Futile Care: Why Illinois Law Should Mirror the Texas Advanced Directives Act

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I. INTRODUCTION

Futile care is medical care that will not improve the patient’s condition, and it is frequently provided in the United States.¹ These unnecessary procedures increase spending, waste scarce healthcare resources, and fail to meaningfully improve patients’ medical conditions.² The futile care problem is growing due to technological developments that can effectively prolong life for years, or even decades, without regards to the quality of life.³ Currently, in Illinois, physicians can only refuse to provide services if they object based on deeply held moral convictions that typically stem from a religious belief.⁴ This limitation prevents physicians from being able to exercise their professional judgment and refuse treatments they believe violate their ethical responsibilities as physicians.⁵ This problem needs to be ad-

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3. Robert D. Truog, Medical Futility, 25 Ga. St. U. L. Rev. 985, 986 (2009) (“As technology has become increasingly effective at prolonging life, the dark side of this success has emerged in the demands of families to use this technology to sustain life in situations that offer at best no hope of meaningful existence . . . .”); Kasman, supra note 2, at 1056 (“Modern medicine has made it feasible to support human life for an indeterminate period.”).


5. 22 ILL. PRAC., THE LAW OF MEDICAL PRACTICE IN ILLINOIS § 32:12 (3d ed.) (“This definition arguably limits the scope of the Act to decisions based on religious or closely
dressed on a legislative level so that a physician can refuse to provide a futile service on ethical grounds. In Part II this article explains what constitutes futile care. In Part III this article outlines the main arguments of those who oppose providing futile care and discusses the shortcomings of the argument that physicians are required to provide futile services if the patient wishes. Part IV of this article discusses how futile care negatively impacts healthcare systems. Finally, Part V of this article explains why Illinois should change its legislation to reduce futile care by mirroring the Texas Advanced Directive Law.

II. WHAT IS FUTILE CARE?

Deciding when to stop medical treatment, like any end of life decision, is fraught with intense and often overwhelming emotions. This difficulty is exacerbated by the fact that there is no bright-line test for determining when care is futile. The literal definition of futile care is that which serves no useful purpose. Given the complexities involved in making healthcare decisions, determining when care is futile is no small task. One of the most analogous beliefs, as opposed to professional ethical judgments.”); Having to provide futile care contradicts a widely accepted version of the current Hippocratic Oath requires physicians to avoid overtreatment. "Louis Lasagna, Hippocratic Oath (Modern Version) (1964), available at http://guides.library.jhu.edu/content.php?pid=23699&sid=190964.

6. Truog, supra note 3 at 990 (“If a treatment is futile, it is not worth doing . . . “); Thaddeus Mason Pope, Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment, 75 TENN. L. REV. 1, 2 (2007) (“Therefore, while the specific contours of TADA must be refined, policymakers in other states should look to the TADA as a model.”).


8. See Kasman, supra note 2, at 1054; Maureen Kwiecinski, To Be or Not to Be, Should Doctors Decide? Ethical and Legal Aspects of Medical Futility Policies, 7 MARQ. ELDER’S ADVISOR 313, 3332 (2006); Mary S. McCabe & Courtney Storm, When Doctors and Patients Disagree About Medical Futility, 4 J. OF ONCOLOGY PRAC. 207, 207 (2008).


10. See TL Beauchamp, Methods and Principles in Biomedical Ethics, 29 J. Med. Ethics 269, 270 (2003); see Kwiecinski, supra note 8, at 233 (discussing how medical decisions are value-laden and can be based on personal beliefs and values.)
accepted definitions of futile care is a clinical action that does not serve a useful purpose in achieving a patient’s specific goal. Futile care could be an additional round of chemotherapy, keeping a patient on life-support, or using feeding tubes. The relationship between the care being provided and the patient’s goals is fact-specific, and it requires open communication between physicians and a patient or his proxy, if the patient is unable to communicate their desires.

While it is difficult to concretely define futile care it is imperative to understand that all end-of-life care is not futile. For example, futile care is not palliative care. Palliative care strives to reduce a patient’s suffering through the assessment and treatment of their pain. Futile care will not achieve the patient’s desired goal or improve the patient’s prognosis, and therefore will not ultimately ease his suffering. This care differs from palliative care, where the goal is not to treat the underlying condition or pro-

13. Opinion 8.081 – Surrogate Decision Making, Am. Med. Assn (2001), https://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion8081.page (Stating that a proxy, or surrogate decision maker, is an individual who makes health care decisions when the patient is unable to make their own decisions.). Throughout this article proxies will be inferred whenever patients or patients’ rights are discussed.
15. See generally John M. Luce & Ann Alpers, Legal Aspects of Withholding and Withdrawing Life Support from Critically Ill Patients in the United States and Providing Palliative Care to Them, 163, AM. J. OF RESPIRATORY & CRITICAL CARE MED. 2029 (2001) (Discussing what constitutes palliative care.).
16. Id.
17. WHO Definition of Palliative Care, World Health Org., http://www.who.int/cancer/palliative/definition/en/ (last visited May 2, 2014); See Luce & Alpers, supra note 15 at 2031(Discussing how providing comfort is the goal of palliative care.).
18. Kwiecinski, supra note 8, at 324.
long life, but to provide comfort and relief. Treatment that provides the patient with comfort and helps them maintain their dignity during their final stages of life is not futile and should not be withheld.

III. THE FUTILE CARE DEBATE

There are four bioethical principles that are generally accepted when analyzing medical situations, such as the use of futile care: respect for autonomy, beneficence, nonmaleficence, and justice. Autonomy refers to the patient’s right to make his own healthcare decisions. Supporters of providing futile treatments think that the decision to end treatment should lie entirely with the patient. These individuals believe that patients are in the best positions to understand the value of a treatment and that allowing physicians to refuse to provide futile care is unacceptable medical paternalism. This logic is flawed and opponents of providing futile care recognize that autonomy applies to physicians as well as patients. Accordingly, respecting patient autonomy refers to respecting a patient’s decision to refuse treatment and does not extend to requiring physicians to provide unnecessary treatment based on the patient’s demands, as this violates the physi-

19. See WORLD HEALTH ORG., supra note 17.
20. Harvey Max Chochinov, Dignity-Conserving Care — A New Model for Palliative Care, 287 JAMA 2253, 2253 (2002) ("The Basic tenets of palliative care can be summarized as the goal of helping patients to die with dignity."); Ash & Arons, supra note 2, at 307.
22. Kwiecinski, supra note 8, at 337 (quoting Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891). “No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person”).
23. Id.
24. Raanan Gillon, Paternalism and Medical Ethics, 290 BRIT. MED. J. 1971, 1971 (1985) (Explaining that medical paternalism is the belief that sometimes a physician must do what they believe is best even if their belief conflicts with their patient’s wishes.).
25. Mary Ann Baily, Futility, Autonomy, and Cost in End-of-Life Care, 39 J.L. MED. & ETHICS 172, 173 (2011) ("Other people deserve to have their autonomy respected also, and to make their own decisions about what they will or will not do.").
The second principle, beneficence, requires physicians to promote the well-being of their patients. The beneficence argument used by proponents of letting patients demand futile treatment is closely linked to their autonomy argument. Supporters of futile care rely heavily on how fact-specific the determination of what constitutes futility is for the individual patient. This argument is incorrect; when a physician provides services that do not meaningfully benefit a patient’s condition, he is not acting in a patient’s best interest. Further, while determining what is futile is a fact-specific inquiry, physicians can discuss desired goals with their patients and use that information in addition to their medical expertise to determine if a specific treatment is futile. The combination of specialized knowledge and experiences place physicians in the best position to determine if a treatment is futile, and that decision should be respected.

The third bioethical principle is nonmaleficence. Nonmaleficence is a complementary imperative to beneficence. Beneficence imposes a positive duty on physicians to act in a patient’s best interest while nonmaleficen-
cence imposes a duty on physicians to avoid causing unnecessary harm.\textsuperscript{34} Determining what constitutes nonmaleficence is particularly challenging in futile care cases because physicians can have difficulty assessing whether or not a patient will view treatment as beneficial.\textsuperscript{35} Despite this difficulty, there are still situations in which physicians adamantly believe that certain treatments or procedures will only create pain and prolong inevitable death.\textsuperscript{36} In such situations, it is a violation of a physician’s ethical duty to do no harm if he continues to provide care that does not further any legitimate medical benefit to the patient.\textsuperscript{37} These situations illustrate why it is wrong to require physicians to provide futile treatments against their best judgment, and why the law in Illinois should be amended so that physicians can refuse to provide futile treatments based on ethical objections.

The final bioethical principle to consider when analyzing medical situations is justice.\textsuperscript{38} Justice refers to the appropriate allocation of scarce resources and the obligation to fairly distribute these resources.\textsuperscript{39} The question of justice is particularly relevant considering the limited healthcare resources available and the key role physicians play in limiting unnecessary spending.\textsuperscript{40} For example, families caring for patients in a vegetative state frequently run out of money, at which point Medicaid starts covering the

\textsuperscript{34} Id.

\textsuperscript{35} See Sonia Frick et al., Medical Futility: Predicting Outcome of Intensive Care Unit Patients by Nurses and Doctors—A Prospective Comparative Study, 31 CRIT. CARE MED. 456, 460 (2003).

\textsuperscript{36} Eugene Cauvin, The Toll of Prolonging Life, (Mar. 12, 2010), available at http://healthcarecostmonitor.thehastingscenter.org/eugenecauvin/the-toll-of-prolonging-life/ (“I wish to go on record as saying that many patients at the end of life whose families opt for inappropriate life-sustaining treatments are subjecting them to an indignity and suffering akin to being tortured.”).

\textsuperscript{37} Id.

\textsuperscript{38} Kwiecinski, supra note 8, at 334.

\textsuperscript{39} See Beauchamp, supra note 10, at 269 (discussing how justice is the “obligation of fairness in the distribution of benefits and risks.”).

\textsuperscript{40} Kwiecinski, supra note 8, at 334; Cauvin, supra note 36; Maxwell J. Mehlman, The Patient-Physician Relationship in an Era of Scarce Resources: Is There A Duty to Treat?, 25 CONN. L. REV. 349, 350-51 (1993) (“If costs are to be controlled, it is generally recognized that physicians must be induced to change their practice patterns.”).
Further, when a physician is providing futile services they are spending valuable time that could be spent with patients who may survive. These wasteful uses of limited resources violate the bioethical principle of justice.

IV. THE CONSIDERABLE COSTS OF FUTILE CARE

Futile care is especially prevalent when patients are in intensive care units (ICUs), in their final months of life, or in persistent vegetative states. The costs incurred providing futile treatments in these three areas alone have a serious effect on the United States healthcare system. These costs should not be ignored, especially considering how many people currently go without any medical treatment due to lacking resources. Opponents to providing futile care recognize that providing a treatment that does not serve a patient’s goal, especially considering how many people go without basic care, violates the concept of justice.

In 2013 the Journal of the American Medical Association (JAMA) conducted a study on futile care in five ICUs that spanned three months. The results of this study showed that 232 of 1,136 patients, or 19.6 percent, received care that was either probably futile (8.6%), futile (11%), or futile on the day that the patient transitioned to palliative care (1%). Overall, the JAMA study found that these five ICUs spent approximately $2.6 billion on

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41. Fine, supra note 12, at 310.
42. Mehlman, supra note 40 at 388 (discussing the scarcity of healthcare resources.).
43. See Beauchamp, supra note 39 (discussing bioethical principle of justice.).
44. See generally Fine, supra note 12 (discussing futile treatments and patients in persistent vegetative states); see generally Kasman supra note 2 (discussing futility in end-of-life care); see generally Huynh et al., supra note 1.
45. Fine, supra note 12, at 310; Huynh et al., supra note 1.
46. See Baily, supra note 25, at 175 (discussing how the public does not understand the need for limits on health care).
47. Fine, supra note 12, at 310 (“According to the Institute of Medicine, 18,000 deaths per year are directly attributable to a lack of health insurance.”).
48. See generally Huynh et al., supra note 1.
49. Id.
futile care over the course of the study. The Centers for Medicare and Medicaid Services (CMS) conducted a study that further demonstrates how considerable the costs associated with futile care are on the already strained healthcare system. According to CMS, each year approximately $107 billion of the $446 billion Medicare and Medicaid budget is spent on aggressive life-sustaining procedures that prove to be futile.

These studies demonstrate how significantly futile procedures impact the healthcare system, including patients and their families. For example, the leading cause of bankruptcy is medical costs. One example of futile care that may lead to bankruptcy is providing care to a patient who is in a persistent vegetative state as that care costs between $40,000 and $100,000 a year.

Futile care proponents incorrectly believe that the costs associated with futile care do not place a sizeable burden on the healthcare system. They also argue that limiting treatments that a patient desires, based on cost, is an unethical method of rationing healthcare. However, it is important to realize that stopping futile care is not rationing because rationing involves denying beneficial treatments, and futile treatments provide no benefits. Further, based on how many people are currently uninsured, this argument

50. Id.
51. Id. (In addition to the emotional and physical costs, there are the financial costs to society to be considered as we underwrite medically futile treatment.).
52. Id. ("About 80% of that money is spent during the final month, often on mechanical ventilators, resuscitation and other aggressive life-sustaining care. More often than not, the aggressive steps taken to save someone’s life are futile.").
53. Fine, supra note 12, at 310 ("Medical costs are the leading factor in bankruptcy.").
54. Id. (discussing how there are between 10,000 and 100,000 patients in persistent vegetative states in the United States at any given time.
55. John Luce & Gordon Rubenfeld, Can Health Care Costs be reduced by Limiting Intensive Care at End of Life?, 165 AM. J. RESPIRATORY CRITICAL CARE MED. 750, 750 (2002) ("[C]hanges in the use of expensive critical care resources near the end of life and efforts to reduce suffering are desirable, they are unlikely to yield significant cost-savings.").
56. Kwiecinski, supra note 8, at 336; Ash & Arons, supra note 2, at 306 ("Some people find it unpleasant, even morally offensive, to contemplate how the economics of health care policy might affect end-of-life care.").
57. Halevy & Brody, supra note 14, at 938 ("Rationing refers to the withholding of efficacious treatments which cannot be afforded. Futility refers to ineffective treatment.").
is unpersuasive.\textsuperscript{58} Lastly, providing futile care places strains on the facilities and physicians by increasing costs and using limited time and resources.\textsuperscript{59} The negative impact that providing futile care has on the entire healthcare system, by using scarce monies and resources, demonstrates that futile care violates the bioethical principle of justice and should not be provided.

V. REDUCING FUTILE CARE IN ILLINOIS

The Illinois Health Care Right of Conscience Act (the Act) currently allows physicians to refuse to provide certain treatments.\textsuperscript{60} However, the language of the Act is broad and does not directly address futile treatments.\textsuperscript{61} Instead, the Act states that providers will not be held liable for refusing to perform treatments that are contrary to their conscience.\textsuperscript{62} According to the Act, the conscience includes deeply held moral convictions that typically stem from a belief in God.\textsuperscript{63}

This language is problematic because it fails to protect physicians who believe that providing futile care violates their ethical duties as physicians.\textsuperscript{64}

\textsuperscript{58} There were 47 million uninsured Americans in 2012. \textit{Key Facts about the Uninsured Population}, \textsc{The Henry J. Kaiser Fam. Found.}, (Sep. 26, 2013), http://kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/. In 2012 45 percent of Illinois residents were either uninsured or on some form of public insurance. \textit{Health Insurance Coverage of the Total Population}, \textsc{The Henry J. Kaiser Fam. Found.}, http://kff.org/other/state-indicator/total-population/.


\textsuperscript{60} 745 ILL. COMP. STAT. 70/4 (1998).

\textsuperscript{61} 745 ILL. COMP. STAT. 70/3(a) (1998) (“Health care’ means any phase of patient care, including but not limited to, testing; diagnosis; prognosis; ancillary research; instructions; family planning, counseling, referrals, or any other advice in connection with the use or procurement of contraceptives and sterilization or abortion procedures; medication; or surgery or other care or treatment rendered by a physician or physicians, nurses, paraprofessionals or health care facility, intended for the physical, emotional, and mental well-being of persons.”).

\textsuperscript{62} 745 ILL. COMP. STAT. 70/4 (1998).

\textsuperscript{63} 745 ILL. COMP. STAT. 70/3(e) (1998).

\textsuperscript{64} 22 ILL. PRAC., \textsc{The Law of Medical Practice in Illinois} § 32:12 (3d ed.) (“This definition arguably limits the scope of the Act to decisions based on religious or closely
Further, in Illinois the language for the Power of Attorney for Health Care implies that a patient or his proxy can require futile treatments in all situations.\textsuperscript{65} This language, when read with the Act, indicates that a patient or their proxy can require futile care even when the physician objects to the procedures on an ethical ground.\textsuperscript{66}

To protect physicians who do not wish to provide futile care, Illinois should adopt legislation that is analogous to Texas’s Advanced Directive Act. Under the Advanced Directive Act, a physician can refuse to provide life-sustaining treatment so long as they provide the patient with a reasonable amount of time to transfer to another facility or physician that will provide the life-sustaining procedures.\textsuperscript{67} The Advanced Directive Act provides the patient with procedures giving them a meaningful opportunity to contest the physician’s decision.\textsuperscript{68} Before a physician can stop life-sustaining treatment there is a review by an ethics or medical committee.\textsuperscript{69} The patient receives notice of the time and procedures of the committee, can attend the meeting, and can receive a written explanation of the decision the committee reaches.\textsuperscript{70} If the committee decides that treatment is futile and the patient or proxy still wants to pursue treatment the facility will assist the patient in transferring to a different facility and continue to provide the life-sustaining treatment for ten days.\textsuperscript{71} These procedures provide the patient with adequate options and protect both the physicians and healthcare facilities involved.\textsuperscript{72}

Illinois should adopt a policy that mirrors Texas’s Advanced Directive

\textsuperscript{65} 755 ILL. COMP. STAT. 45/4-10(b)(2) (1998) (“I want my life to be prolonged to the greatest extent possible in accordance with reasonable medical standards without regard to my condition, the chances I have for recovery, or the cost of the procedures.”).

\textsuperscript{66} 745 ILL. COMP. STAT. 70/3(e) (1998); 755 ILL. COMP. STAT. 45/3-10(b)(2) (1998).

\textsuperscript{67} TEX. HEALTH & SAFETY CODE ANN. § 166.045(c).

\textsuperscript{68} TEX. HEALTH & SAFETY CODE ANN. § 166.046.

\textsuperscript{69} Id.

\textsuperscript{70} Id.

\textsuperscript{71} Id.

\textsuperscript{72} Id.
Act so that physicians are not required to provide futile care that conflicts with their ethical beliefs regarding what healthcare is appropriate. Mirroring Texas’s Advanced Directive Act will provide legal and moral safe harbors for Illinois physicians who want to stop providing futile treatments. In addition to protecting physicians who believe that providing futile care violates their ethical duties, adopting a policy similar to the Texas Advanced Directives Act will reduce the burden on Illinois physicians and hospitals.

VI. CONCLUSION

Millions of Americans are unable to afford basic healthcare. Public healthcare providers, such as Medicare and Medicaid, are already struggling financially, and this problem will continue to grow as the baby-boomers reach age sixty-five, drastically increasing the number of Medicare beneficiaries. In light of the number of people without any health care, it is irresponsible to continue using scarce resources on valueless procedures. Futile services provide no benefit to the patient, the families, or the healthcare system.

Providing futile care violates all four basic bioethical principles. Because providing futile services is ethically irresponsible, physicians should not be required to supply futile services when they find the services ethically objectionable. To address this dilemma, Illinois should follow Texas’s

lead and change its legislation on futile care to mirror the Texas Advanced Directive Act in order to allow physicians to stop providing futile care that they find ethically objectionable.