. Russell E. Smith (Braintree, MA: Pope John XXIII Medical-Moral Research and Education Center, 1989), 286–304. See also Pius XII, "The Prolongation of Life," Address to an International Congress of Anesthesiologists (November 24, 1957), which is cited in note 155 of the Charter; the address has been reprinted in *National Catholic Bioethics Quarterly* 9.2 (Summer 2009): 327–332.

[3] Edmund D. Pellegrino, "The Origins and Evolution of Bioethics: Some Personal Reflections," *Kennedy Institute of Ethics Journal* 9.1 (March 1999): 73–88.

[4] Jeffrey P. Burns and Robert D. Truog, "Futility: A Concept in Evolution," *CHEST Journal* 132.6 (December 2007):1987–1993.

the patient who is considered "useless," not the particular treatment. This approach stands in contrast to the practice of those well-meaning doctors who legitimately determine when treatment is not effective and is therefore truly futile in the medical sense. Such decisions are obviously appropriate and sometimes necessary.

A national dialogue on this profound utilitarian shift, and on the concept of futile care, is needed to avert the infliction of grave injustice on sick and suffering patients. When patients are already under siege from illness, it is particularly iniquitous that they should be assaulted anew by unethical policies that strip them of their Christian autonomy, that is, the right to make their own health care decisions based on Christian principles and in virtuous imitation of Christ.[5]

Both state law and federal law require a medical facility to give patients written notice of any procedure it is unwilling or unable to provide or withhold in accordance with an advance directive.[6] These laws should incorporate notification of a facility's futile-care policy.

Many states have enacted laws establishing procedures for hospitals to follow in rendering futile-care decisions.[7] These laws shield physicians and hospitals from "wrongful death" lawsuits and criminal liability for causing patients' deaths but contain little or no protection for at-risk patients. In our opinion, based on extensive research and experience, the state with the worst futile-care law is Texas. This should be cause for grave concern, not only for Texans but for all Americans. Rev. Peter Clark, SJ, writing for the American Medical Association, stated in 2007, "The Texas law became a model for other states and for individual hospitals seeking to make changes in statutory regulations and institutional policies regarding end-of-life treatment decisions."[8]

Texas Medical Futility Law

In 1999, the Texas Advance Directives Act was amended (§ 166.046 of the Texas Health and Safety Code) to enable doctors and hospitals to withhold or withdraw "life-sustaining treatment"[9] from patients *even against their expressed directives*.

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[5] For Christian autonomy to be fully operative, patient virtue is essential. See Ralph A. Capone, "Moral Refusals of Limited Resources," *Ethics & Medics* 39.9 (September 2014).

[6] For a state law, see Texas Health and Safety Code § 166.004 (Acts 1999); and for a federal regulation, see Provider Agreements and Supplier Approval, 42 C.F.R. § 489.102 (2006).

[7] See Thaddeus Mason Pope, "Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment," *Tennessee Law Review* 75.1 (Fall 2007).

[8] Peter A. Clark, "Medical Futility: Legal and Ethical Analysis," *Virtual Mentor* 9.5 (May 2007): 375–383.

[9] "'Life-sustaining treatment' means treatment that, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificial nutrition and hydration." Texas Health and Safety Code § 166.002, Definitions, n. 10.

Federal law requires hospitals (and other medical facilities and programs) to inform patients of their right to execute an advance directive in order to ensure that their treatment wishes will be known and honored in the event they become incapacitated.[10] Furthermore, the Texas Advance Directives Act's form of written directive was "designed to help you [the patient] communicate your wishes about medical treatment" (§ 166.033) and, in regard to the medical power of attorney, the law stipulates, "treatment cannot be given to you or stopped over your objection" (§ 166.163). Yet § 166.046 empowers physicians to override patients' wishes, thereby contradicting and nullifying these earlier patient protections.

The medical futility section of the Texas Advance Directives Act states, "If an attending physician refuses to honor a patient's advance directive or a health care or treatment decision made by or on behalf of a patient, the physician's refusal shall be reviewed by an ethics or medical committee" (§ 166.046). (Appointed by the hospital, this committee's impartiality is highly questionable.) Further, the patient or patient's decision maker (usually family) "shall be informed of the committee review process not less than 48 hours before the meeting called to discuss the patient's directive." Patient advocates in attendance have described the proceedings to us. Physicians and other hospital personnel present a list of reasons to "justify" their planned treatment withdrawal, and the family is asked if they have questions.

The underlying flaw in this process is that it ignores the patient as a person with a story and a desire to live. Rather, the patient is conceived of as a consumer of health care resources. This way of dehumanizing patients extinguishes empathy. As "consumer," the patient is "guilty" (of resource wasting) and the family is given scant opportunity to prove otherwise. The process simply reaffirms the hospital's assessment of the patient's utilization of health care resources. Thus, adversarial medical "experts" advocate for the cessation of treatment against the patient's family and/or friends who desire treatment to continue and who are, most likely, not professionals and are generally ill-equipped to defend their position. The committee follows with a written notice of its decision that life-sustaining treatment is "inappropriate."

Receipt of this notice marks the start of a ten-day countdown. "The physician and the health care facility," states the law, "are not obligated to provide life-sustaining treatment after the 10th day after the written decision." Finding another facility that will honor the patient's directive and transferring the patient—at the expense of the patient and/or family—are monumental tasks which often prove impossible within the ten-day window.

An Unethical Assault on Life and Freedom

If a patient's death is deemed imminent by treating physicians and natural death is expected before the end of the twelve days, the process would be unnecessary. Thus, medical-futility decisions are reserved for those expected to live longer, perhaps for extended periods. Once rendered, futility determinations effectively force hospital

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[10] Patient Self-Determination Act, Pub. L. 101-508, §§ 4206 and 4751, codified at 42 USC §§ 1395 et seq. (1994).

exit for these patients either by transfer or imposed death. For patients and families, any justification for medical-futility decisions is irrelevant; what matters is life itself, which is ever more precious when facing one's death.

The law shields doctors and hospitals from liability for refusing to provide desired life-sustaining treatment, including food and fluids. The wishes of patients who desire to live should be honored whenever possible. The Pro-life Healthcare Alliance summarizes the following case, which was reported by Texas Right to Life:

> In March 2012, a family called Texas Right to Life pleading for help to save their father Willie's life. Willie went to a Houston hospital complaining of chest pains. The diagnosis was pneumonia and, shockingly, leukemia. Surgery and chemotherapy were suggested. Before being sedated, Willie looked into his daughter's eyes and said, "Fight for me, baby. I ain't done living."
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> Armed with Willie's medical power of attorney, his family told doctors to continue treatment. The doctors decided otherwise. The hospital ethics committee met and told the family to move Willie out of their hospital within 10 days or treatment would cease.
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> Willie's family could pay for his transfer to another facility, and he also had ample health insurance. A hospital social worker told them she would try to find another facility. As the 10-day deadline approached, she told them no facility would accept Willie and she could do nothing more. Too late, they realized that the social worker had painted a picture of a patient no hospital wants, one whose quality of life was gone, with no hope of recovery.
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> Finally, this desperate family turned to Texas Right to Life. The CEO of a hospital with a religious-sounding name was contacted, but refused to take Willie. A team of pro-life people contacted many attorneys to take the case and asked politicians to pull strings to save Willie's life. All were happy to try to help, but neither the law nor time was on their side.
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> Willie's family watched helplessly as, one by one, each treatment was stopped. He wasn't fed or given water. In a couple of days, Willie was dead.[11]

Transfers of critically ill patients do occur, but the ten-day deadline presents obstacles. Finding an appropriate facility takes time, as do resolving insurance and payment issues and arranging details. Sometimes another facility will accept a patient on certain conditions, for example, once the transferring hospital inserts a feeding tube, weans the patient from a ventilator, or provides "swallow therapy" so the patient can be fed orally. However, to fulfill these conditions often takes longer than ten days. Eliminating this deadline by requiring treatment-until-transfer would incentivize the hospital to stabilize and improve the patient's condition in order to facilitate their transfer. This would also be in the patient's best interest, providing every opportunity for him to recover and/or become eligible for admission to multiple care settings.

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[11] "Impacts of 'Futile Care Theory' in Texas: Willie," Pro-life Healthcare Alliance, accessed October 22, 2014, http://www.prolifehealthcare.org/CaseInPoint.html, summarizing Elizabeth Graham, "Houston Hospital Withdraws Treatment from Patient Against Family's Wishes," Texas Right to Life, March 20, 2012, http://www.texasrighttolife.com/a/860/Houston-hospital-starving-and-dehydrating-patient-against-familys-wishes#.VEf2S2ddXmc.

Most importantly, given proper treatment over time, the patient may disprove the experts' "medical futility" judgment, as happened in the following case:

> In 2012, twelve-year-old Zachary suffered a gunshot wound to the head. Within 48 hours of arriving at Cook's Children's Medical Center in Fort Worth, Texas, the medical staff's conversation focused on the quality of his life instead of the medical care that would foster healing and recovery. Even though Zachary was seriously injured, his brain stem was not harmed. A week after his injury, the hospital ethics committee began the medical futility process. Zachary's parents pleaded for the hospital to give him more time to recover. But, on the very day Zachary began to breathe on his own, the attending physician withdrew his food and water. Fortunately, the ten-day countdown was stopped when a patient advocate (called in by Zachary's mother) pointed out to the hospital's attorney that they had not followed the law and therefore would not be immune from liability.
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> After being transferred to Children's Medical Center in Dallas, where he received treatment and reconstructive surgery, and then to a rehabilitation facility, Zachary regained his ability to speak, see, and walk, and his full cognitive abilities.[12]

Futility, Irony, and Warning

Currently, prisoners on death row enjoy more legal rights and protections than patients in Texas hospitals. A prisoner has a jury of peers and a lengthy appeals process. A patient handed a medical-futility decision is deprived of these basic civil liberties. There is no appeal. The law does not even allow courts to examine the medical evidence or reverse what may be an imposed death sentence. If a transfer cannot be accomplished within ten days, the patient's or surrogates' only hope is that a court will grant them a time extension. The law allows this *only* if they can demonstrate "by a preponderance of the evidence, that there is a reasonable expectation that a physician or health care facility that will honor the patient's directive will be found if the time extension is granted" (§ 166.046).

In a previous era, § 166.046 of the Texas Health and Safety Code would have been widely viewed as an unethical assault on human life and freedom. The central pillar of Judeo-Christian ethics—the inviolable and inalienable right to life—is being replaced by utilitarian calculations that devalue certain lives based on a nebulous concept of the common good. This new tyranny must be opposed by all persons of good will. If it were not that actions once understood as inimical to the good of individual persons have been enshrined into law, this appeal would be unnecessary.

A liberal society cannot let stand legislation abetting doctors, hospitals, and administrators to make unilateral treatment decisions, especially when doing so is an attack on innocent human life. This law turns physicians into adversaries of those they once vowed to heal and comfort. As Christians, we are bound in charity and fidelity to serve others by opposing this ever-expanding assault on the sanctity and dignity of human life.

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[12] John Seago (patient advocate, Texas Right to Life), in discussion with Julie Grimstad, August 12, 2014.