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Medically Inappropriate or Futile Treatment: Deliberation and Justification[1]

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This paper reframes the futility debate, moving away from the question "Who decides when to end what is considered to be a medically inappropriate or futile treatment?" and toward the question "How can society make policy that will best account for the multitude of values and conflicts involved in such decision-making?" It offers a pragmatist moral epistemology that provides us with (1) a clear justification of why it is important to take best standards, norms, and physician judgment seriously and (2) a clear justification of why ample opportunity must be made for patients, families, and society to challenge those standards and norms.

Keywords: *futility, medically inappropriate treatment, pragmatism*

I. INTRODUCTION

The debate about when a life-sustaining medical treatment for a critically ill patient should be discontinued is linked to, but distinguishable from, the right-to-die debate. Our primary interest is the former—the unhelpfully labeled "futility debate." It is often stated, also unhelpfully, in terms of who gets to decide. Can a physician decide to stop treatment, or does the decision belong to the patient, or the next of kin or proxy?[2] The "futility" language is unhelpful because there really is no debate about stopping treatment when it is literally, and in the extreme, futile. We will thus use “medically inappropriate or futile” rather than plain “futile,” except when we are discussing the history of the debate. The language of who gets to decide is unhelpful because, as we shall argue, unilateral decision-making is vanishingly rare, for good reason. A better way of putting the question is: why should we pay attention, and what should that attention look like, when physicians object to providing a treatment on the grounds that it violates the norms of medicine or best practice?

The debate over medically inappropriate or futile treatment is conducted intensely in the press, in the courts, and around dinner tables, as we think about how medical treatment, especially at the end of life, should be ideally and practically delivered. Opinion is sometimes divided along religious lines, but to suggest that this is the main source of the dispute fails to acknowledge that the matter also involves how we think about autonomy, the authority of experts, and how scarce resources are distributed fairly in society. The conflict often seems irresolvable, and efforts to answer the question of whether or when physicians may refuse to provide treatments they deem medically inappropriate or futile, but are nonetheless demanded by patients or their surrogates, have often been characterized as intractable failures (Helft, Siegler, and Lantos, 2000). In this paper, we offer an explanation of why the disputes are so deep, but we also offer a way of resolving them. On our pragmatist or deliberativist model, there is often a right answer or a truth of the matter at stake, and we can employ a decision-making method more likely to reach it. That method is appropriately deferential to medical knowledge and judgments, while guarding against a self-sealing vision of how that knowledge is shaped and reshaped. These are important conclusions, for the stakes here are very high indeed—they are about life and death, about human suffering, and about doing the right (or wrong) thing in circumstances that are often extreme.

A note of authorial narrative is required. We were three of many who produced the recently published “An official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Futile and Potentially Inappropriate Treatments in Intensive Care Units” (hereafter: “the ATS Guidelines”, Bosslet, et al., 2015). While what we write here cannot be taken to be an extension of that policy statement to which all the authors would sign on, it grew out of those discussions. For it seemed that a justificatory framework was required in order to make best sense of the position taken in the ATS Guidelines. Hence, we three put together a short, medical journal-size, justificatory skeleton in “Medical Futility: A New Look at an Old Problem” (Misak, Truog, and White, 2014). But this difficult and complex topic merits a more sustained treatment, which we offer here.

One of our overarching points will be that decisions about whether to offer or withhold treatments for critically ill patients must be based on reasons that appeal to standards and norms embedded in medical practice and in society at large, including norms about the role of the patient, family, and physician in decision-making. By “norms of medical practice,” we do not mean what this or that physician currently happens to do, but rather, we mean the best standards that currently exist. These might be what are written in official guidelines, as one would expect a well-designed guideline to accurately capture best practice. But since the guideline-makers are themselves fallible and since the standards evolve, there need not be unanimity about those standards. Indeed, disagreement about and inquiry into them is how they are propelled forward.

We shall argue that appeals to such standards are appropriate when justifying refusals of care, but it is important to preserve genuine opportunities for those standards to be challenged by patients, families, and advocacy groups. This may seem simply a matter of common sense. But one thing the debate has shown is that if we do not have a clear and strong justification for why it is right to appeal to such reasons, decisions are at risk of being and/or appearing to be arbitrary. It is this justificatory gap that we aim to fill. Throughout this paper, we shall draw on a moral epistemology—on a theory of how we can make sense of aiming at right answers in seemingly intractable matters.[3] We shall argue that the debate about medically inappropriate or futile treatment must be seen as an example of how we make decisions in a democratic and decent society. Once it is seen in this way, we will find some signposts, in what otherwise might seem a confusing landscape, for how decisions ought to proceed.

Another of our overarching points will be that no medical decisions are taken unilaterally or in isolation from a dense network of values. Rather than asking when the values of physicians can trump the values of patients, or vice versa, we should be asking how, as a democratic society, we ought to balance the multitude of values. This is—and always will be—a work in progress. That is, the question should not be “who decides—the physician or the patient?” but rather how to come to the best solutions in general, and also in gray areas where our decisions must outrun the norms and facts. These questions will be answered, always in provisional ways, as societies address hard questions about rights, equality, and the distribution of scarce resources.

II. A BRIEF HISTORY OF THE DEBATE

A short and critical history of how the futility debate has unfolded provides a useful window into understanding the nature of these disputes and how we ought to rethink them.

The issue was identified by Plato and the Hippocrateans, and the view that futile treatment should not be provided, even to dying emperors, was endorsed up to the Christian Byzantine period (Lascaratos, Poulakou-Rebelakou, and

Marketos, 1999). Physicians, an unknown Hippocratic author stated, should "refuse to treat those who are overmastered by their disease, realizing that in such cases medicine is powerless" (Jones, 1981, 192–93). Not until the early 1900s were physicians deemed to have responsibility for obtaining the consent of a patient before performing a medical procedure. That responsibility was minimal until the various rights movements (civil rights, women's rights, patient's rights) of the 20th century progressed. The view that physicians should in effect make decisions for patients then fell into disfavor in democratic and progressive societies. Today, the language of "shared decision-making" between patients and clinicians, in which patients "are part of the decision-making team," has become the dominant model endorsed by both society and the medical profession.

Yet many physicians chafe at the notion that all medical decisions should be "shared." They correctly observe that many "technical" decisions continue to be made without input from the patients themselves. For instance, in intubating a patient, physicians choose the size of endotracheal tube and do not discuss the pros and cons of its being bigger or smaller. As we will emphasize below, even such technical decisions involve value judgments, and most of those values are shared, making the decisions straightforward. Most patients would find it odd and unwelcome if their physicians involved them in these routine decisions. But a relatively small slice of medical decision-making has become deeply contentious in this respect: those decisions involve the use of potentially life-prolonging but also potentially medically inappropriate treatments for patients near the end of life.

During the 1990s, efforts were made by the medical profession to develop criteria for "diagnosing" futility. These approaches regarded futility as a medical problem that could be identified in much the same way as kidney failure or a bacterial infection. For example, Schneiderman proposed two definitions of futility, one quantitative and the other qualitative. The quantitative definition stated: "when physicians conclude . . . that in the last 100 cases a medical treatment has been useless, they should regard that treatment as futile." The qualitative definition stated: "If a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, the treatment should be considered futile" (Schneiderman, Jecker, and Jonsen, 1990, 949).

This "definitional" approach appealed to many clinicians and was imported by a number of hospitals into their institutional policies. It was attractive because it framed futility in the familiar medical language of prognosis and treated it as a medical problem to be diagnosed under the expertise and authority of physicians. If physicians recognized that this approach hinged on certain value judgments—such as that treatments with less than a 1% chance of success are not worth providing or that a life in an intensive care unit is not worth living—they nevertheless assumed that it was appropriate for them to make these judgments.

As the definitional approach came under greater scrutiny, the American Medical Association proposed an alternative "process-based approach to futility determinations," on which health care institutions adopt a "fair" process to deal with futility conflicts, carried out by ethics committees or other institutional bodies set up with an eye to respecting all the parties (AMA, 1999, 939–40). While many hospitals today have adopted this so-called procedural approach, Texas has gone so far as to enshrine it in legislation (Texas Health and Safety Code, 1999). Under Texas law, if a disputed case is reviewed by a hospital ethics or medical review committee and if the committee agrees with the judgment of the responsible physician to withdraw treatment, then either alternative clinicians willing to provide the requested treatment must be found within 10 days, or the treatment may be withdrawn. The law denies access to the courts for substantive appeal of the judgment, and also grants physicians civil and criminal immunity, provided they follow the relevant rules and process. The Texas approach has been described as "highly formalized" (Smith et al., 2007, 1271). It does not build in a definition of medically inappropriate or futile treatment and does not require clinicians to meet any specific substantive threshold of argument in their decision. It is a process designed to put in place a higher degree of security with respect to an individual clinician's claim that a requested treatment is medically inappropriate.

But, of course, substantive judgments are made all along the line. With the Texas approach, physicians are to employ their own understanding of medical inappropriateness in order to make frontline judgments. Similarly, the review committee must employ their understanding of inappropriate treatment in order to determine whether they agree with the frontline physician's assessment. The Texas law is thus not a pure procedural approach, where in deciding whether a decision is valid one looks only at whether the correct procedures were followed, not at the content of the decision. A pure procedural approach might ask the following kinds of questions: if the procedure requires that the frontline decision-maker has to give reasons, did he or she give reasons (whatever the content of those reasons might be)? Is the frontline decision-maker given a checklist that permits him or her to make the judgment, without engaging in any evaluation of its wisdom? Both the Texas approach and the ATS Guidelines more substantial than a pure procedural approach. We shall argue below that this substance is unavoidable and justified.

Nonetheless, we shall suggest that the process-based approach used in Texas is problematic in that it does not provide sufficient motivation and opportunity for patients to challenge existing understandings of best medical practice. A 2007 survey of hospitals' experience with the Texas Act found that very few of the institutional committees have patient representatives or advocates (Smith et al., 2007). They are heavy with physicians and administrators who will have financial and/or social ties to the hospital

(Truog, 2007). Moreover, only a small number of cases that go to review committees in Texas result in the cessation of treatment being reversed (Fine and Mayo, 2003; Smith et al., 2007), and since the law prohibits any judicial involvement other than in extending the time for an alternative care provider to be identified, families may not unreasonably think that resistance is futile (Fine and Mayo, 2003). Even if justice happens to be served by the law, the appearance of justice is not. It may look as if the review committees are in place to deny families' requests for treatment the physicians believe to be inappropriate. That is, it is worrying that the Texas Act provides no real mechanism for patients or families to challenge the physicians' judgments about what are best standards of practice, and no rationale to see those standards as open to challenge. It leaves little or no opportunity for patients or society to challenge the current boundaries of practice. This creates a vision of how medical practice standards are shaped and reshaped that is not responsive to external critique.

The debate continues. Outside of Texas, court challenges have been brought by patients and their families, at times arguing against the withdrawal of a life-supporting treatment, at times arguing that a certain treatment must be offered. We shall suggest that, too often, these cases are put in terms of who has the right to decide. Part of our reasoning will be that no individual or committee in isolation makes a decision about whether to end or prolong life. Rather, we as a society determine, sometimes not as self-consciously as we should, what medical treatments will be offered to a patient. It is those societal decisions that are reflected in current best medical practice.

In what follows, we shall suggest a framework in which we can justify certain kinds of policies about medically inappropriate or futile treatment. It is a framework in which the distinction between substance and procedure is blurred, since it makes little sense to think of a method as being purely procedural or purely substantive. Frontline clinicians must give substantive reasons for their judgment to withhold or not offer a treatment, but those reasons must be part of a decision-making process that draws on values shared by physician and patient, the medical facts, the wishes of the patient, and the best understanding of good medical practice.

Our model sees the boundaries for authority in decision-making as resulting from an ever-evolving dialogue between the medical profession and the society it serves, and of which it is a part. We will offer a guide for decision-making, a guide that builds in and justifies the reliance on existing norms of practice, as well as what the AMA rightly was after—a "fair process" that ensures that substantive judgments are made carefully and reflect the values and wishes of the patient, the profession, and society. Our approach also improves on the AMA's by expressly providing for and justifying a second, broader practice—namely, the practice of justifying the ongoing *challenge* of those standards of care.

III. STARTING FROM WHERE WE FIND OURSELVES

In this section, we outline the moral epistemology that provides the backing for the practical policy framework we advocate. It is a very particular kind of pragmatism, derived from the founder of the tradition, Charles S. Peirce and his successor C. I. Lewis, and finding resonance in contemporary political theory. The central insight of pragmatism is that in any kind of inquiry, we begin with an inherited set of beliefs, theories, principles, policies, and practices. What we aim at is to get the very best belief, theory, principle, policy, or practice we can, starting from where we find ourselves in that evolving body of knowledge. Indeed, it is only against such a background of accepted belief that something can be put into doubt and a new belief adopted. Our beliefs, while all fallible, do not come into doubt all at once. Those that have not been thrown into doubt are stable and we retain them until a reason to doubt arises. Inquiry, Peirce said, "is walking upon a bog, and can only say, this ground seems to hold for the present. Here I will stay till it begins to give way" (Peirce, 1931–1958, 5.589). A patch of ground gives way when experience upsets a settled belief. While we are unable to step outside of our practices and system of belief so that we might figure out first principles, that does not entail that we are cast into a sea of relativism, where any answer is as good as any other. Ours is the kind of pragmatism that focuses on an experience-driven inquiry in which we try to discover the best answers to our questions.

This pragmatist epistemology is not simply one theory, picked from a bushel of potential philosophical theories that might underpin our moral practice. Indeed, it is not a standard kind of *moral theory* at all. It does not say that the good or the right can be reduced to the maximization of utility, or the upholding of universal rights, or the contract into which we think idealized agents stripped of their contingent characters and situations would enter. The pragmatist epistemology we invoke is one that is grounded in, and articulates the conditions for, inquiry, including inquiry about what is good or right. It explains how we aim at truth, despite the fact that we are fallible inquirers, working within situations that are uncertain and demanding, sometimes impossibly so.

On this kind of pragmatism, a true belief is one that would be indefeasible, would not be improved upon, would never lead to disappointment, or would forever meet the challenges of reasons, argument, and evidence. It should be clear that on this view, we can never say, with certainty, that we have the absolute truth in hand. For we can expect that as more experience and reasons come to light, we may well make further revisions in our evolving web of belief. On this low-profile conception of truth, truth is the best that human inquirers could do. While truth is what would stand up to all evidence and reasons, what we aim at here and now are beliefs.

Thus, the pragmatist of the sort we are describing is not a skeptic about truth. He is simply skeptical that any one moral theory will give us the right answers to our ethical questions, as if a black box/great book/true moral theory could be found with all the answers contained within it. The pragmatist of the sort we are describing argues that inquiries or deliberations that are aimed at getting the right answer need to take account of as much experience and reasoning as they can. In moral inquiry, these will include reasons based on rights, on utility, on the importance of relationships, on facts, on resource constraints, and so on.

Some of the great political and legal theorists of the 20th century, such as Ronald Dworkin[4] and John Rawls,[5] have put forward versions of this position. Rawls called his the method of reflective equilibrium: we aim to get ourselves in a position of equilibrium of competing ideas, interests, intuitions, and claims, then we test that equilibrium against experience with the aim of bringing our intuitions into alignment with it. Dworkin puts the point in terms of the law being a practice that tries to make the best moral sense of relevant legal materials, including statutes, precedent, and the written constitution if there is one. At the heart of these pragmatist positions is the idea that in any kind of inquiry aimed at getting things right, we approach our fundamental problems by working with and interpreting the present situation, in an effort to resolve controversies and move to a position that better respects evolving values and the discovery of new facts. Thus, pragmatism offers us a way of making sense of aiming at right answers or the truth of the matter, without taking truth to be something absolute or written in stone. While a true belief is one that would be indefeasible, what we need to focus on is not that end state. For how could we possibly aim at an answer to our question that goes beyond our current abilities and knowledge? What we need to focus on is getting the belief that best stands up to all current reason, argument, and evidence. And the way to do that is to take in as much information, evidence, and perspective as possible.

It might seem that conflict of interest and variation of judgment play too great a part in ethical deliberation for it to aim at getting things right. But as Lewis argues, these features distinguish value judgments from other judgments by degree, not by kind. All data are influenced by interpretative factors, and in other matters we simply do not look as often to these factors as explanations for why our judgments diverge. We tend to look rather to differences in the external world to explain differences of opinion. And we tend to emphasize divergence of belief in ethics because it is *important* for us, and for *all* of us, to do so. Disagreement about treatments at the end of life, for instance, as opposed to disagreement in mathematics or physics, is compelling for everyone. But also, like any other kind of inquiry, moral inquiry is not wholly interpretative. It must be responsive to experience and to changing facts and standards. The pragmatist, that is, rejects any hard and fast distinction between fact and value. Beliefs about both facts and values are shaped by human capacities, prior commitments, theoretical structures, interests, and needs. Any discourse that relies on a sharp distinction between fact and value, such as that which is sometimes found in the medical ethics literature, is misguided.[6]

There is a practical as well as a conceptual reason for thinking that objectivity holds in ethical matters. To those who think that conflict of value and interest is so rife in ethics that questions about value are intractable with no better or worse answers to be had, the pragmatist argues that we have to *hope*, if there is to be any chance of improvement in the quality of our lives and deaths, that there is enough commonality in the experience of value so that inquiry will arrive at right answers. Otherwise, there is no point in making value judgments. As Lewis puts it:

> if there were a complete absence of community in our value-findings . . . or if communities of value-apprehension in the presence of the same object should be mere matters of chance, then no one could, with the best will in the world, learn how to do anybody else any good—or for that matter, how to do him harm. (Lewis, 1971 [1946], 423–24)

We have no choice but to start from where we find ourselves and work toward better solutions for individuals and society, based on the assumption that there is commonality enough in our value-findings, yet knowing that we will not get anything like unanimity, and that deep disagreements are likely to remain.

The pragmatist thus encourages us not to think of the diversity of values as a necessarily irresolvable clash. As a society, we have resolved all sorts of conflicts that were once thought to be irreconcilable, having to do, for instance, with race, gender, and sexual orientation. That is not to say that all disagreement has disappeared or that it is inevitable that it will eventually disappear. On many moral and political matters, whatever choice is made will be such that some valuable things will be lost and some good reasons will be un-acted upon. That is, there will be a residue of regret. We also know that our answers are often provisional and likely to be altered down the line. But the fact of regret and the fact that our questions and answers may shift with changes in our values, knowledge, technology, and our very understanding of ourselves should not make us think that there is no subject matter at all to get right or wrong.

Notice that this pragmatist position has a built-in recommendation for deliberative democratic structures and processes. If we want to arrive at the best answers in ethical matters (as in any other inquiry), we ought to structure our institutions so that evidence and voices are heard and openness is promoted, in order to maximize the chances that we are getting the best input (and hence best output) possible. We shall see below that with respect to medically inappropriate or futile treatment determinations, every decision inevitably involves the clinician in a kind of deliberative model of decision-making, in which values, interests, and expertise are all in play.

IV. FUTILITY, REVISITED

In this section, we outline some of the concrete lessons we can learn from the abstract moral epistemology described and defended above. In the next section, we will suggest a practical framework for policies with respect to medically inappropriate and futile treatment that also aligns with the pragmatist moral epistemology.

One lesson to be learned is that rather than seeing the history of the futility debate as a succession of failed attempts at solving a problem that still awaits its definitive answer, any proffered solutions to the problem should be seen as the next iteration in a moral inquiry into a complex and difficult matter. Within a democratic society, the futility debate is an ever-fluid dialogue involving the medical profession, the legal profession, and citizens (both patients and health care workers) who are subject to its policies, practices, and laws. These policies and laws do not offer permanent or absolute solutions, but rather are part of the continual redefining of the boundaries of decision-making authority between physicians and patients, involving a variety of professional, cultural, religious, civic, and legal values or mechanisms. Disputes around medically futile and inappropriate treatment are not problems in search of clear-cut and final solutions, but rather they are dynamic problems best addressed in the ways characteristic of a liberal democracy.

A second lesson, following hard on the heels of the first, is that we should develop approaches to dispute resolution that are responsive to new arguments and articulations of what we value. As we develop policies that are more and more responsive, we have some reason to hope they are gravitating toward better answers to the profound end-of-life problems that press upon us. There is no guarantee that this hope will be fulfilled. But we can say one thing with confidence. Policies that diminish the ability of all voices to be heard are likely to compromise our solutions. The same holds for policies that would diminish the value of the store of knowledge contained in our best medical practices—which is of course at the core of our evolving body of background belief. So, while there is no preset and timeless answer to any question about what should be done in a specific kind of case and what weights should generally be accorded to patient rights and autonomy, resource considerations, and professional judgment about whether a treatment is inappropriate or futile, that is not to say that there are no better or worse policies and that there is no right or wrong answer in a particular case. We are already some distance to finding our way though the thicket of problems surrounding medically inappropriate or futile treatment.

A third set of implications involves how we should think of the conflict that often seems overwhelming in end-of-life decisions. The 1999 AMA statement on futility cited the conflict of values in which futility determinations arise as a reason for moving away from a definitional approach and toward a process-based approach. It noted conflicts such as those between the religious and personal values of the patient/proxy with the physician's medical values and values about appropriate resource distribution (AMA, 1999, 937). The family, for instance, might value the preservation of the life, however temporary, of their loved one at any cost. The physician might see relatively imminent death as inevitable and his or her values might call for ending the suffering involved in life-support with a move to palliative care, while keeping one eye on fair allocation of resources. The values in the mix include considerations of the dignity of the patient, the emotional burdens of physicians providing what they take to be inappropriate treatment, the desire on the part of the physician to minimize exposure to lawsuits (Gigerenzer, 2013), patients' physicians' personal moral and religious beliefs (Antiel et al., 2011; Curlin et al., 2007), and more general values such as the rights and autonomy of patients, legal values, and the need to distribute limited medical resources fairly.

One thing we can say about the conflict of values is that on the moral epistemology we have put forward, conflict is only to be expected, and, although we aim for its resolution, we must not think that conflicts can be tidily resolved. How to ethically manage the end of life is a complex and important matter, fraught with deeply held differences. It will often be the case that not all the values can be satisfied—whatever choice is made, some valuable things will be lost and some good reasons will be un-acted upon. For it is often the case that no one kind of value definitively trumps all others, even for an individual. For instance, a family might want treatment continued for a critically and irreversibly ill loved one, but nonetheless be devastated by the additional suffering involved. Or a physician may encourage a patient to continue with a painful course of treatment in hopes of a cure and then regret the additional suffering that the patient experienced when the treatment proves unsuccessful. "Regret" here is not being used as in "regret that this decision was made," but as in "regret that not all the values could be satisfied."

Another thing we can say with respect to the conflict of values is that it is the burden of our society-wide deliberation to speak to the whole mix of values. Those views that would have it, for instance, that refusals of treatment are best justified by moral claims made by individual physicians,[7] are short-circuiting our society's discourse. There is no a priori and direct route to a simple answer. Rather, we aim to best satisfy our multiple values, knowing that our resolution is fallible. In those instances in which the clash of values is so deep that it cannot be satisfactorily accommodated by collaborative deliberation and the exchange of reasons, court cases are often the structures in which they are played out.

The position we outline here has implications for how to think about these court cases as well. First, we should think of them as part of the ongoing dialogue, and as one of the ways in which existing values and standards are challenged by patients, families, physicians, and hospitals. Thus, in a recent Canadian Supreme Court case brought by two physicians (Cuthbertson v. Rasouli, 2013), the physicians were fulfilling an important duty to engage in public debate. The values in conflict in this case were not atypical. The family argued that Rasouli, a devout Muslim, would want to be kept alive even in the unfortunate circumstances he was in. The physicians argued that keeping him alive would not result in any reasonable quality of life and would go against best medical practice. The physicians declined to apply to the board established by statute intended to resolve such disputes—the Ontario Consent and Capacity Board—as they argued the matter was not a matter of consent, but a medical matter about whether the disputed therapy was inappropriate or futile.

The way the case was framed illustrates a second point that can be derived from our position. The first sentence of the physician's factum (written argument) in *Rasouli* is: "This case raises the important question of who determines what medical treatments will be offered to a patient: a physician or the patient (or patient's substitute decision-maker)."[7] Bioethicist Arthur Schafer also described the case as a conflict of values between the family and the physicians:

> The Supreme Court of Canada's 5-2 decision in *Rasouli* is a clear victory for the family. Sadly, it is a loss for common sense and common humanity. It is also a blow against physician integrity and potentially damaging to the Canadian health-care system. (Schafer, 2013)

But this framing is regrettable. We should not think of the debate as determining who gets to decide. It is misguided, that is, to portray disputes about medically inappropriate or futile treatment as being a war between values and interests, with victories to be won or lost between families and physician integrity, or between families and the financial viability of the health care system. For every such conflict arises against a backdrop of society-wide values, and in resolving a particular conflict we make another move in our joint community-wide deliberation, aimed at getting an answer that best reflects all the values that ought to be reflected. As we shall show below, it is far from always the case that the values of families and physicians conflict.

A related point is that the fact that every conflict arises against a backdrop of agreement means that thinking of the debate in terms of whether or when physicians may act unilaterally is a distorting lens through which to view inappropriate or futile treatment determinations. For medical decisions are never made unilaterally, even though at times this may appear to be the case. Even when physicians think themselves entitled to make a decision on their own, that is a misrepresentation of the genealogy of their decision-making. Medical decisions are made in the context of an evolving web of belief and an implicit agreement between patients, physicians, and societies at large. Under the implicit terms of this social contract, it has been agreed that physicians should make certain kinds of judgments. This is in large part because they are made with a wealth of input from clinicians' education, experience, interactions with colleagues, and appreciation of the laws and norms of society and the profession. There is much that goes into a legitimate decision, and because of that, we see the decisions as legitimate, even if they do not fully satisfy us. For instance, when we take a child to the emergency room (ER) with a broken ankle, we might see that despite the child's pain, distress, and long wait, the triage system makes sense, and that it is right that more urgent cases are being treated before our own non-life-threatening one. Here, we are aware of the agreement we have implicitly made: that more urgent cases be seen first. We can be aware of this, even through our own distress and even while we advocate for shorter waiting times in the ER. In these cases one does not feel that an *injustice* has been served upon one. Much has gone into the decision: triage expertise, political compromises that the electorate has legitimized, and a long history of how best to deal with urgent medical matters. Similarly, when an intensive care physician refuses to provide extracorporeal life support (ECLS) to a person dying of advanced metastatic malignancy and multisystem organ failure, this is in a real sense a shared decision, even if the physician overrules the patient or family and even if he does not in the moment seek other opinions. What is being requested falls outside the boundaries of best medical practice, and much has gone into the determination of that best practice.

But also interwoven into the legitimacy of decision-making is the fact that those decisions and the policies on which they rest are open to scrutiny, criticism, and revision. Especially at the very frontiers of medicine and our societal values, we will need to engage in sustained debate about whether we are confronted with an instance of institutions reasonably not devoting scarce and expensive resources to treatments that have little hope of improving the patient's condition or of reasonably prolonging life, or whether our standards and values are such that those institutions must change their practice.

Finally, the *Rasouli* case illustrates one more point. The physicians' worry was, in effect, that the process in place in Ontario fails in the opposite way that the Texas approach fails. Their worry was that the process is not adequately equipped to take medical values seriously. The Court ruled that the Consent and Capacity Board was in fact the place for such decisions to be made and maintained that it did and must take seriously medical values. On our position, it cannot be overstressed that any legitimate dispute resolution procedure must in fact and in appearance weigh the requisite values, including medical values, appropriately. Of course, "appropriately" is itself a value term, and its best unpacking must itself be undertaken in debate and deliberation.

The question we must answer is how to develop a policy for decision-making that takes into account medical knowledge and standards, shared values, unshared values, and that provides a process for fairly determining the best outcomes. We present below a sketch of such a model. On it, the role of physicians and existing medical standards and practices is significant. How could it be otherwise, given that the locus of much medical knowledge rests there? Those standards and practices form an essential part of the background of belief and expertise that condition our judgments. But by reframing the futility debate as a debate within society, attention is shifted away from the question of unilateral decision-making toward one of balancing the legitimate perspectives of patients and physicians against a backdrop of societal constraints and values. Attention is shifted toward the question of whether processes ensure, for instance, that all values be taken seriously, that like cases are treated alike; that guidelines (AMA statements, specialty society guidelines, etc.) be open to challenge and revisable in ongoing deliberation, and so on.

The 1999 AMA statement bemoaned the frequent recourse to the courts and argued that the medical system ought to put in place a process that reduced the need for the involvement of the legal system. On the whole, we agree and offer some suggestions for such a process in the next section—a process that acknowledges that a vast majority of medical decisions, even those about inappropriate treatment, are straightforward, while building in a mechanism to challenge those boundaries. It is important to note, though, that while it would indeed be unfortunate and unmanageable if many decisions about inappropriate or futile treatment were bumped up to the courts, courts are nonetheless one important mechanism in which we work through end-of-life issues.[8] Such cases tend to be highly publicized, with the result that the public is engaged through op-eds, social media, letters to the editor, and so on. And of course, legal resolutions are not the end of the matter. For the law, on the view we put forward here, is merely part of the ongoing democratic process of weighing our sometimes conflicting values.

V. A MODEL FOR POTENTIALLY INAPPROPRIATE TREATMENT POLICIES

In many cases, the connection between the values of the patient and best medical practice is clear and forms part of our background assumptions. The values of an otherwise healthy post-surgical patient are best served by periodically checking vital signs to identify impending problems; those of an otherwise healthy child with bacterial meningitis are best served by antibiotics; those of a young man with sudden cardiac arrest are best served by CPR. Sometimes, for instance in emergency treatment, there is a set of widely accepted norms of practice that allow clinicians to initiate treatment without consent. And in intensive care units, where decisions must often be made on very short notice, care would grind to a halt if moment-to-moment decisions (e.g., which pressor or antibiotic to initiate) could not be taken by those charged with caring for patients. Similarly, it is accepted that physicians refrain from treatment in those rare instances in which the label "futile treatment" is apt, as when CPR is withheld from a patient in rigor mortis or following decapitation. Here, clinicians initiate or abstain from treatments without being required to first negotiate and gain consent with patients or their surrogates.

All of these *Straightforward Un-Negotiated* cases involve decisions that have the best medical knowledge behind them and where the values (making the patient better, not engaging in literally futile treatment) are assumed to be shared with the patient. The fact that some values can be assumed to be shared does not entail that duties to inform, discuss, and communicate with patients and their families fall by the wayside. It is important not to confuse the absence of the need to negotiate with the absence of the need to communicate. But we have here a justification of going straight to the best standard of care in many clinical cases.

Another value that patients and their families can be assumed to share with physicians is not to simply prolong a painful, torturous, and imminent dying process with treatment that has no hope of restoring the patient to a decent quality of life. This value is itself full of embedded value concepts such as "decent quality of life." What happens when the reasonable assumption that such values are shared does not hold? If a family does not think that prolonging a painful death for no benefit is unwarranted, does the physician have an obligation to participate in the torturous dying process? Does the family have a right to keep it going? These pressure points can be relieved (insofar as they can be relieved) only through a society-wide discussion and ensuing policy. Indeed, in the *Straightforward Un-Negotiated* cases there is often a formal rule or a law already in place—for example, we might give lifesaving treatment to children under laws prohibiting child neglect, even if their parents refuse. But we shall see below that on the frontiers of our implied agreement, the law, the medical profession, and citizens have much more to do by way of public deliberation.

Conversely, many medical decisions should not be made without negotiation—they are in the *Straightforward Negotiated* category, in which shared decision-making is clearly called for. Consider, for example, the decision between surgery, radiation, or "watchful waiting" for treatment of prostate cancer (Slomski, 2012). While physicians may have strong preferences for a particular approach, individual patients will assign different values to the different options in terms of balancing the probability of cure with the risk of side effects or have different views about the specific nature of the side effects associated with each approach. Here, accepted practice is that the physician and the patient must reach an agreement about which path to pursue.

The vast majority of medical decisions fall into one of these two straightforward categories. Patients should, and generally do, recognize that the impracticalities of requiring a negotiation in the *Straightforward Un-Negotiated* category are prohibitive, and physicians should, and generally do, recognize the need to negotiate with patients in the *Straightforward Negotiated* category. Both patients and physicians implicitly endorse this division of labor, reflecting the trust that patients have in the knowledge and experience of physicians, while at the same time expecting of the medical culture (the culture the medical profession and society have jointly created) that physicians understand the importance of incorporating the preferences and values of patients into decisions of the second type. Without these assumptions, the very practice of medicine would be imperiled.

Many decisions, however, fall in a *Gray Zone* between the straightforward poles. These cases might arise from scientific uncertainty about what course of care will best achieve the values agreed upon by clinicians and patients. Here, clinicians are duty bound to consult their colleagues and the literature, as well as the patient and family. But *Gray Zone* cases might also arise because the values of the patient or surrogate are in tension with those of the physicians.

In thinking about how to resolve non-straightforward cases, it is important—indeed it is a core point of this paper—to see that the categories do not have impermeable boundaries and that the very drawing of the boundaries is a matter for the medical profession, patients, and the public. In well-functioning democratic societies, this too is a discussion that takes place not only within the walls of hospitals and in ethics committees, but in society more broadly (Brock, 2007). The querying by patients and families of some straightforward medical decisions is part of the evolution of our practices. The same holds for the challenges to the status quo made by physicians, hospitals, and commentators. Physicians can and must express their views in this public debate, both individually and collectively through professional organizations and other forms of civic engagement. Their views often carry considerable weight, as they will partially rest on that background of specialized but revisable belief that has been built up over the decades. But the fact that a physician or the profession has particular beliefs and standards does not mean that those beliefs and standards are true, or justified, or ethically correct. There are many examples (see below) where medical judgments have been driven, for instance, by unjustified paternalism or the desire to avoid lawsuits. Citizens have the right and duty to challenge professional views and may seek to shift the line between the categories through social action, advocacy for legislation, or litigation (White and Pope, 2012). The lines between the categories are not static; they are continually being adjusted as these professional and social influences interact. And of course, no democracy functions perfectly—the debates may be unduly influenced, for instance, by politicians' desire for electoral success. These imperfections are themselves the subject of debate and activism in well-functioning democracies.

A different kind of expression is also open to physicians, as it is to all citizens—civil disobedience. While we have argued that there is weight to the profession's established consensus, we have also argued that that consensus is, and must be, open to challenge. Sometimes that challenge will need to take an extreme form (think about the history of the provision of abortion). But in refusing to provide treatments or insisting on offering them against the policies set by their institutions and by legislation, physicians of course incur the risks and consequences that accompany all civil disobedience.

Undoubtedly, further challenges and revisions to our practices regarding inappropriate or futile treatment will be warranted, but our current practices, enmeshed in institutional policy and legislation, embody our current view about how to balance and respect the various values that define the relationship between patients, physicians, and society. It is not that the status quo is right simply by virtue of being the status quo. Its weight is as it is because our current practice and policy reflects the best we have come to at this point in time and because we need a background of settled belief and practice on which to proceed, even when proceeding means revising. In a democratic society, we can think of that background as a public conscience by which we have undertaken to be guided. That public conscience must be constantly under scrutiny so that we ward against self-satisfied conservatism. But unless and until current standards and best judgments are challenged, either from within or from outside the medical profession, current best practice will and must largely determine both whether a treatment is inappropriate or not and whether there is a need to arrive at a negotiated agreement around initiating or foregoing particular medical interventions.

It is also important to remember that the views of the medical profession are rarely monolithic, especially when it comes to *Gray Zone* cases, and so a degree of variation in practice is likely to be present. One example is decisions about CPR for patients with advanced and terminal illness. Although many hospitals have policies that permit physicians to write a Do Not Resuscitate order without the need to negotiate an agreement with the patient or surrogate, others specifically reject this approach.[9] This lack of consensus is not to be disparaged. It reflects the fact that there are no bright lines on this particular matter.

Variation also exists at the level of individual physicians, who have beliefs and unconscious biases that may affect the way they counsel patients and surrogates in negotiated or gray area decisions, and in the way they come to un-negotiated decisions. Physicians can influence the choices patients make by being a "risk taker" versus a "risk avoider," by presenting options in one order rather than another, and in their use of statistics and even tone of voice (Epstein and Peters, 2009). Indeed, numerical and statistical literacy will vary from physician to physician and patient to patient. In addition, the forces of defensive medicine, which lead physicians to overuse diagnostic testing and treatment in order to deflect litigious claims that they did too little, and fee-for-service reimbursement incentives, which likewise encourage overuse of medical resources, also can distort decision-making.

But note that distortions exist in all kinds of decision-making. One virtue of the view we present is that there is no illusion that decision-making is devoid of human interests. Hence, we can be alert to and transparent about these complexities and potential biases. While our position gives shared aims the attention they deserve, it also puts the unshared aims in sharp relief and allows us to expose and work on eradicating the interests, such as those of defensive medicine, that we agree ought to be eradicated.

In thinking about how to resolve cases in the *Gray Zone*, it is also important that the solutions not jeopardize the functionality and legitimacy of those practices that are not controversial. Some argue, for example, that since no medical decisions are strictly free of values, every decision must involve a negotiated agreement with the patient (Veatch, 1994). This view puts at risk entire swaths of uncontentious practice. In general, neither patients nor physicians would endorse this as a functional solution, nor should they.

In the next section, we will provide examples that will flesh out the ideas we have set out.

VI. THE PAST, PRESENT, AND FUTURE: THE HISTORY OF FUTILITY REVISITED

In the early 1970s, physicians did not seek the negotiated agreement of patients and surrogates in discussions about continuing mechanical ventilation in terminally ill patients. Since removal of the ventilator usually directly leads to the death of the patient, physicians considered it an act of killing that was thereby ethically and legally prohibited. Within a changing social context, ascribing greater value to liberty and the rights of patients to refuse unwanted medical treatments, this position was questioned and challenged in many venues, including secular and religious social discourse, legal and political fora, and within the profession itself. By the end of the decade, professional norms had shifted dramatically, with wide consensus that whether to continue mechanical ventilation in terminally ill patients was a decision that required a negotiated agreement with the patient or surrogate (Meisel and Cerminara, 2004).

Some might interpret this as showing how social and legal reform corrected the unethical behavior of physicians in the early 1970s. But a better understanding is that these physicians were guided by their best judgment about what kinds of decisions demanded a negotiated agreement. They were behaving ethically by the standards of the time. When those standards were questioned and challenged, motivated by a shift in underlying cultural and social priorities, the dialogue between medicine and society evolved, which led to a change in the understanding of best practice.

Today, the debate is often focusing on whether physicians always need to negotiate decisions to initiate mechanical ventilation when requested or demanded by the patient or family. Some hospitals have policies that allow them to decide not to initiate ventilator support when they believe it to be inappropriate or futile (Pope, 2011). Yet other hospitals will not refuse mechanical ventilation. In a number of cases, physicians have been required by the courts to initiate or provide mechanical ventilation against their judgment (Miles, 1991). Multiple jurisdictions are engaged in this debate, showing various degrees of deference to physician authority (Pope, 2011). That is, demands for mechanical ventilation and other life-sustaining treatments have been in the *Gray Zone* for at least the past two decades, with no clarity in sight. They have ignited debates in the media and academia; they have appeared frequently in the courts and are the subject of legislative experimentation in the United States (White and Pope, 2012). While these conflicts are sometimes described as intractable, in our view this is precisely the conversation we as a society must have, while recognizing that perfect and final resolution will likely never be reached. The solutions will most likely be indefinitely iterative. And as we move along the path we are on, tools need to continue to be developed for the bedside, for physicians and other health care professionals to address and comfort the patient and family who, for instance, would like a treatment that is considered inappropriate or futile.

The future of the debate is likely to remain complicated. For instance, when patients with severe forms of respiratory failure can no longer be supported with mechanical ventilation, they can sometimes be kept alive with ECLS—a variety of techniques that involve surgical placement of cannulae or devices to artificially sustain cardiac and/or pulmonary function. ECLS is a powerful tool for keeping patients alive, and indeed it is very difficult for a patient on ECLS to "die" unless the support is actively removed. At present, physicians offer ECLS to only a select group of ICU patients, such as those who have reversible forms of cardiac or pulmonary failure or as a bridge to transplant in suitable candidates. Physicians consider the decision to offer the treatment to fall into the *Straightforward Un-Negotiated* category. While they may debate behind closed doors whether a particular patient is a candidate for ECLS, these matters are currently considered to be entirely within the purview of medical expertise. Once a decision has been made to offer ECLS, then the decision of whether to proceed is one that must be negotiated with the patient or surrogate, but unlike mechanical ventilation, virtually no intensive care physicians believe that patients or surrogates have a right to demand this therapy (Crow, Fischer, and Schears, 2009).

Looking ahead, one might wonder whether this practice will be challenged. Both mechanical ventilation and ECLS are technologies that support failing organs. ECLS is more demanding than mechanical ventilation—in terms of expense, expertise, and human resources—but fundamentally they both are tools for keeping patients alive. As patients and surrogates become more familiar with ECLS, will they demand it in situations where physicians believe its use would be inappropriate or futile? Will physicians succeed in deflecting what they judge to be unreasonable demands? Will the media begin to cover this controversy, will the courts become involved, will professional societies take a public position on the issue, will laws be passed? Any or all of these have the potential to reshape the boundaries of the implied social contract that currently prevails.

Another controversy that might well unfold in the future has to do with choosing between patients in making triage decisions in the ICU. Intensivists often must decide to move patients out of the ICU—even when the patient would likely benefit from continued ICU care—to make room for another patient in need of a bed (Truog et al., 2006). In these circumstances, the intensivist may be trying to maximize the overall value of limited ICU resources. Unlike many of the cases discussed above, triage decisions often involve a judgment about balancing the relative benefits of ICU care to one patient versus another. For example, a physician may be aware of a trauma patient with the potential for life-threatening hemorrhage in the emergency department, at a time when no beds are available in the ICU. She may mentally review the current patients in the ICU and decide that one of them is benefitting less from the ICU care than would the trauma patient and may then make a decision to move the less ill patient to a regular hospital bed. Such cases, when they arise, are often explained to patients and family members in terms of “your loved one did not need to be in the ICU anymore,” without revealing that the decision was not justified by an objective standard of need of that individual, but only by comparison to the needs of another. Another common—and much more worrisome—scenario has to do with decisions made in for-profit health care systems to triage patients out of the ICU in order to allow surgeons to perform complex but elective surgery on other patients who will need an ICU bed after surgery. Here, the ICU physician is balancing the risks of moving a patient out of the ICU earlier than would otherwise be the case, in order to advance the financial goals of the hospital and providers involved in the elective surgery. A less ethically worrisome, but nonetheless fraught, example is that of epidemics such as the 2002–2003 SARS epidemic in Canada, when decisions about how to ration scarce ventilator and ICU resources are forced upon a hospital. Institutions have emergency plans to deal with epidemics, and each of them involves difficult but necessary triage policies that in effect determine how to decide who will have a chance to live and who will not.

Without such triage practices and policies to determine relatively straightforward decisions, most hospitals would be paralyzed, making it impossible to schedule surgeries, have enough ICU beds for the critically ill, and deal with epidemics. Triage decisions currently fall squarely into the *Straightforward Un-Negotiated* category, so much so that they are rarely even disclosed to the patient or surrogate.[10]

Of course, one possible reason why clinicians believe that decisions about ECLS and triage should not be disclosed is precisely that disclosing them might give families the view that they should be negotiable and open up a whole new can of worms. Given the trends toward greater transparency with patients and families, these boundaries may come under scrutiny. As in the case of refusal of mechanical ventilation, we may come to see our current practices as incompatible with the rights of patients and responsibilities of physicians, even in light of the requirement to maximize resources for the ill and the requirement that hospitals run smoothly.

It may be that while tensions between the perspectives of patients and physicians have in the past dominated such debates, societal values are likely to play more of a role in the future. In our democratic and multicultural society, we will need to decide together how best to respect those values that are likely to make substantial demands on medical resources. We are moving into the world of personalized medicine, which will only put into sharper relief the tensions that arise between the care of individual patients and population-based heath care policy. The development of ever more sophisticated and expensive treatments will force societies to consider how much of other goods (e.g., education, infrastructure, defense) they are willing to sacrifice for these additional medical benefits (Meltzer and Detsky, 2010).

VII. CONCLUSION

One upshot of our argument is that unilateral decision-making by clinicians or families is not what is at issue in the so-called futility debate. Indeed, the concept of unilateral decision-making hardly makes good sense, for every decision made at the end of life is made against the background of a body of expertise, policy, and shared value that exists in part because of an implicit agreement between patients, the medical profession, and society. But if the debate is not about “who decides?”, then what is it about? We have argued that much of the debate should be centered on whether our current implicit social contract allows a certain decision to be taken in an un-negotiated way in which clinicians move straight to a decision, whether it requires negotiation, or whether it falls into a gray, potentially contentious domain.

Another upshot of our argument is that the trust placed in physicians and other health care providers is not made in an unthinking, authoritarian way. Our placing trust in the judgments of physicians in the straightforward cases is both reasoned (we have reasons to do so) and deliberative (it is the subject of much discussion in society). There is a distinction in administrative law between submissive deference and deference as respect.[11] The latter requires a willingness and ability on the part of the decision-maker to offer reasons to justify a decision, and when one defers to that decision it is because the reasons suffice—they are good enough to justify the decision. Our argument runs along similar lines. Deference to physician authority must not be submissive deference due to a glorification of physicians as authority figures. The deference that ought to be accorded to physician judgment is one that respects their education and expertise, is based in trust that the physician is acting in the best interests of the patient, and asks for reasons and justification. The corresponding duty on the part of physicians is that they must be prepared to give reasons for their decisions and, on the frontiers of medicine and policy, they must advocate for their best understanding of medical and ethical practice. This requires them to call upon their education and experience to sometimes say, in effect, "I know you want to be intubated, but I am confident that this will lead to a worse death for you, and cause more pain and suffering for your family. Therefore I will not intubate you, but provide you with palliative care, unless I am compelled to do otherwise by an external authority." Those external authorities, such as hospital ethics committees and legislators, also must take genuine, and often bold, stands about what they believe to be right and wrong. Passing the buck and avoiding controversy are not good decision-making strategies. Moreover, it is not what society expects of our medical professionals or those who are charged with lawmaking and the review of law. There is an obligation on the part of all of us to express opinions and to put them in play in the dynamic equilibrium that is the crucible in which these important decisions are made.

Notice that nothing we have said distinguishes, in general, the futility debate from debates in other kinds of inquiry. Even in the law, when we have a clear and codified set of rules in statute, we are engaged in interpretation of and debate about those rules. Rules, that is, are prescriptions designed to govern a wide range of situations. But no matter the care taken to draft them and the degree of clarity they achieve, those who have to apply them to particular situations are going to have to interpret the rules in light of their understanding of the rule's purpose, the practical constraints, the general values in society, and the values of sound practice, including values having to do with being sensitive to the interests of those affected by the decision. Those who are engaged in decision-making about medically inappropriate or futile treatment do not and cannot have a definitive code or rule book. What they have are accepted best standards of medical practice, often set out in guidelines (such as the AMA statement and the new ATS Guideline), legal resources, and local hospital policies that aim to follow those requirements. They also have the conflicting mix of their own values and the values of their societies to work with.

The analysis of decision-making presented here has the virtues of accurately reflecting practice, of not setting up unattainable utopias, and of encouraging deliberation, genuine shared decision-making, and the discussion of hard questions in the medical profession and in public arenas. It also has the virtue of not pretending that the judgment of clinicians is excisable. Society educates and trains clinicians and expects them to use that informed judgment. The view offered here, we submit, takes us a step closer to an ethically robust, fair, and practical strategy to manage hard cases in decent, evolving, and democratic societies.

NOTES

1. This paper has been improved by the comments of David Mazer and three anonymous referees.
2. See, for instance, the American Medical Association's (1999) statement on medical futility, which refers to both competing approaches, also Plows et al. (1999).
3. A full defense of this pragmatist moral epistemology would have to be book-length. See Misak (2000), Talisse (2009), and Landemore (2012) for sustained arguments.
4. See Dworkin (2011, 177).
5. This is the Rawls of reflective equilibrium, not the Rawls of the veil of ignorance. See Botti (2014) for how Rawls was influenced by pragmatism.
6. See Halevy and Brody (1996).
7. See Cuthbertson and Rubenfeld (2013, 1).
8. See White and Pope (2012).
9. See Curtis and Burt (2007) and Manthous (2007).
10. See Young et al. (2012) and Danis (2012).
11. The distinction is due to Dyzenhaus (1997).

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