

## Laying Futility to Rest

MICHAEL NAIR-COLLINS\*

*Florida State University College of Medicine, Tallahassee, Florida, USA*

\*Address Correspondence to: Michael Nair-Collins, PhD, Department of Behavioral Sciences and Social Medicine, Florida State University College of Medicine, Tallahassee, FL 32306, USA. E-mail: [michael.nair-collins@med.fsu.edu](mailto:michael.nair-collins@med.fsu.edu)

*In this essay I examine the formal structure of the concept of futility, enabling identification of the appropriate roles played by patient, professional, and society. I argue that the concept of futility does not justify unilateral decisions to forego life-sustaining medical treatment over patient or legitimate surrogate objection, even when futility is determined by a process or subject to ethics committee review. Furthermore, I argue for a limited positive ethical obligation on the part of health care professionals to assist patients in achieving certain restricted goals, including the preservation of life, even in circumstances in which most would agree that that life is of no benefit to the patient. Finally, I address the objection that professional integrity overrides this limited obligation and find the objection unconvincing. In short, my aim in this essay is to see the concept of futility finally buried, once and for all.*

**Keywords:** *futile care, medical futility, qualitative futility, quantitative futility, vegetative state*

### I. INTRODUCTION

Over a decade ago, Helft and colleagues wrote of the rise and fall of the futility movement (Helft, Siegler, and Lantos, 2000). Notwithstanding their and other significant criticisms, the concept is considered no less relevant today than ever (Wilkinson and Savulescu, 2011). Although a few stalwart supporters continue to defend a substantial concept of futility as justifying unilateral treatment decisions (Schneiderman and Jecker, 2011), the trend is toward a process-based approach to futility disputes, aimed at deliberation and resolution, and taking into account multiple perspectives (Halevy and Brody, 1996; Council on Ethical and Judicial Affairs, 1999). This trend toward

futility determination as a process is encouraging, yet it does not go nearly far enough. The use to which the concept of futility has been put in clinical decision making is fatally flawed, and it does not justify unilateral decisions<sup>1</sup> to withhold or withdraw life-sustaining treatment, even when futility is determined through a process or subject to ethics committee review. My aim in this essay is to see the concept finally buried, once and for all.

## II. THE ARC OF THE HISTORY OF MEDICAL ETHICS

Prior to the 20th century, the moral locus of the physician–patient relationship was considered to lie with the physician, rather than the patient. That is, the physician’s obligation of beneficence, to act for the good of his patient, was the ethical core of that relationship, and concepts such as informed consent were foreign to this ethical framework. Physicians were to be gentle but firm and directive with their patients, and it was for the physician to decide what was good for the patient: hence the phrase, “doctor knows best.” However, at the turn of the 20th century, and gathering significant steam from the 1960s through the 1980s, a really quite radical shift occurred, changing the focus of the ethics of medicine and health care from the positive obligations of the physician to the autonomy and liberty rights of the patient. Two key, intersecting strands of events can be identified as particularly important in bringing about these changes. First, a number of significant and well-known judicial decisions firmly established patients’ legal rights of informed consent and informed refusal as having priority over a two-and-a-half millennia old tradition of physician paternalism. Second, a number of widely publicized medical research scandals, the most influential of which was the US Public Health Service syphilis trials in Tuskegee, Alabama, resulted in a previously unknown oversight of medical research and medical practice, along with a strengthened emphasis on the rights of patients and subjects.

By roughly the 1980s and 1990s, however, it began to seem that the pendulum had swung too far. Autonomy, the ability to be self-governed or to be a good ruler over oneself, generates liberty rights, and hence refusals of treatment carry significant moral weight. But refusals are not the same as requests or demands. Autonomy rights do not generate the authority to have one’s demands met, yet medical professionals began to point out that patients or their surrogates were demanding treatments that professionals considered contraindicated, whereas physicians nonetheless felt obligated to provide these treatments against their professional judgment ([Blackhall, 1987](#)). Thus, the concept of futility began to receive significant attention, with the most influential account being that of [Schneiderman, Jecker, and Jonsen \(1990\)](#). On this account, physicians are entitled to use their professional judgment to determine that certain treatments are futile and to withhold or withdraw those treatments without patient consent. Futility judgments are

professional judgments outside the domain of patient rights. If the professional determines that a treatment is futile, it need not be offered at all, the patient has no decision to make in the first place, and therefore professional futility judgments are logically antecedent to patient decisions.

As Brody and Halevy have aptly pointed out, the concept of futility must be understood against the backdrop of the purpose for which it is used. “In short,” they write, “the function of invoking futility is to authorize physicians to unilaterally limit life prolonging interventions in certain cases, while preserving the rights of patients and surrogates to decide about the provision of such interventions in other cases” (Brody and Halevy, 1995, 124). Thus, the concept of futility as a professional judgment acts as a corrective to the excesses of patient autonomy, providing a more suitable balance between professional integrity on the one hand, and patient autonomy rights on the other.<sup>2</sup>

### III. THE CONCEPT OF FUTILITY

Futility is a simple concept: futile activities are useless, or are activities that are unable to achieve any meaningful goal, such as Sisyphus’ endless task of rolling a boulder up a hill, only to watch it roll back down and then begin again. As is well known, however, translating this concept into the health care context is not quite so simple, and a number of futility concepts have been identified, including qualitative futility, quantitative futility (Schneiderman, Jecker, and Jonsen, 1990), strict physiologic futility (Truog, Brett, and Frader, 1992), lethal condition futility, and imminent demise futility (Brody and Halevy, 1995). My aim in this section is to identify what all of these concepts have in common. Thus, I will briefly attend to the formal structure of the concept, which will lay the groundwork for showing why futility (in any of its more specific incarnations) does not justify unilateral decisions about end-of-life treatment.

The first and most obvious structural property of the concept of futility is that it is a relation between an intervention and a goal (Youngner, 1988; Truog, Brett, and Frader, 1992). For example, “CPR is futile for the goal of discharge from the ICU for Mr. Jones” is a substitution instance of the propositional function, “ $x$  is futile for achieving  $y$ .” This makes clear that it is meaningless to state that a treatment is futile *tout court*. For example, “CPR is futile” has no truth value because it is a propositional function whose second variable must be specified. Although this is a helpful first start, probabilities must also be taken into account. Thus:

Let  $T = \{t_1, t_2, \dots, t_n\}$  be the set of possible treatments

Let  $G = \{g_1, g_2, \dots, g_n\}$  be the set of goals of treatments

Let  $P = [0, 1]$ , with numerical values representing the range of probabilities defining the likelihood that a given goal or outcome will occur

Let  $f_i : T \times G \rightarrow P$  be a function from the Cartesian cross-product of  $T$  and  $G$  to  $P$ .

Hence our formulation of the binary function:

$$(1) f_1(t_i, g_i) = p, \text{ with } p \in P$$

and its associated definition of futility:

$$(2) \text{ If } f_1(t_i, g_i) \leq n, \text{ with } 0 \leq n \ll 1, \text{ then } t_i \text{ is futile for achieving } g_i.$$

It should be apparent that formulation (1) is a definition of efficacy, the likelihood that a given intervention will achieve a certain goal, and thus formulations (1) and (2) clarify the relationship between efficacy and futility: futility is merely the low end of the continuous range of efficacy (Lantos et al., 1989). The concept of futility introduces a dichotomous cut over the continuum of probabilities that describe the efficacy of a treatment with respect to a goal. Formulation (2) also makes apparent that whether a treatment is futile with respect to a given goal is relative to a specification of the value of  $n$ . The most influential suggestion is Schneiderman and colleagues' proposal that  $n = 0.01$ , though there is nothing inherent in the concept of futility itself to set the value there and not at some other value (zero is the only value representing "pure futility").

Not all health care goals admit of a binary description of their success. Although a goal such as discharge from the hospital does, other goals such as relief from pain or degree of lucidity admit of both partial and complete achievement. Furthermore, a probability of occurrence is associated with each value of the measure of degree of success for a given goal. For example, it may be unlikely that a patient's pain will not be affected at all by a pain medication, likely that her pain will be partially alleviated, and very unlikely that her pain will be completely alleviated. We account for this as follows:

Let  $E = [0, 1]$ , with numerical values representing the degree or amount of effect achieved with respect to a given goal; for example, 1 would represent complete pain relief, 0 would represent no effect on pain, and values between 0 and 1 represent an ordered range of partial pain relief (" $E$ " is to remind us of "effect").

Let  $P = [0, 1]$ , with numerical values representing the range of probabilities defining the likelihood that a given degree or amount of effect of a given goal will occur (this is the same set  $P$  defined above; in its previous definition the value of  $E$  was implicitly assumed to be 1).

Let  $f_2 : T \times G \rightarrow P \times E$  be a function from the Cartesian cross-product of  $T$  and  $G$  to the Cartesian cross-product of  $P$  and  $E$ .

Then our new formulation of efficacy becomes:

$$(3) f_2(t_i, g_i) = (p, e) \text{ with } p \in P \text{ and } e \in E.$$

Its associated definition of futility is:

$$(4) \text{ If } f_2(t_i, g_i) = (n, m), \text{ with either}$$

- (a)  $0 \leq n \ll 1$  and  $0 \ll m \leq 1$ , or  
 (b)  $0 \ll n \leq 1$  and  $0 \leq m \ll 1$ , then  $t_i$  is futile for achieving  $g_i$ .

Intuitively, if there is a low probability of a high effect (case (a)) or a high probability of a low effect (case (b)), then  $t_i$  is futile for achieving  $g_i$ . As with formulation (2), the values of  $n$  and  $m$  in both cases need to be specified in order to complete the definition, and there is no obvious a priori reason for setting them at any particular value (except 0 and 1). Note that (3) is the more general version of the definition of efficacy, with (1) being the special case in which the value of  $e$  is always set at 1.<sup>3</sup>

Formulations (1) and (3) define probability distributions describing the efficacy of possible treatments for achieving health care goals, in a particular individual at a particular time (I will also refer to them as “efficacy curves”). Given a particular patient at a time, a goal, and an intervention, it is a fact about the world as to what is the likelihood that that intervention will achieve that degree of success for that goal.<sup>4</sup> That fact about the world is not identical to epidemiologic information from groups of patients nor is it identical to any individual physician’s doxastic states referring to that fact. Instead, epidemiologic information is an epistemic tool (among several) that physicians can use to formulate their beliefs regarding the efficacy curve for a particular patient, and those beliefs, and the statements that express them, are fallible.

Thus, for any given statement that the efficacy curve for a particular patient is so-and-so, a *confidence rating* must be appended to rate the degree of confidence that that statement is correct. The confidence rating is analogous to significance in inferential statistics: it provides a measure of the reliability of the statements made. It is to be noted that this confidence rating is not a measure of the certainty that an individual physician *feels* with regard to her statement (i.e., it is not a subjective measure of the strength of her belief). Rather, it is an objective and normative measure describing the level of confidence that any observer *ought to have* with regard to the reliability of that statement.

All of the major concepts of futility proposed in the literature are captured by this model. For example, Schneiderman and colleagues’ concept of qualitative futility states that a treatment should be considered futile if it merely preserves permanent unconsciousness or cannot end dependence on medical care that can be provided only in an ICU (Schneiderman, Jecker, and Jonsen, 1990) or, as they later extend the concept, if it cannot end dependence on treatment that can only be provided in an acute care hospital (Schneiderman and Jecker, 2011). We can state this idea using the model in two different ways. One would be to state that the goal of treatment is, for example, to restore consciousness. If the probability that a given treatment (e.g., artificial nutrition and hydration) will achieve the goal of restoration of consciousness for a given patient is very low (perhaps less than 1%), then the treatment is futile for achieving that goal. Another means of accommodating their idea is by restricting certain goals from being members of the

set  $G$ . At least for Schneiderman and colleagues, the preservation of biological life in the absence of consciousness and the preservation of life in the hospital in the absence of the ability to survive outside the hospital are not legitimate or acceptable members of  $G$ . Their concept of quantitative futility is simply captured by setting the value of  $n$  in formulation (2) to 0.01. Each of the other major concepts of futility is captured by the model in obvious ways, either by restricting the membership of  $G$ , by setting  $g_i$  to a specific goal (such as cure of a lethal condition), or by specifying values of  $n$ .

When a futility dispute arises, the nature of the dispute can thus be clarified in terms of the model: is it a dispute about what, in fact, is the true efficacy curve? Is there agreement on the efficacy curve but disagreement about the appropriate values of  $n$  (or  $n$  and  $m$ )? Is it a dispute about the appropriate goal of treatment for this particular patient (i.e., selecting a  $g_i$  from among the set  $G$ ), or perhaps does it draw on more general concerns about the legitimate or appropriate goals of health care (i.e., determining the appropriate membership of the set  $G$ , in general)? Answering this last question about the legitimate goals of health care is critical to understanding and resolving the futility debates.

#### IV. THE GOALS OF HEALTH CARE

Some conception of the appropriate goals of health care operates implicitly (and sometimes explicitly) in the debate about futility. The two most controversial outcomes include life in the absence of consciousness and the maintenance of life for a brief time in the hospital when discharge from the hospital seems impossible. Schneiderman and colleagues consider both of these outcomes to fall outside of the domain of acceptable goals of health care. They write, “The ends of medicine lie not with mere biological survival nor with the patient imprisoned within machines and tubes. At the very least, the ends of medicine require providing the patient with the capacity to participate in the human community” (Schneiderman and Jecker, 2011, 19). Furthermore, they argue that *effects* must be distinguished from *benefits*, and the aim of medicine is “to benefit the patient as a whole” (Schneiderman, Jecker, and Jonsen, 1990, 950), not merely to cause an effect on the patient’s anatomy or physiology. Importantly, their concept of what constitutes a “benefit” is rooted in the medical profession’s history and traditions; it is not tied to the patient’s view of what constitutes a benefit.

By contrast, Veatch and Spicer adopt the perspective of the social contract: health professionals are granted special licensure by society, in that they are the only ones granted the authority to use the life-saving technology needed or desired by patients. But this (as with all professions) is based on an implicit social contract: the rights and privileges of the profession bring with them certain responsibilities. To identify some of



those responsibilities we should ask: “what would be a reasonable agreement made between a citizenry and those it is going to license to hold a monopoly on knowledge about and use of life-prolonging technologies?” (Veatch and Spicer, 1992, 27). Using the Rawlsian concept of the veil of ignorance, they argue that, in ignorance about one’s own preferences regarding life-sustaining treatments that others deem to hold no value (e.g., life-sustaining treatments in the hospital when survival outside the hospital is no longer possible), any rational deliberator under the veil of ignorance would want to assure some reasonable opportunity to gain access to those disputed treatments, even if the individual professional responsible for the patient’s care considers those treatments to have no value. This is because the rational deliberator under the veil of ignorance will not know whether she is in fact among the minority who would seek to pursue life-sustaining treatment when others would not. The same argument can be used to identify appropriate goals: a rational deliberator under the veil of ignorance would include, as a condition of exclusive rights to access life-saving technologies, that the goal of maintaining life be acknowledged as an appropriate use of those technologies, even if most would consider life for that patient to have no value or be of no benefit to the patient whose life it is.

This change of perspective—from focusing exclusively on the allopathic medical profession and its history, to focusing on the larger social structure within which the practice of health care is embedded—is critical. Health care is a collaborative social practice, dependent on many professions and occupations. It is a multi-trillion-dollar, international enterprise involving physicians, nurses, pharmacists, respiratory therapists, social workers, and many others. The funding for this massive endeavor is largely provided through public sources (i.e., taxes). Most industrialized nations guarantee some form of health care, considering it a public good to be provided using public funds, akin to education or police service. Although the United States is an exception by treating health care largely as a market-based good, nonetheless there are numerous publicly funded safeguards and subsidies in the United States as well.

Furthermore, it is critical to recognize the large public investment made in the education of professionals, even in the United States. Each of the above-named professions requires a specific educational or training pathway, most involving university training and beyond. Public funds are involved in government-funded student loans and grants, state and federally funded or subsidized universities, colleges, and professional schools, as well as other sources of professional education (e.g., all accredited medical residency programs in the United States are funded through Medicare). Furthermore, billions of dollars in public funds are spent each year on research, from research into the molecular mechanisms underlying disease processes, to the development and testing of new technologies, to the most effective means of framing health care educational messages.

Although the above points are obvious (and can be greatly elaborated), it is important to reflect on just how much of a shared social endeavor health care is, both in its practice and in its funding. This is relevant because it suggests two important points about the appropriate aims of health care in the context of futility debates: determining what constitutes the appropriate aims of a shared social practice is not a purely individual decision (either by patient or physician), and second, it is not solely a matter of the allopathic medical profession attending to its historical roots or what it conceives of as the aims of medicine (*pace* Schneiderman, Jecker, and Jonsen). The appropriate question is: what are the acceptable aims of *contemporary health care*, which includes the practices of multiple professions and occupations, and is *largely publicly funded*?

Veatch and Spicer were on the right track in looking to the social contract to shed light on the futility debate and to the veil of ignorance to define the terms of that contract. In attempting to identify the appropriate aims of health care in light of reflection on its shared social nature, both in practice and in funding, a different Rawlsian tool is also useful: the overlapping consensus (Rawls, 2005). Instead of trying to identify the aim of *medicine*, we should instead seek to identify the goals of *contemporary health care* that can achieve an overlapping (but not perfect) consensus in a democratic society in which we do not all share the same basic worldviews or value systems.

Part of what has made the concept of futility such a lightning rod, both within the health care professions and without, is that a good part of these debates is tied to fundamental moral and religious concerns that shape basic worldviews and value systems. The concept of health and the practice of health care each bear intimate connections to some of the most deeply moral (and for some, religious) aspects of human existence: life and death, suffering, freedom from pain, autonomy, the opportunity to pursue interests, human flourishing, a good or meaningful life, quality of life, and so on. Indeed, there is an intimate connection between potential goals of health care and views of moral status. For example, the goal of preserving normal cognitive functioning can be seen in relation to Lockean or Kantian views about personhood and moral status: Locke saw personhood (implying moral status) as requiring self-consciousness and the ability to conceive of oneself as persisting over time, with both a past and a future, whereas Kant saw the dignity of humanity as rooted in rationality and moral agency. The goal of alleviating pain and bodily suffering, even when higher-order cognitive or linguistic functions and the ability to communicate are lost (e.g., in advanced dementia), can be tied to Benthamite considerations of sentience as sufficient for moral status, although the Kantian perspective would deny that such an individual holds full moral status. The goal of preserving life, even in the presence of profound disability, including permanent unconsciousness, can be connected to traditional sanctity-of-life views associated with the Judeo-Christian-Islamic tradition.



Surely, there is no consensus on what is minimally sufficient for full moral status. The Kantian would insist on moral agency and rationality, the utilitarian on sentience, and for the Abrahamic religions, human life itself is sacred and thus sufficient for full moral status. Yet, these views on moral status can strongly influence one's conception of the acceptable goals of health care (i.e., the membership of *G*), and thus views on futility.

To determine the acceptable goals of a shared social practice that is largely publicly funded, I argue that the focus should be on tolerance and overlapping consensus, constrained by the (admittedly ill-defined) notion of "reasonableness." The different views of moral status mentioned above, and the concomitant health care goals they suggest, are each held by reasonable, morally serious people. They are not arbitrary or idiosyncratic but are connected to respected intellectual and religious traditions. For many, such views form a core part of one's conceptions of self, world, and morality. In light of reasonable disagreement about fundamental value judgments such as the minimally sufficient determinants of full moral status and in light of the public funding for a shared social practice that is intimately connected to these deep value judgments, the most appropriate stance to take here is one of tolerance for reasonable views, based on the fact that reasonable people do in fact hold such views, and for reasons that all can appreciate as relevant if not sufficient.

Furthermore, there is indeed overlapping consensus that each of these goals—preserving autonomy and cognitive abilities, minimizing pain or bodily suffering, and preserving life—are important and meaningful. The only dispute is which of them serves as minimally sufficient for full moral status when the others cannot be achieved, though everyone would agree that if all three can be achieved, and the patient is able to function as part of the human community (as Schneiderman and Jecker describe it), then that is clearly the optimal outcome. Thus, the appropriate aims of health care, the membership of *G*, surely includes the goals of medicine identified by Schneiderman and colleagues mentioned above; but it also includes the goal of the preservation of life, even in the context of profound disability or terminal illness, or when most people would judge that person's life to hold no value or to be of no benefit to her.<sup>5,6</sup>

## V. MORAL AND EPISTEMIC AUTHORITY (AND THEIR LIMITS)

### Moral Authority and Its Limits

The authority to determine the set of acceptable goals of contemporary health care lies in the hands of society at large, and it should be answered by appeal to an overlapping consensus and tolerance for reasonable views; thus, membership in *G* is fairly permissive, and includes traditionally conceived goals of medicine, as well as the goal of preserving life itself. Given

G, it is clear that determining what the goals of treatment *ought* to be for an individual patient is a value-laden determination whose moral authority to make lies with the patient (or, the patient by way of her surrogate).

In the vast majority of health care interactions, clinicians and patients share the same goal: that the patient becomes well again or stays well. But in those rare instances of intractable conflict that arise in futility disputes, the moral authority to determine value judgments, such as what constitutes a benefit, whether likely harms outweigh likely benefits, and, particularly, which goals are to be pursued and which goals are not to be pursued, ultimately lies with the patient, not the professional. To assume otherwise is to commit what Veatch (1972) has called the fallacy of the generalization of expertise: knowledge about physiology and pathophysiology does not generalize to “moral expertise” or to the moral authority to determine what is *good* for another. If it did, then the nuclear physicist would have special moral expertise or authority in determining when it would be morally right to use a nuclear weapon to demolish a city, and the electrical engineer would have special moral expertise or authority in determining whether or when the use of the electric chair in the death penalty is morally right. These of course do not follow, and neither does it follow that the physician has special moral expertise or authority in determining value judgments for another person. This idea lies at the core of the well-accepted notion that the fundamental moral justification for any health care interaction is not the physician’s beneficence; it is the patient’s *consent*. Those in the helping professions have no authority to help without that consent, either explicit, tacit, through a surrogate, or at least reasonably presumed, as in a life-threatening emergency.

This is not to say that health care professionals are themselves unjustified in making any value judgments, or that they should play no role in the patient’s decision making, or that the health care professions are not committed to achieving moral ends. For example, Tomlinson and Brody argue that the standard objection to futility judgments as rooted in inappropriate value judgments is misguided, because making value judgments is a necessary part of medical practice. They write, “the real question can no longer be *whether* value judgments can be made [by physicians]... the question is *which* value judgments physicians may use in deciding whether to meet patients’ demands” (Tomlinson and Brody, 1990, 1278). Schneiderman and Jecker (2011, 121) similarly acknowledge the standard objection, writing,

We agree that physicians could never claim authority to render futility judgments under the guise of some purely objective and value-free “scientific” or “technical” expertise. Instead, the proper basis for assigning physicians authority to set standards for the practice of medicine is that an ethical dimension is an integral component of the historical and contemporary role of the profession in society.

Both of these responses miss the point. They set up a false dichotomy in which physicians may either override informed patient (or legitimate

surrogate) decisions about life-sustaining treatment on the one hand, or on the other hand, they may not make any value judgments whatsoever and must simply do whatever the patient wants. Neither of these options is either realistic or acceptable.

The question is not *whether* physicians can make value judgments. They can, do, and should. Nor is the question whether the health care professions embody an ethical component integral to their practice—they do. Rather, the question is whether, in the rare case of intractable disagreement, the physician's assessment of the values at stake can *override* the informed patient's or legitimate surrogate's assessment of the values at stake. When this rare intractable disagreement occurs, the weight of the moral authority to determine value judgments on patient care lies with the patient or surrogate, and this is particularly so when the value judgments involved reflect deep, fundamental questions about life's value or the meaning of life.

There is an important difference between refusals and requests (mirroring the difference between negative and positive rights), and requests do not carry the same moral weight as refusals; yet this analysis is too simple for the health care context. Some requests do generate limited obligations, particularly in the context of special relationships, or in the context of a promise. Being a professional involves an implicit social contract, hence, a promise. The contract is that health care professionals will be granted license to gain specialized knowledge and skills, and to have exclusive access to the technologies of health care, in exchange for using their knowledge, skills, and access to technologies for the benefit of the public. If a patient is involved in a doctor–patient relationship (and the doctor is on duty, responsible for that patient's care, etc.), and the patient requests assistance in achieving one of the socially accepted goals of health care, then, barring some overriding reason not to comply, that patient's request does generate a limited obligation on the professional. This is both because of the social contract (and hence is a matter of promise-keeping), but also because of the obligation rooted in the special fiduciary relationship.

Crucially, only those goals that are members of the set  $G$  can generate obligations to the patient. If a patient requests the assistance of a health care professional (who is on duty, etc.) in achieving goals outside of  $G$ , for example, purely cosmetic enhancement (which I assume for the moment is outside of  $G$ ), presumably the professional and the patient are free to enter into that relationship if they choose. In other words, this *may* be permissible. But the patient's request does not generate even a limited obligation on the part of the provider. On the other hand, a patient in pain or distress who requests assistance from a professional does generate a limited obligation for the professional, and similarly for other requests that reflect goals of treatment within the set  $G$ . Thus, the moral authority of patients and surrogates to choose among goals of treatment (such that their doing so generates limited obligations on the part of the professional to assist) is limited to the goals in

$G$ , which includes at least the cure of maladies, alleviation of pain and suffering, and the preservation of life.<sup>7</sup>

Yet, even the constrained authority to select only from among  $G$  (such that doing so generates obligations for the professional) is further limited by justice in the fair allocation of resources. A patient's request for assistance in achieving goals within the set of acceptable aims of health care does not generate an obligation to comply if doing so would result in an unjust distribution of resources. I will return to this point in the following section, but for now it should be noted that Schneiderman and colleagues were absolutely right in distinguishing rationing, a matter of fairly distributing resources at the policy level, from futility, which is always with respect to an individual patient (Schneiderman, Jecker, and Jonsen, 1990, 953).

### Epistemic Authority and Its Limits: Diagnosing the Vegetative State

Health care professionals, by contrast, have *epistemic* authority rooted in specialized knowledge and experience. They are presumptively the best source of information on factual questions, including both diagnosis and prognosis. Therefore, given a treatment, a goal, and a particular patient, the knowledgeable and experienced health care professional is the best source of information for determining the likelihood that that treatment will achieve that goal. Where the moral authority of the patient is limited by the appropriate aims of health care and by distributive justice, the epistemic authority of the professional is limited, very simply, because knowledge claims are fallible. This is reflected in the confidence rating mentioned above, which can be applied to both prognostic assertions as well as diagnostic assertions. I begin with diagnosis.

For the most part, people do not dispute diagnoses of pneumonia or renal failure, yet the diagnosis of the vegetative state is often disputed. Furthermore, this is one of the most common triggers for claims of futility, and indeed forms the core of Schneiderman, Jecker, and Jonsen's influential account of qualitative futility: an intervention that only sustains permanent unconsciousness is, on their account, futile. Therefore, it is worth a brief excursion to consider the reliability of the diagnosis.

The vegetative state is considered a state of "wakefulness without awareness" (Jennett and Plum, 1972; Multi-Society Task Force on PVS, 1994). Patients in the vegetative state exhibit sleep-wake cycles and thus lie with their eyes open while awake, but do not exhibit apparently purposeful or meaningful behavior, and do not appear to be aware of their environment. In particular, reliable and reproducible eye-tracking, in which a patient follows a moving object with her eyes, is inconsistent with the diagnosis. Although there is severe brain injury in the vegetative state, such patients do maintain a number of neurological functions, such as control of heart rate, blood pressure, and ventilation, as well as hormonal regulation. Most patients in the

vegetative state are not on a ventilator, and about half do not need feeding tubes, as they are able to swallow normally (Ashwal, 2004).

There is *no* definitive anatomic correlate to the vegetative state (e.g., it is false that the vegetative state involves destruction or complete dysfunction of the “higher-brain,” i.e., the cortex). Sometimes cortical cell bodies are destroyed from anoxia; other times there is widespread axonal shearing from trauma (Bernat, 2006); and yet other times there is damage to the thalamus with relative sparing of the cortex (Kinney et al., 1994). There are no imaging or electrophysiologic modalities, nor are there any biomarkers, that can confirm or refute the diagnosis. The diagnosis can be neither confirmed nor refuted by autopsy. It is *essentially* a clinician’s determination of whether the preserved behaviors of an individual patient, which can include blinking, grunting, crying, smiling, movement of eyes and extremities, and more, are “meaningful” or “purposeful”; furthermore, finding behavioral signs of awareness is partially a function of how hard you look. Therefore, it is no surprise that the misdiagnosis rate for the vegetative state hovers around a 30%–40% false positive rate (Childs, Mercer, and Childs, 1993; Andrews et al., 1996; Majerus et al., 2005; Schnakers et al., 2009; Seel et al., 2010; cf. Giacino et al., 2014 for a recent review). That is, about 30%–40% of the patients in these studies who were diagnosed as being permanently unconscious in fact showed subtle yet reliable and reproducible signs of conscious engagement with the environment. They were at least minimally conscious, whereas according to their diagnosis they were not.

The false positive misdiagnosis rate is based on finding subtle overt behavioral signs of awareness in patients who had been falsely labeled as “permanently unconscious.” However, even in patients for whom *no* overt behavioral signs of awareness is evident, a range of brain function can be preserved, involving activation of a number of brain areas in response to sensory and noxious stimuli, including primary (and occasionally secondary) somatosensory cortex, insular cortex, anterior cingulate, the midbrain, and the thalamus (Laureys et al., 2000; 2002; Kassubek et al., 2003; Boly et al., 2004); semantic processing involving disambiguation of ambiguous words (Owen et al., 2005; Coleman et al., 2007); intentional acts of imagination (Owen et al., 2006); and indeed, communication through brain–machine interface has been shown to be possible in a patient lacking overt signs of conscious awareness (Monti et al., 2010). There are multiple studies using various neuroimaging and electrophysiologic techniques that demonstrate the preservation of a range of neurologic (including cortical) functioning in patients who lack unambiguous behavioral responsiveness. Because of the wealth of evidence suggesting the unreliability of diagnosing lack of awareness, one group, The European Task Force on Disorders of Consciousness, has called for simply abandoning the term “vegetative state” and replacing it with “unresponsive wakefulness syndrome,” so as not to presuppose that patients lacking the ability to behaviorally respond also lack awareness

(Laureys et al., 2010). It is worth repeating that this evidence is with respect to patients who show *no* overt signs of purposeful responsiveness; the 30%–40% false positive rate refers to patients who do show subtle behavioral signs of awareness that are missed by clinicians.

In a recent review, Giacino et al. (2014) write, “Unfortunately, diagnostic error is common among patients with VS and [minimally conscious state]. Misdiagnosis may contribute to premature withdrawal of life-sustaining care and lead to inappropriate medical management (for example, neglect of pain treatment)” (2014, 103). Additionally, “Despite the rapidly growing evidence indicating that a substantial percentage of patients with [disorders of consciousness] recover over time, a belief prevails that these disorders are hopeless and attempts to treat them futile” (2014, 110).

In light of the accumulated evidence, particularly the clinical misdiagnosis rate, it is clear that the confidence rating for the claim that any individual patient lacks awareness is very low. In fact, given the accumulated literature on this topic, at this point it is simply irresponsible to *unequivocally* assert of any individual patient that she is permanently and completely unconscious. Note well: this is *not* to say that the converse claim, that some individual patient is aware, has a higher confidence rating than the claim that she is not. It is instead simply to emphasize that the most epistemically justified stance at this point, given the evidence available including the high false positive rate and the range of preserved brain functions that are normally involved in sensation and nociception, is one of tentative and revisable agnosticism. Some patients may or may not completely lack awareness, but the bedside clinician simply cannot determine this with a reasonable level of confidence to justify unilateral life-ending decisions over objection.<sup>8,9</sup>

### Epistemic Authority and Its Limits: Prognosticating Death

Confidence ratings need to be considered for prognostic statements as well. One component of attempts to resolve the futility debate has involved an effort to devise prognostic systems that could assign a reliable probability to a patient’s death. Similar to the vegetative state and qualitative futility, this idea forms the core of Schneiderman and colleagues’ account of quantitative futility: an intervention that has less than 1% chance of success is, on their account, futile. One of the largest and most successful prognostic systems is the APACHE (Acute Physiology and Chronic Health Evaluation), now in its fourth iteration (Zimmerman et al., 2006) and based on data from over 100,000 ICU patients. Although the APACHE IV system and others like it have good utility for the purpose of evaluating performance of American ICUs relative to benchmarks, their use in the context of the futility debate is problematic, for a number of reasons.

First, no amount of empirical data will settle the normative question of what probability of death (or, what value of  $n$ , or of  $n$  and  $m$  in the model



above) constitutes futility. Such systems can be helpful as decision-making aids in patients' decision making, but they are clearly unable to resolve the futility dispute because this component of it is not an empirical question.

Second, such prognostic systems often consider discharge from the hospital as the key outcome (as, e.g., the APACHE system does). But for some patients, staying alive for another day to see family again is tremendously valuable and a successful use of treatment, even though a study that takes discharge from the hospital as the outcome would count that patient in the "unsuccessful" cohort. This imports a normative assumption into the study design, and does not address the question of what outcomes are valuable (nor could an empirical study address that question), and it does not even provide relevant factual information on the likelihood of survival of this particular patient for, say, one more day.

Third, the difference between groups and individuals is important. No amount of epidemiologic data will definitively establish the true probability of death for an individual patient. This is due to the reference class problem: assigning a probability to an event requires establishing the case within an appropriate reference class, but any event can be correctly described as being a member of multiple reference classes, which changes the probability assigned (cf. Reichenbach, 1949; Hájek, 2007). In other words, every event actually has multiple probabilities because probability is always with respect to a reference class, and this holds under every plausible interpretation of probability. Hájek argues that the problem cannot be solved, but it can be "dissolved," by reformulating Kolmogorov's axioms of probability theory to take conditional probability (rather than unconditional probability) as basic. As he correctly argues, however, this only dissolves what he calls the *metaphysical version* of the reference class problem; it does not address the *epistemological* problem, which is precisely what is at issue in this context. Namely, of all of the conditional probabilities that do in fact apply to some given event (say, the patient's dying within 2 days), which is the one that should guide us in practical decision making? We can surely single out one of the many conditional probabilities and insist that that is the one that ought to guide decision making, but that is tantamount to claiming that we have solved the reference class problem (Hájek, 2007, 583–84), which we surely have not.<sup>10</sup>

Fourth, the literature on prognostication is inconsistent and difficult to interpret, despite the presumed success of the APACHE system. For example, one study retrospectively examined over 5,500 cases of out-of-hospital cardiac arrest and found that two simple rules had excellent specificity and positive predictive value for identifying patients who will not survive to hospital discharge, with the rule for basic life support providers at 99.8% specificity and the rule for advanced life support providers at 100% specificity (Sasson et al., 2008). Yet, a more recent prospective study involving over 1,100 patients with out-of-hospital cardiac arrest attempted to derive a

prediction rule based on logistic regression analysis involving a number of relevant factors, such as initial cardiac electrical rhythm, time until basic life support, etc. (Pircher et al., 2009), and was not nearly as successful. This study found that the specificity of the derived rule for predicting nonsurvival based on out-of-hospital factors was only 2.9%; a similar rule using in-hospital factors allowed a specificity of 8%. As the authors state, “with our simple parameters for a prehospital scoring algorithm, it was not possible to predict either the survivors (to optimize therapy) or the patients who would die (to discuss early withdrawal of therapy)” (Pircher et al., 2009, 1198). Furthermore, a recent systematic review of clinical studies used to support or refute claims of futility found that “most studies that purport to guide determinations of futility are based on insufficient data to provide statistical confidence for clinical decision-making. . . . Many studies draw disparate conclusions based on statistically similar data” (Gabbay et al., 2010, 1083).

In their most recent “Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care,” the American Heart Association writes:

There are no clinical neurologic signs, electrophysiologic studies, biomarkers, or imaging modalities that can reliably predict death or poor neurologic outcome . . . within the first 24 hours after cardiac arrest in patients treated with or without therapeutic hypothermia. . . . There is a tendency to withdraw care prematurely in the post-arrest patient, and this has contributed to a selection bias in the current literature on prognostic testing. (Morrison et al., 2010, S670)

This last point by the American Heart Association is critical, because it implies that much of the literature on prognostication, including the APACHE system, is rendered less reliable for the purpose of judging futility in individual patients, due to the selection bias. Wilkinson has identified this more generally as the “self-fulfilling prophecy in intensive care” (Wilkinson, 2009): predictions of poor outcome become self-fulfilling when decisions to limit or withhold life-sustaining treatment are made on the basis of that prediction. This artificially inflates the mortality rate for certain conditions and makes interpretation of the prognostic literature problematic. Self-fulfilling prophecies have been implicated in mortality rates in hemorrhagic stroke, hypoxic brain injury, critical illness more generally, and brain death (Wilkinson and Savulescu, 2011, 162). The authors of the most successful prognostic system, the APACHE IV, repeatedly acknowledge the role that decisions to forego life-sustaining therapy play in determining patient outcomes (Zimmerman et al., 2006, see pp. 1297, 1304, and 1305).<sup>11</sup> Thus, the self-fulfilling prophecy generates not only artificially elevated mortality rates; it also renders clinical experience less reliable as an epistemic guide to likely outcomes.

None of this is to say that incorporating prognostic judgments into one’s decision-making framework is unreasonable, or that physicians and other health care professionals should not be presumed as the epistemic authority in these situations. However, to repeat Brody and Halevy’s important point,

the function of invoking a futility judgment is to enable *unilateral* decisions to limit life-sustaining treatments in some cases (Brody and Halevy, 1995). In these cases, presumably the epistemic authority of the professional is believed to justify overriding the moral authority of the patient or surrogate. But if the professional's epistemic authority overrides the patient's moral authority to make her own health care decisions, it would seem to follow that the confidence rating in the professional's factual claims ought to be quite high. Or at the very least, the lower the confidence rating, the less ethical justification there will be for overriding the decisions of the *prima facie* rightful decision maker.

It is of course another value judgment to determine how reliable is reliable enough with respect to confidence ratings in different scenarios. Yet, it would seem reasonable that the confidence rating that measures the reliability of the physician's claims should not be *lower* than it is in more usual contexts, if the epistemic authority of the professional is asserted to provide some justification for unilateral life-ending decisions. But, ironically, the paradigmatic cases of futility disputes involve epistemic complications and uncertainties that lower the confidence rating, and are specific to these kinds of cases, not found in most other contexts. The diagnosis of the vegetative state is extremely problematic, and prognosticating about the timing of patient death with reasonable precision is rendered problematic by the self-fulfilling prophecy and the reference class problem; yet these are the most common factors involved in futility disputes. It seems that the confidence rating for other claims made by health care professionals outside of futility disputes is, in general, higher than it is within the context of futility disputes. Therefore, the presumed epistemic authority of the professional surely does not justify overriding the *prima facie* moral authority of the patient or surrogate to direct treatment decisions. It is to be emphasized that the present considerations *overdetermine* my objection to the presumption that epistemic authority can override moral authority, since this presumption commits the fallacy of the generalization of expertise anyway.

### Summary of the Model

To summarize: examining the formal structure of the concept of futility reveals what all of the proposed subtypes have in common and therefore allows generalizations to be made to all kinds of futility from examination of the model. Analysis of the model's different components clarifies the different roles played by professional, patient, and society. Determining the membership of  $G$ , the acceptable goals of health care, is a sociopolitical question that should be resolved by appeal to tolerance and an overlapping consensus. Given  $G$ , selecting which goals of treatment should be pursued, and which should not be pursued, involve value judgments whose moral authority to make lies with the patient or the surrogate. This moral authority

is limited by the membership of  $G$ , and by distributive justice. On the other hand, health care professionals have presumed epistemic authority based on specialized training and experience and thus are the best source of information on factual questions such as diagnosis and prognosis. However, that epistemic authority is limited, and in the case of the paradigmatic futility dispute, the confidence rating is typically lower than it is elsewhere due to specific epistemic complications that do not usually arise in other contexts. Finally, epistemic authority (even if it were unlimited) in a technical domain does not generalize to moral expertise or to the moral authority to override legitimate value judgments on the nature of a good life or a good death, when those judgments are made by a person with capacity, or by her legitimate surrogate. Therefore, the concept of futility simply cannot justifiably play the role that it has been alleged to play. It does not justify unilateral decisions to withhold or withdraw life-sustaining treatment over patient or legitimate surrogate objection, and this holds even if those overriding decisions are subject to review by an ethics committee.

Before concluding this section I will address one objection: can we not say, at the very least, that professionals have some highly restricted authority to unilaterally limit life-sustaining treatment in at least some cases? For example, in a case of strict physiologic futility, where the treatment is guaranteed not to work because it has no pathophysiologic rationale? Or when cardiopulmonary resuscitation (CPR) and advanced life support are used on a patient in cardiac arrest, are providers obligated to continue until they have family permission to stop, or until physical exhaustion?

Plausible though these cases may seem at first blush, neither of them is what the futility debates have ever really been about. Treatments with no pathophysiologic rationale are not at issue; if certain treatments were not life-sustaining, then the patient would be dead and there would be nothing to dispute. The dispute is about actually (or potentially) life-sustaining treatment, such as mechanical ventilation for a patient in respiratory failure or dialysis for a patient in renal failure. Some authors invent colorful examples to illustrate the concept of futility, such as insulin for pneumonia (Schneiderman, Jecker, and Jonsen, 1990). Yet these kinds of irrelevant treatments are not what is at issue in real futility disputes. Furthermore, as Brody and Halevy have pointed out, a futility judgment, as it is actually used to purportedly justify unilateral treatment limitation, needs to be *prospective*, not retrospective (Brody and Halevy, 1995). Deciding when to stop advanced life support, *after* it has been earnestly attempted, *is* a professional judgment. In one sense, this might be considered a retrospective evaluation of efficacy: the intervention was attempted, and it did not work to restore spontaneous circulation; therefore, we know *now* (but did not know *then*) that it is ineffective in restoring spontaneous circulation in this particular patient. However, the more salient professional judgment here is that *the patient is already dead*. And I hasten to reiterate: these cases are not what

the futility debates have been about. The question is whether professionals have the authority to unilaterally and over objection decide that potentially life-sustaining treatment will be withheld or withdrawn from a *living* patient; and the analysis above clearly shows that they do not.

## VI. INEFFECTIVENESS IS NOT THE ISSUE

Mr. K is an 84-year-old man with late-stage Alzheimer's disease. He is barely responsive and has developed pneumonia secondary to aspiration. Sadly, a bitter futility dispute has arisen with respect to his care, first involving the clinicians and family, but has since enlarged to include ethics consultants, the ethics committee, hospital risk management, and now the courts. The dispute arose because the family insists on an intervention that is, according to the physicians, a case of strict physiologic futility: there is no pathophysiologic rationale and it is effectively guaranteed not to achieve its aim. The hospital refuses to allow this intervention, yet the family insists. One might think that if there were ever a case of justified refusal of treatment based on futility, this would be it. What is this futile intervention? Mr. K's 5-year-old granddaughter has a magic teddy bear that she wishes to place next to her "Pop-Pop," because she believes that it will help him feel better.

That a bitter dispute would arise over this case is obviously intended to be silly, but this is a clear example of strict physiologic futility—the least controversial of all kinds of futility. For another example (if the magic teddy bear seems too unrealistic), consider the patient dying of metastatic cancer who requests a specific vitamin because he believes that it "just might help keep me alive a bit longer – I mean, you never know, right doc?" This is also not the sort of case that creates acrimonious futility disputes, and even Schneiderman, Jecker, and Jonsen use this as an example of what they consider a reasonable "exception." Even though they would describe this as futile and justifying unilateral refusal by the physician, they see this as a case of "compassionate yielding" that would be, according to them, optional for the physician (Schneiderman, Jecker, and Jonsen, 1990, 953). However, this is a clear case of a treatment that is very likely ineffective in achieving the patient's own goal of extending his life. If the most uncontroversial cases of ineffectiveness, such as the magic teddy bear or vitamin case, do not trigger anyone's judgments that treatment ought to be withheld, unilaterally if necessary, it follows that ineffectiveness per se is not really the issue that drives much of the moral concern about these kinds of cases.

It is helpful to examine the way that "futile" treatments are described in the literature. In one of his recent articles on the topic, Schneiderman described purportedly futile interventions in the following terms: "rib-cracking CPR"; "painful"; "burdensome"; "avoid unnecessary harm" (Schneiderman, 2011, 125); "inhumane, unwanted care" (Schneiderman, 2011, 128). These concepts

are of obvious relevance to clinical decisions, *but they do not refer to ineffectiveness*. The concept of futility as it is actually used in clinical decision making is probably roughly coextensive with some disjunction of other important concepts, such as harm or wrong to patients (broadly construed to include some concept of human dignity), inappropriate surrogate or inappropriate surrogate decisions, and unjust allocation of resources. These are the concepts that do the real theoretical work, and they need to be recognized as such in order to focus on what is actually ethically salient, and thus to make ethically optimal decisions. Consider for example the following cases, description of which serves as the introduction to [Halevy and Brody's \(1996, 571\)](#) article on the influential Houston futility policy:

An infant born with multiple congenital abnormalities that rendered survival unprecedented required high-dose vasopressors to maintain blood pressure. After several days, gangrene developed in the extremities, and the parents sequentially demanded amputations of several limbs in an attempt to “do everything.” The surrogate decision maker for a comatose woman dying in an intensive care unit (ICU) was her estranged husband; they separated because of repeated spousal abuse. Despite many conferences with the husband recommending comfort measures and a do-not-resuscitate order, the husband demanded that the medical staff “do everything to my wife.” A public hospital serving an indigent community of several hundred thousand had a full ICU, and 3 patients were being kept in the emergency department on ventilators. One of the patients in the ICU was a gentleman who had been ventilator dependent and unresponsive for 4 ½ months after a cardiac arrest; his daughter insisted on full support because she was hoping for a miracle.

In each of these cases, the health care team felt that further treatment was futile. However, as the magic teddy bear and vitamin cases demonstrate, ineffectiveness, *qua* ineffectiveness, does not generate (most people's) moral judgments that continuing such treatments is wrong; other concepts are doing the work.

In the first case, the concern is really about excessive harm to the infant, or that the weighing of likely benefits to likely burdens is so obviously skewed. Furthermore, since this is a case of surrogate decision making in which something like a “best interests” standard rather than a substituted judgment standard would have to be invoked (or better yet, the not unreasonable standard; cf. [Rhodes and Holzman, 2004](#)), the health care team is legitimately questioning whether the parents' surrogate decisions should be accepted. In the second case, there is clear concern as to whether the estranged husband bears appropriate care and concern for the patient ([Rhodes and Holzman, 2004](#)). Due to the history of spousal abuse, their estrangement, and the troubling language of “do everything *to* my wife” (rather than “*for* my wife”), again the health care team has legitimate concerns as to whether he should be the appropriate surrogate, and thus, whether his decisions should be accepted. Finally, the third case involves the just allocation of limited resources in the use of ICU space. Treating the gentleman currently in



the ICU is not futile for the goal of maintaining his life, but it may—or may not—be *unjust* (cf. [Nair-Collins and Hitt, 2012](#)).

In-depth discussion of any of these concepts is outside the scope of this essay, so I will only make a few brief comments. There is a critical distinction between patient decision making and surrogate decision making. If the patient has decisional capacity, then the patient has the final say in value judgments such as the appropriate weighing of likely benefits and likely burdens, what constitutes a benefit, and what the individual goals for her treatment ought to be. (This is not to say that patients can demand anything at all, because, as mentioned above, the patient's moral authority is limited by the membership of *G* and by distributive justice.) On the other hand, surrogate decisions, while almost as strong as patient decisions, are somewhat more limited. Clinicians have a fiduciary responsibility to the patient to assure that the surrogate has appropriate care and concern (i.e., has the right motives) and makes decisions for the patient that are in line with certain limitations, such as [Rhodes and Holzman's \(2004\)](#) not unreasonable standard, [Diekema's \(2004\)](#) harm threshold, or more traditional "best interest" standards. Finally, although distributive justice is an extraordinarily difficult and complex concept, there is at least reasonable agreement that justice involves treating like cases alike. Since there is no guarantee (or even a reasonable expectation) that limits imposed on patients by one clinician will be similarly imposed on similar patients by other clinicians, it follows that bedside rationing cannot be just. Limits to the use of health care resources based on distributive justice can and should be set; however, this needs to be done at the policy level, not at the bedside, to assure that like cases even *can* be treated alike ([Schneiderman, Jecker, and Jonsen, 1990](#), 953).

The concept of futility, if used to justify unilateral, overriding decisions to limit life-sustaining treatment, is irreparably flawed. It does not justify unilateral decisions, even when subject to review by an ethics committee. Furthermore, futility *qua* ineffectiveness is not what generated much of the moral concern in the first place. Rather, more ethically defensible concerns such as harm or wrong done to patients, inappropriate surrogates or their decisions, and the just allocation of resources seem to be underlying many of the kinds of cases labeled "futile." In order to make principled and defensible clinical decisions and public policies, these more salient concerns need to be articulated explicitly and held up to critical case-by-case scrutiny; but the label "futility" should be dropped altogether.

## VII. PROFESSIONAL INTEGRITY AND CONSCIENTIOUS OBJECTION

Some argue that if health care professionals are not empowered to make value judgments regarding patient care, such as whether likely benefits outweigh likely harms, or whether a particular intervention (such as CPR) is

reasonably worth pursuing, then health care professionals are stripped of their own autonomy and moral agency. But physicians, qua professionals, must be granted the authority to make such value judgments, including determining the legitimate uses to which their skills will be put. This is a matter of professional integrity. As Tomlinson and Brody (1990, 1278–79; emphasis in the original) have argued:

An appeal to the integrity of the *physician* [qua professional rather than qua individual person], however, does carry more weight [than an appeal to the integrity of the individual patient] because the protection of this integrity is necessary for creating and sustaining a profession that . . . is still an acceptable and noble livelihood for morally sensitive persons. This requires permitting the profession to make some judgments about the means to be employed in achieving the social goods for the sake of which medicine is instituted and permitting it some latitude in interpreting the meaning and scope of those social goods.

Although this appeal to professional integrity seems to have been influential, it does not stand up to scrutiny. Gampel (2006, 92) has recently clarified the argument, identifying three versions: (1) that individual physicians should be free to exercise their own medical judgment, (2) that the profession as a whole may provide futility standards to govern practice, and (3) that the moral integrity of the individual physician limits treatment demands. No version of the argument is successful.

The first version is obviously unsatisfactory. Individual physicians may not simply adopt their own idiosyncratic views or values and then act on that basis, in the absence of external standards. This is what generates the presumption that physicians ought to follow a “standard of care,” and if not, they should be able to explicitly justify why some individual case is different and should be treated differently from what is considered a standard of care. Thus, if there is a case to be made for professional integrity overriding patient authority to make value judgments, it must be rooted in the profession’s authority to govern standards of practice, including the authority to determine what constitutes futility and how physicians ought to care for patients in such cases.

However, this second version of the argument also fails. Gampel has argued that there are three critical differences between futility cases and other areas of medical practice in which the profession has much greater latitude in determining standards, of which I will only mention two. First, the treatment in question is usually the only treatment that has any chance at all of prolonging life, and denying that treatment is to consign the patient to death. This is quite different from most other cases of clinical decision making, in which a number of different options might be available. Second, in futility cases, health care professionals are attempting to override very deep values tied to religion and fundamental philosophical questions, particularly questions about when life is not worth living, or the nature of a good death.

It is hard to imagine that the medical profession has such sweeping authority to determine these deep value judgments and impose them on others.

Furthermore, as Gampel rightly points out as well, the profession is not self-contained and the autonomy of the profession is not unrestricted. "Medicine functions within a political and legal context which helps shape its values, and the same can be said about its ends" (Gampel, 2006, 100). This point is made obvious in considering the role of informed consent and respect for autonomy more generally: these values were externally imposed on the health care professions, and legitimately so. As Veatch and Spicer (1992) have argued, exclusive license to practice in the health care professions generates a social contract, a condition of which would surely include the use of one's knowledge, skills, and access to technologies to achieve certain socially accepted ends (such as the preservation of life) even if the individual provider, or even the profession more generally, does not accept those goals as worthy of pursuit. Finally, as I have argued above, health care is a collaborative, shared social practice that is publicly funded. Although the medical profession plays an important role in this practice and thus has a legitimate voice in determining the goals of health care and its norms of practice, the shared nature and public funding for health care necessitate an appeal to overlapping consensus in determining its legitimate ends; the allopathic medical profession is not granted a monopoly on determining what constitutes a legitimate use of shared, publicly funded health care resources.<sup>12</sup>

Finally, the third version of the argument appeals to the moral integrity of the individual provider and attempts to ground authority to refuse life-sustaining care in the more general principle that health care providers should not be forced to engage in practices that they deem deeply immoral. This version of the argument appeals to conscientious objection as grounds for refusal. For example, Schneiderman and Jecker (2011, 112) write,

The use of futile measures is ethically objectionable in situations where it runs contrary to the physician's personal moral standards. In this case, a refusal to allow the physician to withhold or withdraw futile interventions does not take seriously the physician's own sense of personal moral integrity. It would be akin to forcing physicians who oppose abortions to perform them.

Although the general principle that protects individual professionals' right of conscientious objection within certain constraints is important and worthy of maintaining (cf. Wicclair, 2011), it is a serious mistake to suppose that futility cases qualify as legitimate instances of conscientious objection.

At the core of legitimate conscientious objection is a respect for the moral integrity of persons, in that larger social structures will not be used to force certain individuals to engage in acts that they themselves find so deeply immoral that it would violate their own sense of self (even though those acts are generally considered acceptable by the larger society). The notion

of integrity, or of maintaining one's sense of self as a "whole" person that is operative in this context, entails that to be forced to engage in a certain act would be experienced as an assault on one's self or identity, and this can result in feelings of guilt, shame, remorse, and loss of self-respect (Wicclair, 2011, 26). The traditional case of conscientious objection involves killing in war, and in health care, a clear example is the provision of an abortion for a provider who sincerely believes such a procedure to involve deeply immoral killing. Common to both cases is that the principle of not-killing that would be violated forms a core, central aspect of that individual's ethical values and sense of self.

In the case of futility, what core value—central to the provider's sense of herself as a moral agent—would be violated, such that forcing the provider to engage in the act of continuing to provide life-sustaining treatment would be experienced as an assault on her sense of self or identity? The paradigmatic case of conscientious objection involves *not* killing; the paradigmatic case of futility involves sustaining or attempting to sustain life. Shall we say that no individual provider should be denied the authority to determine for another that her life is not worth living, or that the chance of survival is too slim to justify attempting to save that other person's life, because if we did, the individual provider would be "torn apart," or would experience an assault on her sense of self? Once made explicit, no one could even begin to take seriously such a claim.

It is worth pointing out an important source of confusion here. If a health care professional sincerely believes that, for example, a surrogate is making an inappropriate decision that involves significant harm to the patient without corresponding benefits, and that the decision violates some reasonable standard for surrogate decision making, then that professional has a fiduciary *obligation* (not mere permission) to investigate further, to consult with colleagues, and possibly even to pursue avenues to override the surrogate's directives. But this has nothing to do with conscientious objection, which involves (1) an act that is well established as permissible within the larger community, such as abortion, and (2) an individual who deeply disagrees with the larger community's moral assessment of that act. Allowing a patient to be harmed by surrogate decisions is not accepted within the health care professions or the larger community, so objecting to certain interventions on the grounds of inappropriate surrogate decisions do not qualify as conscientious objection.

To conclude this section, appeals to professional integrity, either by way of the authority of the profession to determine standards or by individual conscientious objection, are not successful in establishing the legitimacy of unilateral decisions to limit life-sustaining treatment. This is not to ignore or minimize the distress that health care professionals might experience in certain cases. Although most "futility" cases can be resolved through discussion, consultation, and procedures put in place for deliberation and joint

resolution, not all will lead to an agreement among family or patient and providers, and these cases can be distressing for providers. In these relatively rare scenarios, as I have argued above, health care professionals have a limited moral obligation to assist the patient in achieving her goals, assuming those goals are among those identified by the appeal to overlapping consensus, and this includes the preservation of life, even if only for a short time or in the context of profound disability, including the unresponsive wakefulness syndrome. As Burns and Truog (2007, 1993) have argued,

For the small number of intractable disputes that remain [after persistent efforts to find common ground], we argue that our efforts should be directed more at finding better ways to support the patient's family and each other in providing that care than in seeking to overrule the requests for care that we regard as unreasonable.

In agreement with Burns and Truog, I offer a friendly amendment: in those rare cases of intractable dispute, rather than attempting to override the rightful decision maker's legitimate moral authority in determining value judgments in patient care, our efforts should be directed toward finding better ways to support and sustain health care professionals in fulfilling their professional ethical obligations.

#### VIII. CONCLUSION: LAYING FUTILITY TO REST

Futility is still a much discussed topic, and as any clinician, ethics consultant, or ethics committee member knows, the concept has hardly left the clinic. It is still appealed to routinely in clinical decision making and is one of the most common reasons for an ethics consult or ethics committee review. In this essay I have analyzed the concept and argued that it does not serve the purpose for which it is used, namely, to justify unilateral decisions to limit life-sustaining treatment. Determining the legitimate goals of health care is a sociopolitical question to be addressed by an overlapping consensus and an appeal to tolerance for reasonable views, not by appeal to the history of the medical profession; the moral authority to select among these goals lies with individual patients or their legitimate surrogates; the epistemic authority of health care professionals is limited, and in the paradigmatic futility cases, there are specific epistemic complications that lower the reliability of professionals' descriptive claims; and the presumption that epistemic authority (even if it were unlimited) can override moral authority is an instance of the fallacy of the generalization of expertise anyway. Finally, appeals to professional integrity are unsuccessful in justifying the use of futility judgments to unilaterally override patient or legitimate surrogate decisions to continue life-sustaining treatment.

I conclude this essay by urging that the word "futility" be finally and permanently excised from the clinical lexicon. The concept of futility is not a necessary corrective to the "excesses" of patient autonomy; instead, it reflects

the same confused fallacy of the generalization of expertise as did the earlier tradition of unjustified paternalism, a tradition that has been broadly, and rightly, rejected.

## NOTES

1. A word about “unilateral decisions”: I am here using the phrase to mean any decision by health care providers or hospital administrators that overrides the decision made by surrogates or patients. Thus, even if a process of internal review is used (such as by an ethics committee, as in the Texas Advance Directives Act), if the hospital or health care provider overrides the decision made by the patient or surrogate (even after review and time given for transfer), this is a unilateral decision, as I am using the term.

2. This is not to suggest that the concept of futility was first articulated in the 1980s, as it surely was not; an oft-repeated quote attributed to Hippocrates states that physicians should not attempt to treat patients who are “overmastered by their disease” (Hippocrates, 1923, 193). Yet, the significant difference between traditional Hippocratic views of medical ethics and more modern views should not be elided. Within the Hippocratic tradition, *all* treatment decisions were believed to be the domain of physicians. On an autonomy-centric view, patient rights to make value judgments about what is *good* supersede physician beneficence (with some exceptions). Thus, the new use of futility as a tool to unilaterally override patient decisions is quite different from its use in a more ancient context. Because of these different contexts, it might even be reasonable to consider them as simply different concepts.

3. By availing myself of the language of sets and functions, I am not thereby suggesting that there is a quantitative precision to the concept of futility as it functions in the real world. Rather, my aim is only to make the formal structure of the concept explicit, which enables more careful analysis.

4. Actually, there are multiple “facts about the world” as to what is the probability that that intervention will achieve that degree of success in that patient at that time. This is the reference class problem (cf. Hájek, 2007): the probability of an event’s occurrence is relative to the specification of a reference class, and every event belongs to infinitely many reference classes; therefore, the event’s probability of occurrence changes depending on which reference class is chosen, and hence, there are multiple facts about the world as to what is the event’s probability, because it has multiple probabilities. I will ignore this important problem momentarily, but it has obvious relevance to the use of futility determinations as justifications for overriding patient requests for life-sustaining treatment. I will return to this issue in later sections.

5. A different way to think about this but that reaches the same conclusion is to adopt Mary Anne Warren’s “Transitivity of Respect Principle” for moral status: “Within the limits of [her other principles determining the criteria for moral status], and to the extent that it is feasible and morally permissible, moral agents should respect one another’s attributions of moral status” (Warren, 1997, 170). Similarly, in the context of a discussion of distributive justice, I have argued that we ought to adopt an “as-if” concept of moral status, similar to Warren’s Transitivity of Respect Principle. On this idea, we ought to treat certain individuals *as if* they have moral status (at least for public policy purposes), even if we do not think they do, if other reasonable, morally serious people do in fact treat those individuals as having moral status, for reasons that all can at least acknowledge as relevant (if not sufficient) (Nair-Collins and Hitt, 2012).

6. The concept of “reasonableness” in this context is admittedly under-characterized, and there must be some limits on what can be included in the set of acceptable goals of health care under an overlapping consensus. However, at least the goals identified in the text would be included in this set, and this undercuts the force of the standard concepts of futility, particularly Schneiderman and colleagues’ concept of qualitative futility. Whether additional goals would be countenanced by the overlapping consensus is an important open question. Thanks to a reviewer for helpful comments in this regard.

7. This clarifies the problematic nature of a related false dichotomy that Schneiderman and Jecker seem to presume, presupposing that if physicians may not unilaterally override decisions to continue attempting life-sustaining treatment, then somehow it would follow that they must do whatever the patient wants to achieve any goal at all. For example, they write that if a weight lifter has a goal of becoming a world champion body builder, the physician is not obligated to prescribe steroids to help him or her, because medicine has certain goals of helping patients, not merely doing whatever patients want (Schneiderman and Jecker, 2011, 170). As with the question of value judgments, of course there are limits



to the acceptable goals of health care, and using steroids to achieve short-term athletic success is not one of them. But it does not follow from this that preserving life (or attempting to preserve life) is also not one of the acceptable goals of health care, nor does it follow that physicians hold unilateral authority to make life-ending decisions over patients' or surrogates' objections. As I mentioned in the text, only those goals in *G* generate limited obligations on the professional.

8. A more detailed analysis of the science and philosophy of consciousness with respect to the vegetative state is outside the scope of this paper. For an interesting discussion based on treating consciousness as a natural kind, see [Shea and Bayne \(2010\)](#).

9. Schneiderman and Jecker do acknowledge some of the MRI research on the vegetative state and minimally conscious state ([Schneiderman and Jecker, 2011](#), see note 2 of chapter 1, p. 195). They approvingly quote a commentary by A. H. Ropper who states that research on clinically undetected consciousness is "easily subject to overinterpretation and sensationalism . . . we cannot be certain whether we are interacting with a sentient, much less a competent, person" ([Ropper, 2010](#)). Again, this misses the point. It is true that we cannot be certain that we are dealing with a competent person. But the point is that we cannot reliably state that we are *not* dealing with a *minimally* conscious human. Furthermore, they repeatedly emphasize in many of their publications that medicine is and has always been guided by probabilities, not certainties. So why should we require certainty that the patient *is* conscious in this case? More importantly, they do not address the 30%–40% false positive misdiagnosis rate, in which clinicians miss subtle behavioral cues involving communication and subtle responsiveness. The epistemic warrant for claiming that these patients (who do subtly respond) are at least minimally conscious is much higher than the conclusions based only on neuroimaging.

10. The reference class problem is a deep one for the metaphysics and epistemology of probability theory, yet, like the *grue* problem for induction, it sometimes seems as if the issue is really with the attempt to make explicit in advance what counts as "the most relevant" reference class, or a "natural kind" in the case of induction. Presumably there are some deep regularities to the world, and the reference class problem will be solved piecemeal, by finding those deep regularities and basing reference classes and hence the assignment of probabilities on them. However, this issue is well outside the scope of the present essay. The main point is fairly simple: epidemiologic information, based on averaging out differences between groups, is not identical to information about individual patients.

11. Prendergast and colleagues found that limitation of life support prior to death is the predominant practice in American ICUs ([Prendergast and Luce, 1997](#); [Prendergast, Claessens, and Luce, 1998](#)). In a more recent study, [Azoulay and colleagues \(2003\)](#) found that the decision to forego life-sustaining therapy independently predicted death after adjusting for comorbidities and severity of organ dysfunction, from a sample of six ICUs in France.

12. It should also be noted that "the medical profession" is not a monolith, all walking in lock-step with the views of Schneiderman and Jecker. The same pattern of different views in society about fundamental philosophical and religious questions that necessitates overlapping consensus on the legitimate ends of health care can be found among physicians as well, and some of the most outspoken critics of the use of futility judgments have been physicians.

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