

## **"AND YOU SHALL CHOOSE LIFE"— FUTILITY AND THE RELIGIOUS DUTY TO PRESERVE LIFE†**

*Marc D. Stern\**

Professor Kent Greenawalt has alerted us to a class of public policy decisions which cannot be resolved by objective criteria.<sup>1</sup> Persons with different political views can apply rational criteria to debates on whether airbags save lives, whether a particular effluent kills trees, or whether the disproportionate number of African-Americans refused mortgages reflects discrimination. However, there are issues where policy choices are, in the final analysis, subjective, and for which persuasive objective criteria do not exist. Professor Greenawalt suggests that animal rights and abortion fall into this category. So do questions of when life ends and what steps ought to be taken to extend life in its very final stages. As a result, no single approach to these excruciatingly difficult problems is either possible or appropriate.

### **I.**

The question of whether particular futile treatments ought to be pursued at the expense of other values is not by any means new. The Talmud, which mandates the violation of the laws of Sabbath rest, kosher, and other ritual observances in the interest of curing the ill,<sup>2</sup> records a divergence of views regarding whether ritual restrictions are to be set aside in the case of clinically ineffective, although perhaps psychologically useful, customary folk "cures."

Jewish legal tradition—and the Jewish tradition is overwhelmingly a legal tradition—has decided that clinically ineffective, or futile, treatments may not be pursued, regardless of the psychological benefit they may provide at the expense of ritual observance.

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\* Co-Director of the Commission on Law and Social Action of the American Jewish Congress. B.A., Yeshiva University; J.D. Columbia University School of Law.

<sup>1</sup> KENT GREENAWALT, *RELIGIOUS CONVICTIONS AND POLITICAL CHOICE* (1988).

<sup>2</sup> T.B., YOMA, 83a-85b (Soncino Press 1938). See generally, J.D. Bleich, *The Obligation To Heal in the Judaic Tradition: A Comparative Analysis*, in JEWISH BIOETHICS (F. Rosner & J.D. Bleich eds., 1979). The case discussed involved consuming nonkosher dog liver as a (folk) remedy for rabies. T.B., YOMA, *supra*, at 84a. See generally, Bleich, *supra*, at 28-33.

By contrast, the same Talmud, in the same discussion, also insists that even the momentary preservation of life, when the patient is obviously in extremis and not likely to live, sets aside all ritual restrictions. Life, in short, has immeasurable, intrinsic value, but is not the only value which weighs in the calculus.

But if it is not a new question, the issue of futility is more urgent and more common today than ever. Modern medicine can do things about which doctors fifty years ago could not even dream. Moreover, futile treatments are not cheap. Advances in medical technology have made pursuit of futile medical treatments a burden on the nation's medical bills, although there is disagreement about the extent of the burden.

The treatment of Baby K's anencephalia—futile treatment in the opinion of her doctors and many medical ethicists—has reportedly cost over \$400,000 in two years.<sup>3</sup> That money is not likely to be diverted from the salaries of major league ballplayers and team owners or Hollywood movie stars.

The amount of medical money expended on Baby K's behalf would purchase a fair amount of prenatal care, healthy baby care, or inoculations for those Virginians who could not otherwise afford them. Realistically, there is only so much money to spend on health care and only so many doctors and intensive care unit (ICU) beds. Spending it on Baby K may mean that some other medical need will go unfulfilled. If in fact the choice between Baby K and the health of hundreds of other children is the political, moral, and religious choice (it is not clear that in fact that is the case<sup>4</sup>), that dilemma also poses a moral and religious challenge.

To judge from the remarks offered at this Conference, the emerging consensus of medical ethicists appears to be that physicians are under no obligation to provide futile medical care. By futile, I do not mean treatments which have no effect whatsoever, such as laetrile as a cancer cure. I mean, instead, cures which extend life for some period of time (with varying degrees of consciousness) but which do not produce any substantial long-lasting (how long?) improvement in life circumstances.

The literature, for example, discusses as an example of futility

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<sup>3</sup> See Gina Kolata, *Battle Over A Baby's Future Raises Hard Ethical Issues*, N.Y. TIMES, Dec. 27, 1994, at A1; Marylou Tousignant & Bill Miller, *Baby K's Mother Gives Her The Prayer That Many Deny She Has*, WASH. POST, Oct. 7, 1994, at A1.

<sup>4</sup> The problem, of course, is that legislatures may use the savings not to fund other health care, but to build prisons or to "fund" tax cuts. See *Pereira v. Kozlowski*, 805 F. Supp. 361, 365 (E.D. Va. 1992) (weighing possible alternate uses of Medicaid dollars).

the application of cardiopulmonary resuscitation (CPR) to terminal cancer patients.<sup>5</sup> CPR, in almost half the cases, allows a person to live, perhaps miserably, for some additional period of time. It does not cure the patient, and it does not ease the pain of terminal cancer. On the contrary, CPR, as practiced in hospitals, is apparently painful in itself, a factor which should be of substantial relevance to the ethical debate. What appears to be the emerging consensus in favor of a rule against futile treatments is not without its critics.<sup>6</sup> Others are far better equipped than I am to address the relative merits of the futility debate in medical and philosophical terms.

We should not overestimate the legal importance of the debate. Even if the futility point of view should ultimately prevail among clinicians, its widespread acceptance by them would not pose any legal problem where the patient has in legally binding fashion expressed a desire not to be treated under circumstances where the doctrine is relevant, either explicitly, by living will, or via a surrogate. One would expect to see the greater use of these decision-making devices in the future as they become more common and as more families are confronted with the need to reconcile their love for a relative with the burdens of end-state illness. The trend to living wills and proxies will accelerate given federal laws requiring health-care facilities to discuss health-care proxies and living wills with patients.<sup>7</sup> This statute should make a dent in the general unwillingness of Americans to face their own deaths.

Where the patient has expressed no wishes on the matter, but the family<sup>8</sup> is united in agreeing not to pursue "futile" medical treatment, the problem is again to a large extent ameliorated (except, perhaps, for hospital legal departments, sometimes euphemistically known as risk management departments). This will be the case particularly in the growing number of states where surrogate

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<sup>5</sup> I assume that we are not discussing physician-assisted suicide, which is a quite different subject, although it in part stems from the same impulses as the futility debate. However, there is generally thought to be a difference between active and passive measures which readily distinguish futility from physician-assisted suicide.

<sup>6</sup> See, e.g., R.D. Truog & A.S. Brett, *The Problem with Futility*, 23 NEW ENG. J. MED. 1560 (1992).

<sup>7</sup> See generally 42 U.S.C. § 1395cc (1994). See M.A. Nevins, *PSDA: How Are We Doing?*, 8 TRENDS HEALTH CARE, L. & ETHICS 68 (1993).

<sup>8</sup> I assume that families will act in good faith to exercise their judgments in the interests of the patient. This is a highly artificial assumption, since some families will act out of guilt, others from a desire to be rid of a burden, and still others out of a wish for monetary gain. Presumably, appropriate safeguards can be devised to minimize these risks.

decision making is authorized. Such decision making will undoubtedly attain increased acceptance in the next few years, formalizing what has been actual practice. With that acceptance, and a growing, but not total, public acceptance of the notion that not all that is clinically possible to be done should be done, conflicts over implementation of the futility doctrine should decrease. Even today, there are only a handful of litigated cases, perhaps indicating that this problem may not be as great a legal problem as the relatively voluminous literature on the subject would suggest.<sup>9</sup>

We will be left with three categories of problematic cases. The first is the set of cases where the patient is incompetent and has left no instructions, or left contradictory ones, where there is no surrogate, or the family is divided over the course of treatment. Here the question is whether the physician may substitute his or her judgment—or the hospital its judgment—for the patient and make a futility decision in the patient's behalf.<sup>10</sup> This raises the ethical problem of futility in pure form.

So does the second category of cases, where the competent patient has demanded in advance, and with the knowledge necessary to make an informed judgment, care the physician now deems futile. This again illustrates the futility question in pure form.

The third type of case, on which I will focus, involves those cases in which medical authorities decide that further medical care is futile and should be withheld, but the patient or his or her surrogate insists on full care on religious grounds. Some of the best known of the futility cases have arisen in this context—*Baby K*,<sup>11</sup> *Wanglie*,<sup>12</sup> *Alvarado*,<sup>13</sup> and *Doe*.<sup>14</sup>

## II.

When the courts are confronted with these cases, they have tended to defer to the wishes of the patient or his or her relatives who speak on the patient's behalf. However, the religious liberty claims which might support this result have not played much of a

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<sup>9</sup> For a report on a recent case holding that doctors need not provide futile treatment, see Gina Kolata, *Court Ruling Limits Rights of Patients*, N.Y. TIMES, Apr. 22, 1995, at 6.

<sup>10</sup> Nominally, the physician may be making a decision about his or her own participation, but the "object" of the decision making is the patient.

<sup>11</sup> *In re Baby K*, 16 F.3d 590 (4th Cir. 1994).

<sup>12</sup> *In re Wanglie*, File PX-91-283 (Hennepin County, P. Div., 1991).

<sup>13</sup> *Alvarado v. New York City Health and Hosps. Corp.*, 547 N.Y.S.2d 190 (Sup. Ct. 1989), *vacated*, 157 A.D.2d 604 (1st Dept. 1990).

<sup>14</sup> *In re Doe*, 418 S.E.2d 3 (Ga. 1992).

role in the decision of these cases. Instead, the courts have simply decided that doctors and hospitals do not have an absolute right to refuse to provide treatment they deem futile.<sup>15</sup> The same is largely, though not exclusively, true of cases where patients resist medical care on religious grounds.<sup>16</sup> In short, the cases tend to be decided on secular "patient autonomy" grounds rather than on religious liberty grounds.

There are several plausible explanations for the question why the religious liberty issues have not been decided as free exercise cases. First, one of the principal claims which advocates of the futility doctrine make—that the doctor is not merely the agent of the patient, that he or she has independent ethical obligations—is not yet broadly accepted in the courts. Courts which decline to recognize the argument that a doctor may refuse care a patient desires need not pass on the religious liberty claims of the patient to receive treatment in the face of a futility claim, because the patient prevails in any event.

Second, for a decade preceding the enactment of the Religious Freedom Restoration Act of 1993 (RFRA),<sup>17</sup> the status of religious liberty claims was very much up in the air. Courts may have shied away from an uncertain area of the law or one in which judges were reluctant to follow the Supreme Court in the direction it had taken.<sup>18</sup> The Court held that the government need not provide any justification for burdening religious practice so long as religious practice was not singled out from the universe of comparable secular practices for adverse treatment.<sup>19</sup>

Were a rule banning futile treatments to be adopted by a state, or were a state to adopt a rule permitting hospitals or physicians to withhold futile treatments desired by patients, that rule would be a neutral one which need not constitutionally make exceptions for

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<sup>15</sup> One New York case stands the principle on its head and allowed a nursing home to continue care that the family did not want continued; adding insult to injury, the family was required to pay for the care. See *Grace Plaza v. Elbaum*, 603 N.Y.S.2d 386 (1993).

<sup>16</sup> See, e.g., *In re Dubrevil*, 629 So.2d 819 (Fla. 1994); *Taft v. Taft*, 446 N.E.2d 395 (Mass. 1987).

<sup>17</sup> 42 U.S.C. §§ 2000bb to 2000bb-4 (1993).

<sup>18</sup> *Employment Div. v. Smith*, 494 U.S. 872 (1990).

<sup>19</sup> Where, however, religion is singled out for adverse treatment, the Free Exercise Clause does require special justification of the discriminatory treatment of religion. *Church of Lukumi Babalu Aye, Inc. v. Hialeah*, 113 S. Ct. 2217 (1993). If all other secular reasons are recognized, religious ones must be accepted as well. See generally *Smith*, 494 U.S. at 872. Thus, a legal rule saying doctors may honor all sorts of reasons for not terminating futile treatment, but may not accept religious reasons, would be unconstitutional.

persons with religious beliefs requiring the provision of futile care. Between the decision in *Smith* in April 1990 and the enactment of the RFRA in November 1993, a person who had religious objections to nontreatment on grounds of a futility had no federal constitutional religious freedom claim. There may have been available state constitutional free exercise claims, but practitioners have been slow to advance state-law religious freedom claims. There is usually little good reason for not doing so—it is a form of legal malpractice—but it is the case that such claims are not often made.

Even before the decision in *Smith*, when the Supreme Court was theoretically still requiring application of a compelling interest test, several scholars had insisted that it was not doing so in practice.<sup>20</sup> While I think this claim reflects an academic preoccupation with the Supreme Court, and not enough focus on lower court decisions and informal negotiations, it is probably true that appellate courts on the whole were more easily persuaded to defer to state policies stated abstractly than were trial courts faced with “real” persons. It is relatively easy for an appellate court to dilute the force of the compelling interest test in the face of a claim by government of chaos if religion were accommodated. Appellate courts, after all, decide cases on a cold legal record, far removed from the individuals involved in the cases.

By contrast, trial courts frequently confront these cases in the flesh.<sup>21</sup> In the case of futility, this means the reality of a hospital room, with an ill person surrounded by the technological paraphernalia of modern medicine, the angel of death hovering in the background.<sup>22</sup> A rule requiring a court to ratify a physician’s decision to ignore the claim of a patient, or the patient’s surrogate, that a failure to preserve life violates her most deeply held religious beliefs in favor of a neutral government rule—in short, for deferring to an abstract principle in the face of a core religious belief—is difficult for trial judges, particularly when the stakes are life and

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<sup>20</sup> See, e.g., Michael W. McConnell, *Free Exercise Revisionism and the Smith Decision*, 57 U. CHI. L. REV. 1109 (1990).

<sup>21</sup> It has been suggested that judges not visit critically ill hospitalized patients lest their judgment be clouded. See NATIONAL CENTER FOR STATE COURTS, GUIDELINES FOR STATE DECISION MAKING IN AUTHORIZING OR WITHHOLDING LIFE SUSTAINING MEDICAL TREATMENT 83-84 (1991). This is a bizarre suggestion. No one would suggest that death penalty sentences be handed down *in absentia* or that the pictures of murder victims be inadmissible in murder trials because they would cloud the judgment of juries.

<sup>22</sup> For a dramatic and controversial example, see *In re A.C.*, 533 A.2d 611 (D.C. 1987), where a caesarean section was ordered performed on a woman dying of cancer.

death. Courts probably prefer to avoid having to make that sort of decision, especially where a decision can be placed on other grounds.

Third, pointing in a different direction and assuming (as I suspect most judges and people not suffering from terminal illness do) that life is a good, and that extending it as long as possible is likewise desirable, courts are likely to have trouble with the notion that people with certain religious beliefs are granted the privilege of having their lives extended, while others may not be granted the same privilege. That argument has been raised when religious groups sought statutory exemption from laws defining death by "brain death" criteria. New Jersey, by statute, and New York, by regulation, both have such exemptions. Neither, however, was readily achieved, and the opposition centered on precisely this point.<sup>23</sup> There are, indeed, countervailing Free Exercise and Establishment clause implications to a preference for the religious observer.<sup>24</sup> The fact of disparate availability of life-sustaining treatment because of religious differences is sufficiently problematic to encourage judges to stay away from grounding decisions about treatment in the Free Exercise clause.

Fourth, federal constitutional norms and RFRA, its statutory equivalent, come into play only when the government acts. Purely private conduct is not subject to constitutional or RFRA restraints. Some states, however, are willing to protect religious freedom from at least some private action.<sup>25</sup> A decision by a private doctor to refuse to participate in futile treatments is thus not subject to constitutional restraints or to the commands of RFRA. The same is true of nonpublic hospitals. This remains the case even if a hospital receives a significant amount of federal aid in the form of Medicare or Medicaid<sup>26</sup> payments. The constitutional or RFRA rule would be applicable in a government-owned hospital, and it would

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<sup>23</sup> See, e.g., N.J. STAT. ANN. § 26:6A-5 (1993); *Assembly Votes Brain-Death Determination Bill*, STAR-LEDGER (Newark), Mar. 1, 1991 at XX. New York's Task Force recommended only that the patient be free to seek alternate health care arrangements, not that the patient enjoy a right to futile treatment.

<sup>24</sup> The boundary between permissible accommodation and unconstitutional establishment is murky. See *Kiryas Joel Village School District v. Grumet*, 114 S. Ct. 2481 (1994); *Texas Monthly v. Bullock*, 489 U.S. 1 (1989); *Corporation of the Presiding Bishop v. Amos*, 483 U.S. 327 (1987); *Estate of Thornton v. Caldor, Inc.*, 472 U.S. 703 (1985).

<sup>25</sup> See, e.g., Massachusetts Civil Rights Act, G. L. c. 12, §§ 11H and 11I (1994). See also *Redgrave v. Boston Symphony Orchestra*, 502 N.E.2d 1375 (Mass. 1987).

<sup>26</sup> See *Rendall-Baker v. Kohn*, 457 U.S. 830 (1982).

apply to test a Medicare rule, if one were to be announced, that Medicare would not reimburse hospitals for "futile" treatment.

There are other practical reasons why futility claims have not been litigated as freedom of religion cases. Most importantly, many religions have not adopted beliefs requiring that all possible steps be undertaken to extend life in all circumstances. That is, while there are some religious groups which purport to do so, many, perhaps most, do not. This substantially reduces the number of cases in which a clash is likely.

There is also the very important empirical question of whether even adherents of the life-at-any-price faiths, under the intense pressure of dealing with a beloved terminally ill patient, abide by the teachings of their faith to the last possible treatment. In the absence of dogmatic pronouncements, which relatively few seem prepared to make, I suspect a good deal of slippage at the bedside away from bold pronouncements from "headquarters."

Finally, many, if not most, lawyers regard constitutional law as some sort of esoteric subject taught only in law schools, and amounting to a more mysterious version of political science. More importantly, at least until very recently, some law school constitutional law courses have not paid the religion clauses much mind. Lawyers, like everyone else, do not tread where they are unsure of their footing. They have thus tended to stay with more conventional consent or agency theories, both solidly rooted in the common law. The enactment of RFRA — a civil rights statute of a familiar type — probably will change this dynamic.

### III.

It is possible that there will be conflicting claims of religious liberty in this area, a point Professor Smolin has addressed. Doctors and hospitals can, if factually appropriate, make plausible religious liberty claims of their own to justify the invocation of the futility doctrine in the face of patient objection. Many of these cases can be "solved" simply by finding a different doctor or a different hospital. For present purposes, however, I assume that religion claims will be made most frequently by patients against doctors, hospitals, and insurance carriers, and not by doctors or hospitals as a ground for refusing futile treatment.

The debate about futility is in part a debate about science. Is a procedure working? Does it hold out the promise of effecting an improvement in a patient's physical condition? Does a particular procedure carry with it risks of hastening the death of a patient or



inflicting substantial pain? How substantial are those risks, and how do they compare with the likelihood of some positive result? Futility questions cannot be discussed without regard to the answers to these questions.

But if these questions call for "objective" evidence, there are other equally relevant questions which do not lend themselves to quantitative analysis. What are "acceptable" likelihoods of success? Is it 50 out of 100; 75; 10; 1? How do we decide? What does meaningful life entail? Is life meaningful if it requires intensive medical intervention to sustain it? Is there an intrinsic value to life? Does it matter who is paying the bill?

The answer to these questions is not particularly important if a doctor is asked to prescribe an antibiotic effective only against gram-negative bacteria to a patient with an infection caused by a gram-positive bacterium. (I assume no prophylaxis is appropriate, and that piggyback infections are unlikely. I put aside, perhaps too quickly, any possible placebo effect.) In this case, the scientific facts are that the antibiotic has no effect whatsoever on the patient. Prescribing the antibiotic is simply giving the patient expensive snake oil.

Advocates of futility argue that since this much is largely uncontested (although my doctor friends tell me the principle is violated all the time), no different rule is appropriate in judging the utility of CPR.<sup>27</sup> But the cases are morally very different and, for many, the difference is morally significant. The "beneficiary" of CPR in slightly less than half the cases will "survive the initial resuscitation," and fourteen percent will survive to leave the hospital.<sup>28</sup> CPR "works" for these patients; the useless antibiotic has no affect at all.

Tomlinson and Brody nevertheless argue that the futility doctrine ought to be applied to CPR even though they concede that at least some of those patients "might be able to make some valued use of the few additional hours or days" that resuscitation provides them.<sup>29</sup> As I read them, Tomlinson and Brody do not claim that it is possible to know in advance with certainty which patients will have that time or be able to make effective (judged by whom?) use of it. To be sure, there are ways of knowing in which cases it is more likely that the patient will leave the hospital, or that the CPR

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<sup>27</sup> See Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 JAMA 1276 (1990).

<sup>28</sup> *Id.*

<sup>29</sup> *Id.*

will not work at all, but no one I have read claims that this is reduced to anything like a certainty.

In the end, as Tomlinson and Brody concede, indeed proclaim, these are not objectively scientific medical judgments.<sup>30</sup> They are value-laden decisions and are therefore issues regarding which doctors and medical ethicists have no special claim to expertise, and certainly not authoritative expertise which they can enforce on others. Doctors can predict what types of patients generally respond to a particular treatment, what treatments work most effectively, and what the likelihood of success is, expressed as an average. But they speak with no greater moral authority than anyone else on the question of whether a particular life is worth extending for what Tomlinson and Brody disparagingly refer to as a few days or hours, or, indeed, what it means to have "human life."

To be sure, medical caregivers are faced with these decisions more frequently than the rest of us. Because such decisions affect their daily work, and because futility questions can raise special moral questions for doctors, they have a special interest in resolution of the futility debate. Moreover, experience is a powerful teacher. The experience of physicians, particularly those who deal in critical-care medicine, may lend much insight into the decision about whether "futile" care ought to be given. Surely, too, we do not want to encourage the growth of an ethically insensitive medical profession, one whose ethical concerns count for nothing in public debate. But the profession does not have the right to decide for everyone, at least not on the evidence now available.

#### IV.

The fundamental question in the futility debate shares much in common with the national debate over abortion. What is human life? What distinguishes it from the life of other animals? At what stage does that which all recognize as human begin or cease to be human? For most people in most cases, these questions are not hard to answer. To paraphrase Justice Stewart, we know human life when we see life. The crunch comes precisely in those marginal cases in which we must define it. Does being human require some showing of cognitive ability? How much? If so, is a severely anencephalic baby ever human? Can we actually kill it? Is a person whose cognitive abilities have been irreversibly destroyed

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<sup>30</sup> *Id.* at 1280.

by a cerebral hemorrhage still human? And what of those cases when the facts begin to grey?

There is a related series of questions not capable of a rigorously objective answer. Until recently, for example, society banned suicide and, Oregon and Washington now excepted,<sup>31</sup> all states still ban physician-assisted suicide. Why? Why is life precious? Why must we not, or at least why can we not, leave anencephalic babies on mountaintops to perish quietly and cheaply? And most important of all, whose life is it? Are humans obligated by or to God to live, or is life a matter of purely personal choice? Does the state have a claim that we should be forced to live so that we might pay taxes or serve in the Army? Should New York force a person to serve a life sentence before letting Oklahoma carry out a sentence of death the prisoner appears to want carried out?

These are every one of them religious and philosophical questions. In our society, there are those who think that people, at least terminally ill people, have a constitutional right to commit suicide, and to be assisted in doing so. One federal judge has upheld that claim, and another has rejected it.<sup>32</sup> The legal foundation of that claim is nothing other than the abortion cases. (The lawyer opposing Oregon's recognition of that right is a leading right-to-life advocate.) One way of viewing the abortion cases is that because the questions about when life begins are unanswerable, they are left to the individual, not the state, at least as to the time before the fetus can live with assistance outside the womb.

If that is the legal or political rationale for *Roe v. Wade*,<sup>33</sup> it is a rationale that ought to cut both ways. The choice of whether to live or die is ultimately the patient's. And if a patient is religiously commanded to "choose life," not as a matter of secularly acceptable, reasoned decision making, but out of a knowing surrender to the Divine Will, then the state ought to honor that choice as much as it honors the choice to abort a fetus.

With substantial parts of the intelligentsia, this notion of blind obedience to a revealed divine will does not sit well. What religious

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<sup>31</sup> An initiative in Oregon is currently being challenged in court, after a preliminary injunction was issued against its enforcement. Compare *Quill v. Koppell*, 870 F. Supp. 78 (S.D.N.Y. 1994) (upholding New York's ban on physician-assisted suicide) with *Compassion in Dying v. Washington*, 850 F. Supp. 1454 (D. Wash. 1994) (striking Washington's ban), *rev'd*, 49 F.3d 586 (9th Cir. 1995). See also *State v. Kevorkian*, Nos. 99591, 99674, 99752, 99758, and 99759, 1994 Mich. LEXIS 3033 (Dec. 13, 1994) (upholding ban on physician-assisted suicide).

<sup>32</sup> See *supra* note 30.

<sup>33</sup> 410 U.S. 113 (1973).

folks call a surrender to God's will, others call yielding to superstition, or abdicating human responsibility. Some simply cannot and do not believe that any rational person could rationally do something irrational. Tomlinson and Brody, for example, question whether a person insisting on futile treatment has made an informed decision, apparently no matter how much medical knowledge they have.<sup>34</sup> They simply do not believe that a person could choose to endure possibly painful, futile treatments; if they do, the choice is nothing more than a delusion.

These positions are, of course, absurd or, more correctly, arrogant. People who have lived their whole lives in accordance with a religious tradition should be accorded the courtesy—dare I say respect—of living their last hours and days in accordance with that tradition. Having sacrificed much in their lifetimes to put their beliefs into practice, these people should be treated as if they know what they are doing when they choose to die or to live in accordance with that tradition.

I am not tilting against nonexistent strawpersons when I complain that religious decisions are often not taken seriously. I think Tomlinson and Brody may be guilty of this. There is still more proof. One of the nation's leading students of jurisprudence recently published a book on abortion and end-of-life decision making. His argument for choice on abortion depends in crucial part on his certainty that no one, including religious opponents of abortion, takes seriously the claim that the fetus is fully human.<sup>35</sup> My religion also believes that the fetus is not fully human (although it does not believe that the less-than-human fetus can be destroyed for other than a limited number of compelling reasons), but surely the Catholic Church and many evangelical Protestants believe the fetus is fully human. Professor Dworkin's certainty to the contrary is more revealing about his view of religion than it is a descriptive of what religious believers postulate.

Many religious folks, in fact, believe, in the words of *Ethics of the Fathers*, that "against your will you live, and against your will you die"<sup>36</sup>—that our biological lives are not ours to do with as suits our moods. We may not breach our obligation to live to avoid every crisis that life brings. Those who follow such religious traditions deny that one may put an end to suffering because it seems prefer-

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<sup>34</sup> Tomlinson & Brody, *supra* note 26, at 1278-79.

<sup>35</sup> See RONALD DWORKIN, *LIFE'S DOMINION* 109-17 (1993).

<sup>36</sup> *ETHICS OF THE FATHERS*, Ch.4, ¶ 21 [hereinafter *ETHICS*]. The translation of this work is my own.

able to marching on. Of course, some religions believe that some forms of life sustained primarily by mechanical assistance is not life, but that is a religious choice, not a medical one.

These religious beliefs about the end of life are not peripheral ones. They are core beliefs about humankind's place in the world, and the nature of its relation to God. Religious people who insist on prolonging life in the face of being told that it is futile believe that they are servants of a God who has commanded an unquestioning willingness to carry on. The question of whether religious folks should be able to override medical judgments about futility is not one about customary or even optional rituals, or ceremonies for which some alternative is available. It goes to the core of a person's concept of his relation to God.

Plainly, many deny that God did reveal *the* (or any) answer to questions such as these. But whether the believer's understanding of God's word is at least as reliable a source of ethical grounding as the reasoning of medical ethicists is not a question that the government is empowered to answer for the believer. As a matter of principle in a pluralistic society, it should also not be for a private doctor or a hospital ethics committee (to say nothing of a profit-making insurance company) to answer, particularly since it is likely that the doctor or ethics committee often do not share a common idiom, or understanding of the meaning of life, with the religious believer.

It is unfortunate that by frequent citation, Justice Jackson's classic and powerful description of the absence of governmental power over a citizen's religious belief has become somewhat trite. But it still rings true, and it has special relevance here.<sup>37</sup>

No matter how elaborate or elegant the philosophical proofs that futile treatments should be withheld, no matter how much they persuade those who share the premise that ethical decision must be the product of autonomous reasoning, such proofs cannot persuade those for whom autonomous reasoning is not the ultimate arbiter of moral decision making. The problem is not lack of intelligence or nerve, or a stubborn failure to listen to medical ad-

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<sup>37</sup> *West Virginia Bd. of Educ. v. Barnette*, 319 U.S. 624 (1943). Justice Jackson enunciated: "If there is any fixed star in our constitutional constellation, it is that no official, high or petty, can prescribe what shall be orthodox in politics, nationalism, religion, or other matters of opinion or force citizens to confess by word or act their faith therein." *Id.* at 642. Technically, this elemental rule of law does not apply to nongovernmental action. But it is difficult to see why it should not as a matter of public policy.

vice. It is that, at the most fundamental level, the believer and the medical profession often do not share a common language.

It bears emphasizing again here that few, if any, religions insist on every possible measure to extend life. Orthodox Judaism is often cited as insisting on heroic measures to extend life. But respected Orthodox rabbinic authority rejects the proposition that every trick in the doctor's bag must be tried, that every machine be hooked up and allowed to function indefinitely, and that endless pain, suffering, or risk must be borne to extend life.

Many years ago, I was discussing with my revered teacher, Rabbi Joseph B. Soloveitchik, traditional Jewish law's attitude toward brain-death criteria. He indicated then a general sympathy with application of those criteria to determine death (although they have no clear precedent in the Talmudic tradition) but then said something to the effect of "who knows; perhaps the brain-dead person can have a fleeting thought of repentance, some regret for a life not lived as righteously as possible." And so, he said, he was reluctant to decide that "brain death" is an appropriate place to mark death, or whether some later event (i.e., cessation of the heartbeat) is more appropriate.

This discussion took place many years ago. I do not know if it reflected Rabbi Soloveitchik's ultimate views on the attitude of Jewish law to brain-death criteria. My point here is the religious valuation of life's possibilities in some cases will be based on different criteria than those of the medical profession or secular ethicists. To again quote the Talmud, "one hour of repentance and good deeds in this world is preferable to the entire World-to-Come."<sup>38</sup> A person who denies any otherworldly existence surely will tilt the calculus differently. So when Tomlinson and Brody are dismissive of "a few hours or days" of life, they probably speak for millions of decent and thoughtful Americans. But many (but by no means all) religious persons will find them speaking a wholly different language, one that they do not at all comprehend.

Those who favor a futility doctrine may be understood to argue that humanity is more than a certain number of physiological functions working in tandem. That is hardly an "irreligious" insight, and it is not a thought alien to religious thinking. But it is equally easy to make out a religious argument for the anti-futility position. The argument for futility (once futility moves beyond physiological futility) assumes explicit value judgments about what

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<sup>38</sup> ETHICS, *supra* note 35, at Chapter 4, ¶ 15.

life is worth living and about whose life it is. For those who believe that there are divine judgments, not human ones, the futility doctrine cannot avoid conflicting with some deep-felt religious beliefs.

## VI.

The first thing which must be done when confronted with a clash between claims of futility and religious reverence for life is to ascertain that a true conflict exists. That is, the diagnosis must be checked and rechecked, and the medical prognosis must be clarified as much as possible to the doctor, patient, and family. On the other side of the ledger, the patient (or the family or the surrogate decision maker) must be given the clearest possible understanding of the medical situation, with all reasonable alternatives. The physician should spell out the risks and costs of particular courses of action, including risks of accelerated death or increased pain—risks which may sway the ethical and religious calculus for many. If one is to confront ethical clashes at the margins of life, one ought to be certain that a conflict exists. It does no one any good to multiply false conflicts because someone failed to ascertain that a conflict really exists.

This sounds obvious. Perhaps . . . but not necessarily. Several years ago, I was appointed guardian *ad litem* for an adolescent Jehovah's Witness suffering from a lymphoma or leukemia. Her white blood cell counts were dangerously depressed as a result of chemotherapy. Her mother refused to consent to a transfusion. The hospital sought a court order to compel the transfusion, which would ordinarily be given.

The judge who appointed me did so, I was told, because I was supposed to be knowledgeable in religious liberty issues. But as an Orthodox Jew, I approach these issues from a wholly different grounding than did a Jehovah's Witness. It is not just that the two faiths differ on the permissibility of blood transfusions; I could easily have dealt with that difference.

The two faiths have irreconcilable approaches to a clash between ritual prohibition and the saving of a life. For Judaism, danger to life pushes aside all but the most essential religious commands (murder, idolatry, and sexual immorality). This is so even if there is a doubt about the threat to life, or if life will be extended only momentarily.<sup>39</sup> The Jehovah's Witnesses weigh such a clash differently, at least with regard to blood transfusion.

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<sup>39</sup> See *supra* note 2.

This was no minor clash of religious traditions. It was a fundamental difference of world view. I remember wondering how I could decide what was in the best interest of the child when there was this unbridgeable chasm between us. To the very fiber of my being, the choice of life seemed obvious. But for my ward, the choice that was intuitive to me was unspeakably sinful.

Fortunately, it never came to the hard choice. The hospital agreed not to transfuse unless it was absolutely necessary, and then only upon notice to the girl's mother. It also agreed to allow a Jehovah's Witness hematologist knowledgeable in bloodless treatments to examine my ward (and, reluctantly after prodding by an astounded judge, to let that doctor see hospital records) so he could determine if transfusion was absolutely necessary. Everyone left the courtroom more or less happy.

The parties should have been able to reach this agreement by themselves. It took the presence of a third party to work it out, and to avoid a clash between two sets of irreconcilable values. I suspect that in many, but not all futility cases, careful examination of facts and alternatives (both medical and religious) will eliminate or minimize conflict.

Second, the debate over futility raises fundamental ethical concerns. Where futility must be confronted, it should be settled directly and forthrightly. It should not be decided by utilizing review specialists. Insurance companies are in the business of making money. They surely have no expertise in, let alone jurisdiction over, ethical or religious imperatives. Even in making ordinary medical decisions, there is every reason to question the judgment of insurance companies. *A fortiori* this ought to be true of complex and difficult ethical decisions touching upon the very core of human life.

This is not to say that the cost of providing futile care is irrelevant to the moral calculus, or that it is desirable to have theologians decide futility questions as if limited resources were not a problem. If it should turn out that substantial sums are being expended on "futile" care, and that those sums could be redirected within the health-care system to saving many more lives, then difficult moral issues will be raised. If that is the choice, it ought to be faced and decided by the society as a whole, not by an insurance company or a Medicare bureaucrat.

Third, when all is said and done, I think it is useful that there not be—at least not yet—a resolution of the debate over futility. Partly, this is because I believe that in keeping with the happy



American tradition of respect for differing religious practices, religious observers whose religious beliefs require the pursuit of life should be permitted, in what are likely to be their last hours, to put their religious beliefs to the ultimate test. But there is a broader basis for wishing to leave the issue open.

Any notion of futility is rife with the possibility of abuse and extension to an ever-widening circle of cases. It is predictable that there will be hydraulic pressures to extend the circle of patients not meriting treatment on grounds of futility. There are substantial worries about whether these decisions will be made free of bias of wealth and class. Even families cannot always be trusted to make ethically sound decisions. There are, no doubt, families who prefer larger inheritances to keeping Mom or Dad in the intensive care unit for two weeks longer.

Legal and procedural restraints, no matter how carefully drafted, are likely to be eroded in practice. Physician-assisted suicide is generally illegal, but it goes on. Holland, which permits physician-assisted suicide, has seen at least some, and perhaps significant, whittling away at safeguards, although the exact degree is in dispute.<sup>40</sup>

Medical technology has pushed us to the point where decisions about terminating medical treatment must too often be made. Hard ethical decisions which become common cease to be hard. People can become acclimated to almost anything. Funeral directors and police do not cry at the sight of a corpse, and judges become inured to sentencing people to long terms in prison and even to death.

The risk is that in the course of applying a futility doctrine, the awesomeness of the decision will be lost and the fear of making a wrong decision will simply be another malpractice worry. Moreover, the benefits of eliminating "futile" treatments will be seen as so great that the scope of futile decisions will gradually be broadened to less clearly futile cases. Said differently, an ethic of termination may be doubtful today but may not be so tomorrow. The business of judging the value of human life is a corrosive one, one which should be engaged only when there is no alternative, and then only with the utmost seriousness and gravity. Secular safeguards are important. Perhaps they will even work. Surely, such safeguards are indispensable. On the evidence, however, they are not foolproof and tend to lose their "punch" with time.

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<sup>40</sup> See *Dutch Bring A Test Case In Euthanasia*, N.Y. TIMES, Dec. 23, 1994, at A3.

I do not suggest that we as a society ought to blindly accept religious objections to futility. There is a danger—in my judgment a real danger—that overwhelmed by the awesomeness of the task of deciding “who shall live and who shall die,” as the Jewish high holiday liturgy puts it, members of the clergy will ignore the larger ethical questions of allocating resources or of pain, risk, and suffering. It is important that religious leaders also not be allowed to treat futility decisions as “easy” decisions, always to be glibly resolved in favor of extending a particular and identifiable life.

Still, precisely because at least some religious groups have an absolute commitment to life and/or because they reject the idea of total personal autonomy, because they believe that life is a gift from God over which people do not have legitimate dominion, because they are committed to not judging the value of life, and because they are committed to a wholly different vision of life, they stand outside the usual biological and medical consensus and provide a caution, a prophetic witness to the value of life. In this way, even if religious groups which reject futility do not persuade anyone else of the correctness of their position, they will serve as watchmen, warning us of the ethical and moral dangers which lie at death’s door.