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# Medical Futility in Concept, Culture, and Practice

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## ABSTRACT

This article elucidates the premises and limited meaning of medical futility in order to formulate an ethically meaningful definition of the term, that is, a medical intervention's inability to deliver the benefit for which it is designed. It uses this definition to show the two ways an intervention could become medically futile, to recommend an even more limited usage of medical futility, and to explain why an intervention need not be futile in order to be withdrawn over patient-based objections. If an intervention retains some benefit, then patients or surrogates might legitimately consider that benefit in their case and request the intervention. Physicians might still be justified in declining it on the grounds that the burdens greatly outweigh the benefits, but not on the grounds of futility. Finally, the article uses bioethics research and healthcare litigation to clarify the meaning of futility in practice and recommends alternative language when possible.

In 2009, I joined the ethics committee of a hospital in the southeastern United States. Every monthly meeting involved at least one discussion of medical futility. During one of these discussions, futility was attributed not only to an intervention, that is, "this intervention is futile," but also to the situation and even to the patient: "the situation is

futile" and "the patient is futile." As an external member of the committee, I thought about how shocking these phrases would sound to patients and families. I was struck that medical professionals spoke these phrases without recognizing their human dimension. At the same time, I could understand why. They were using technical language to discuss the management of very difficult, persistent clinical problems. I found myself thinking, "I understand what you are trying to say, but medical futility is not the way to say it."

As I listened to these conversations, I noticed that medical futility sometimes does the work it is supposed to do: to withdraw an intervention that should not be continued even though the patient, or more often the family or surrogate, insists on continuing it. At other times, the term confuses the ethical discussion and exacerbates the very conflict it attempts to resolve, creating situations that drain emotional energy and waste time and resources. Thankfully, invoking futility does not always aggravate conflict because the goodwill of medical professionals and families typically enables them to work together to resolve their differences.

The error comes about when medical professionals invoke futility to withhold or withdraw an intervention that may retain some benefit, but which nonetheless may not be worth continuing. Medical professionals need language to express this view, but medical futility does not describe what they really

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mean in this situation. The term is used anyway because it is perceived as the strongest justification, and in some situations the *only* justification for withdrawing treatment over patient-based objections. The more that it is used as the only justification for withdrawing treatment, the more its definition expands to include whatever reasons a physician holds to justify withdrawal. The approach works until a physician invokes futility when an intervention is not really futile, the patient's representatives recognize some benefit to the intervention or simply do not agree, and insist on continuing.

A medical intervention need not be futile in order to be withdrawn. In practice, it may be difficult to establish a neat dividing line between futile and non-futile but not obligatory interventions. Conceptually, however, there is an important ethical difference between interventions that are futile—rendered ineffective or incapable of benefit by the patient's medical condition—and interventions that retain some marginal benefit despite excessive burdens. In the latter case, patients and their surrogates may consider what that benefit, although small, would mean to them and might legitimately request the intervention. Nonetheless, physicians might legitimately decline the intervention.

Medical institutions have long recognized the difficulty of these cases and have developed futility policies.<sup>1</sup> These policies may help medical professionals correctly understand and apply the concept of futility. But the soundness of those policies depends upon the underlying definition and application of futility and how well the policy is understood among the members of the institution. A sound policy should help medical professionals distinguish interventions that are clearly futile from those that are clearly not and to recognize grey-area cases in which it is difficult to distinguish futile from marginally beneficial/overly burdensome interventions.

I share with many authors the essential convictions that it is possible to define and use medical futility, that only medical professionals possess the expertise to recognize futile interventions, and that they are justified in withholding or withdrawing interventions that are truly futile.<sup>2</sup> I propose, however, to define medical futility in terms of an intervention's designed benefit rather than its physiological or quantitative effects or qualitative benefit. These latter definitions, based upon the work of authors such as Lawrence J. Schneiderman and Nancy S. Jecker, tend to apply futility too broadly.<sup>3</sup> Accordingly, this article elucidates the premises and limited meaning of medical futility in order to formulate a definition of the term and to demonstrate

why physicians are justified in withdrawing truly futile interventions. It shows the two ways an intervention could become medically futile—immediate and mediated futility—and recommends more-limited usage of medical futility. Further, it explains why an intervention need not be futile in order to be withheld or withdrawn over patient-based objections. Finally, it uses bioethics research and litigation to clarify the meaning of futility in practice and recommends alternative language whenever possible.

## MEDICAL FUTILITY IN CONCEPT

### The Premises and Limitations of Medical Futility

Medical futility appeals to the meaning of the word futility in order to justify withdrawing a medical intervention. The basic meaning of futility gives persuasive force to various uses of the word, including colloquial, ethical, scientific, and medical uses. As a word in English, futile means “incapable of producing any result; failing utterly of the desired end through intrinsic defect; useless, ineffectual, vain.”<sup>4</sup> Futility implies that a cause cannot produce its effect and, in ethics, that a particular deliberate act cannot achieve its objective. The word describes an act that a person could perform, but never successfully. Thus, medical futility describes an intervention that cannot cause its beneficial effect and for that reason should not be performed.

In the above definition as it applies to ethics, the words “effect,” “end,” and “result” refer to the *benefit* that an intervention is designed to bring about. They never refer *merely* to the intervention's physiological effects. It is always possible to describe the various physiological effects—beneficial, detrimental, burdensome, and neutral—of a deliberate human act, including a medical intervention. But some physiological effects of an intervention are themselves the health benefit. An intervention becomes futile when it fails to bring about its beneficial effects. The beneficial effects may be called the intervention's designed benefit or benefits. Thus, medical futility describes an intervention incapable of accomplishing its designed benefit.

Defining medical futility in relation to its designed benefit rather than its physiological effect better illustrates the concept's persuasive force, as well as its limitations. Schneiderman's definition of qualitative futility in the following passage refers to the effects of a number of common medical interventions as if they were merely effects and not simultaneously benefits: “Medicine today has the capacity to achieve a multitude of effects, raising and

lowering blood pressure, speeding, slowing, and even removing and replacing the heart, to name but a minuscule few. But none of these effects is a benefit unless the patient has at the very least the capacity to appreciate it, a circumstance that is impossible if the patient is permanently unconscious.”<sup>5</sup> The “multitude of effects” listed above, however, are not merely effects, but the designed benefits of specific kinds of interventions. The actual benefit to the patient does not depend upon the patient’s capacity to appreciate it, but on the intervention’s ability to deliver it, given the patient’s medical condition. If an intervention is not capable of “raising or lowering blood pressure,” *et cetera*, then it is futile. If such an intervention is capable of achieving its designed benefit, then the benefit of performing the intervention comes along with the effect, even if the patient is not capable of appreciating it. In that case, the physicians or surrogate, or both, might judge that the burdens of the intervention outweigh the benefits and still decline the intervention, but not on the grounds of futility.

Typically the medical condition of the patient renders the intervention incapable of delivering its designed benefit and thus futile. For this reason, medical futility differs slightly, but importantly, from the dictionary definition of futility above, which attributes a futile act’s failure to an “*intrinsic* defect.” The medical condition of the patient is a circumstance *extrinsic* to the intervention. In order to establish medical futility, then, it may be necessary to show what factors, especially about the patient’s medical condition, render it futile.

Only medical professionals have the medical training and clinical experience to evaluate a patient’s medical condition and identify interventions rendered futile by that condition. This knowledge and experience, used correctly, justify withdrawing a futile intervention. Paul R. Helft and colleagues recall this principle at the origin of the futility movement:

The movement [in the 1980s] to establish a policy on futile treatment was an attempt to convince society that physicians could use their clinical judgment or epidemiologic skills to determine whether a particular treatment would be futile in a particular clinical situation. The idea was that once such a determination had been made, the physician should be allowed to withhold or withdraw the treatment, even over the objections of a competent patient.<sup>6</sup>

Similarly, in “Medical Futility: A Conceptual and Ethical Analysis,” Mark R. Wicclair observes that

“Physicians have scientific and clinical expertise that enables them to ascertain the likely physiological effects of medical interventions. . . .”<sup>7</sup> Clinical judgment and epidemiological skills can judge how well an intervention is likely to achieve its designed benefit and thus to improve the patient’s medical condition. Most patients and their surrogate decision makers are not trained in medicine and, quite appropriately, cannot contribute to this kind of judgment. If the intervention will not work, there is no benefit for the patient or surrogate to consider, and the physician would be justified in withholding or withdrawing it unilaterally.

Clinical judgment and epidemiological skills can also recognize when an intervention is likely to bring some small benefit or to be excessively burdensome. This medical expertise contributes to an overall judgment that the burdens of an intervention far exceed the benefits, and thus that offering or continuing the intervention is not obligatory (even though not futile). In this case, however, the decision whether to offer or continue it also depends upon the value that patients, families, surrogate decision makers, and medical professionals find in performing an intervention of such small benefit. In the end, a physician might decline the request, but it is the value of not performing excessively burdensome and/or marginally beneficial interventions, rather than ineffectiveness of medically futile interventions, that provides the grounds for doing so.

The leading bioethics literature today has, to some extent, incorporated this lesson. A 2015 policy statement by the American Thoracic Society, the American Association for Critical Care Nurses, the American College of Chest Physicians, the European Society for Internal Care Medicine, and the Society of Critical Care (hereafter, the ATS policy statement) observes that “There is now widespread agreement that many of these disagreements, previously called futility disputes, do not hinge solely on technical medical determinations and instead also involve contested value judgments about what is appropriate treatment in patients with far advanced illness.”<sup>8</sup> Presumably “contested value judgments” refers to disagreements between the physician and patient, family, or surrogate about the value of performing an intervention of little remaining benefit or disproportionately great burden rather than an intervention that is futile. The ATS policy statement therefore recommends that “The term ‘futile’ should only be used in the rare circumstance that an intervention simply cannot accomplish the intended physiologic goal,”<sup>9</sup> or, in this analysis, its designed benefit.

The meaning of futility both justifies and limits the use of the term medical futility. Medical futility can describe an intervention rendered incapable of achieving its designed benefit by the medical condition of the patient, and perhaps by other related medical factors. Medical professionals possess the expertise necessary to judge how the intervention is likely to interact with the patient's medical condition. Therefore, they legitimately withdraw truly futile interventions despite objections brought on behalf of the patient. The same expertise enables medical professionals to recognize when an intervention, although not futile, is likely to have marginally beneficial and/or excessively burdensome outcomes. This judgment should contribute to conversations with family and surrogate decision makers about the value of performing the intervention. At the end of such conversations, the physician might decide not to pursue the intervention further, but on the grounds of great burden and little benefit rather than of medical futility.

### **How Medical Futility Applies to Interventions**

There are two ways that an intervention could be futile. First, the intervention does not work. A physician recognizes that the intervention cannot effectively deliver its designed benefit and declines to provide it. Cardiopulmonary resuscitation (CPR) is futile if it will not restore cardiopulmonary function; hemodialysis is futile if it will not adequately cleanse toxins from a patient's blood; and tube feeding is futile if a patient's body cannot assimilate nutrition. Interventions that are futile in this way might be rare, but the grounds for withholding them are obviously strong. An intervention is ineffective, and there is no benefit to consider. Few patients or family members will insist on something that has no immediate beneficial effect.

This version of medical futility is sometimes called physiological futility or quantitative futility, but the term "immediate futility" is more ethically relevant.<sup>10</sup> Physiological futility sounds counterintuitive because an intervention that is not capable of delivering its designed benefit still produces other, sometimes burdensome physiological changes in the body. Seen another way, physiological futility might be taken to mean that the intervention produces *only* physiological effects. But the emphasis on producing physiological effects does not explain why the intervention is futile. Rather, it is the intervention's inability to bring about its designed benefit. Similarly, Schneiderman, Jecker, and Albert R. Jonsen define quantitative futility as the very low probability, based on physicians' experiences in similar

cases, that the intervention will work.<sup>11</sup> The standard of probable effectiveness may serve as a helpful guideline in some clinical situations, but it is more specifically a medical and scientific than an ethical term. Ethics evaluates an action in pursuit of some benefit, and medical futility, as an ethical term, claims that an intervention cannot deliver its designed benefit.

Immediate futility better describes the ethical reality meant by the physician. In its colloquial sense, immediate communicates that no benefit would be possible at the time the intervention was attempted, and therefore that it should not be offered. In a philosophical sense, immediate communicates that the intervention's failure is not mediated by a worsening medical condition over time or by any other factor that would eventually render the intervention futile for a future goal of treatment. This philosophical sense becomes clearer when immediate futility is distinguished from the second way in which an intervention could be futile.

An intervention is also futile if it is somewhat beneficial but is expected to lose the beneficial effect before achieving currently held goals of treatment. The term "mediated futility" accounts for the fact that some factor, such as disease progression over time, will likely arise to render the intervention futile for the stated goals of treatment. Mediated futility resembles qualitative futility because both terms define futility in relation to a goal of treatment. But mediated futility depends upon a medical judgment about how effectively an intervention is likely to support a goal of treatment, and not upon a patient's ability to appreciate the intervention as a benefit. Moreover, mediated futility is not based upon a physician's view of appropriate goals of treatment, even though a physician's view on this matter is sometimes helpful to patients and surrogates. Rather, mediated futility is based upon the physician's integrating empirical, pragmatic, prudential judgments about the value of the intervention for achieving the goals of treatment.<sup>12</sup>

The grounds for withholding or withdrawing interventions that are futile in this way are weaker. Determining mediated futility requires the patient or surrogate to articulate goals of treatment, and in this sense mediated futility cannot be determined by the physician alone. The intervention itself provides an immediate benefit, and the patient or surrogate might re-evaluate treatment goals and either replace impossible goals with possible ones or willingly forgo the intervention. In these circumstances, invoking futility may cut off an important route for peacefully resolving conflict. Moreover, futility in

this sense involves estimating the intervention's future efficacy based on prognosis, a kind of judgment that is typically difficult and uncertain. In these cases of mediated futility, it is better to avoid using futility language altogether and instead be as clear as possible about what benefit the intervention could actually deliver.

The second kind of futility is by far the more common. To take a typical example, medical professionals employ a variety of interventions in the intensive care unit (ICU) that might be futile for the goal of discharging the patient, but not for allowing loved ones to visit a dying patient or for accomplishing another short-term goal. Burdensome or marginally beneficial interventions are not futile if they help achieve the latter goal, even if they are not obligatory. Schneiderman describes this scenario:

What about the terminally ill patient who requests attempted CPR in hopes of surviving for one last visit from a distant loved one hastening to the bedside? Even though the physician is convinced that the intervention would have almost no chance of keeping the patient alive more than a day or so in the ICU, clearly the physician will want to make a compassionate exception to accommodate the short-term goal of the patient. It is important, however, to distinguish this compassionate act from an obligatory act.<sup>13</sup>

Schneiderman rightly recognizes that the intervention is not obligatory, but it is not futile. In this case, CPR is effective and will prolong life until family can visit. It provides an immediate benefit, even if that benefit might be considered disproportionate to its burdens. The patient or surrogate has no obligation to pursue the intervention, but is certainly justified in requesting it. The physician could decline to provide it, but not on the grounds of futility.

Here is a less common example of mediated futility. Two recent articles about liver and kidney transplantation illustrate futility in relation to a specific treatment goal for an individual patient. One article argues against performing dual liver-kidney transplants in which the kidney transplant is likely to fail.<sup>14</sup> The other article advocates for the current MELD (model for end-stage liver disease) allocation system and underlying "sickest-first policy" on the grounds that disease-related factors rather than demographic-, donor-, or surgery-related characteristics primarily determine transplantation outcomes.<sup>15</sup> Both articles use futility to describe transplantation for a patient unlikely to survive more than three months post-transplantation. In other words, they consider the intervention futile for achieving a rea-

sonable, defined goal of treatment: three-month post-transplant survival.

This kind of futility depends upon how somatic factors foreseeably compromise the efficacy of the transplant. These somatic factors are primarily the medical condition of the patient, as well as the quality of the donated organ and the impact of the transplantation method on both. For example, the article advocating the current MELD system recognizes futility on the basis of "disease-specific factors including laboratory MELD score, cardiac risk, previous septic shock, and comorbidities."<sup>16</sup> The article concerning dual liver-kidney transplants recognizes futility according to "pre-transplant illness severity," dialysis duration, the quality of the donated kidney, and (longer) kidney ischemia."<sup>17</sup> In both cases, the intervention is futile because the patient's medical condition and other somatic factors make it impossible for the intervention to achieve three-month post-transplant survival.

Futility cases sometimes involve many interventions, especially when the patient suffers from many combined ailments. Even when considering the combined benefits of a series of interventions, futility is still defined in the two ways outlined above. As a patient's medical condition deteriorates, particular interventions become futile when they cease to work at all. A series of interrelated interventions might provide some immediate benefit, even though it may be considered futile because it fails to achieve the goals of treatment. This weaker sense of futility provides grounds for withdrawing or not offering the intervention, but the patient or surrogate might request to continue that series of interventions for more modest treatment goals. This position respects the fact that patients and surrogates might legitimately pursue interventions of some small benefit, even if medical professionals are not always obliged to provide them.

### **Two Difficulties in Applying Medical Futility**

Sometimes surrogate decision makers have no treatment goals at all. They want everything done so that their loved one will live. It is hard for them to believe that any intervention is too burdensome, even when they are aware of the burdens. In this situation, medical professionals might have a feeling of futility because the surrogate's vague, unstated goal is to preserve life indefinitely, which no intervention will do. But resolving the conflict adequately requires establishing reasonable goals, which invoking futility does not accomplish.

There is another pitfall. Futility judgments should not relate an intervention's effectiveness ar-

*bitrarily* to treatment goals. For example, assisted nutrition and hydration (ANH) nourishes the body and contributes directly to prolonging life and providing comfort, and in that way contributes indirectly to further goals of care. ANH is immediately futile, and surely harmful, for a patient whose body cannot assimilate nutrition. If it can, then ANH is not futile. It might be withdrawn if the intervention will not prolong life or if it imposes significant burdens, such as great psychological discomfort or a significant risk of aspiration pneumonia.

Sometimes ANH is said to be futile for a patient in a persistently unconscious state (PVS) if the patient is unlikely to regain consciousness.<sup>18</sup> This argument does indeed relate ANH to a reasonable goal of care, the restoration of consciousness, but in an arbitrary way. ANH is not designed to restore consciousness and promotes that goal indirectly by nourishing the body and prolonging life, thus allowing time for the reparative functions of the body to achieve what healing they can. As long as ANH nourishes the body and the patient is not actively dying, it should not be considered futile. The burdens of caregiving and financial burdens might influence what care can be offered, but those burdens, a low quality of life, and the undesirability of life in a disabled state do not render ANH futile for a PVS patient.

## MEDICAL FUTILITY IN CULTURE

### Medical Futility as Perceived by Physicians

In today's healthcare culture, use of the phrase medical futility has broadened well beyond its legitimate meaning. Medical futility has so many different definitions that some believe it cannot be defined, but continue to use the term in process-based or mediation approaches to futility cases. For example, Jeffrey P. Burns and Robert D. Truog observe that efforts to define futility by clinical criteria have failed, argue that procedural approaches prove inadequate, and advocate for negotiation and mediation approaches.<sup>19</sup> Thaddeus Mason Pope too observes the difficulty of defining futility and argues that the limitations of mediation give rise to procedural approaches.<sup>20</sup> These authors all recognize that both procedure and negotiation are essential tools and differ in priority and application. But they also despair of the admittedly difficult task of defining futility.

Failing to define medical futility adequately is a serious problem. People always have an implicit definition for the terms they use. Consequently, any process-based or mediation approach to resolving

futility cases must itself have some adequate definition of futility or default to the unwieldy position of confronting whatever definitions are asserted by the parties involved. In the worst-case scenario, each party to a conflict asserts the definition that falls to its favor, and medical futility, evacuated of any real meaning, cannot even justify withdrawing interventions that truly are futile. Faced with this difficult problem, some have suggested abandoning entirely the use of the term, and surely some institutions could do so with positive results.<sup>21</sup> However, it is still widely used in culture and law, and therefore it is necessary to use the definitions outlined above to evaluate the different meanings given to futility in healthcare culture today.

In the article "What Does Futility Mean? An Empirical Study of Doctor's Perceptions," Ben White and colleagues offer a window into current conceptions of medical futility.<sup>22</sup> These authors interviewed physicians in specialties routinely involved in end-of-life care. Conversational in style, each interview began simply by asking each physician to "describe a situation from your experience when a person got treatment at the end of life you didn't think they should have had."<sup>23</sup> The interviews then asked about the definitions physicians gave to futility, cases they had managed, and reasons why they thought treatment should not have been given. Follow-up interviews looked for similarities and differences among the physicians' views and "continued until a stable pattern of agreements and disagreements was established and no new topics emerged."<sup>24</sup> In this way, the research generated a list of perceived meanings for futility that physicians currently hold.

### Refining Perceptions and Avoiding Unnecessary Conflict

Some of these meanings constitute futility. Others do not. Some physicians related futility to patient benefit and offered a variety of definitions: no benefit, insignificant benefit, burdens outweigh benefits, and inability to achieve treatment goals. In reality, only two of these meanings represent futility: the intervention has no benefit or does not achieve treatment goals. "No benefit" implies that the intervention does not work and therefore is futile. An intervention might also be somewhat effective but unable to support reasonable goals of care, and therefore futile in that sense. The other meanings in the list—insignificant benefit, burdens outweigh benefits—might justify not performing the intervention, but imply some benefit whose value patients and patient representatives might legitimately pursue. In those scenarios, interventions cannot be with-

drawn as if they were ineffective based on clinical judgment, even if physicians have other strong reasons for not performing them.

White and colleagues also found that doctors related futility to the patient's quality of life. Here, the meanings of futility vary from no gain in functioning or length of life, to no quality of life, to insignificant quality of life. In reality, only "no gain in functioning" represents futility, because it implies that the intervention does not work. The other meanings—no or insignificant gain in quality of life—allow that an intervention could be somewhat effective, but not effective enough to restore bodily function to an acceptable level. The argument for not offering or continuing that intervention is based on what constitutes an acceptable quality of life and functioning rather than on the capability of the intervention to deliver its designed benefit. Declining such an intervention could not rest on grounds of futility.

Including all of these meanings under the one banner of futility introduces a contradiction that is impossible to overcome and likely to exacerbate conflict. Futility always claims that an intervention is ineffective in one of the two ways outlined above. Sometimes, though, physicians invoke futility when an intervention is somewhat beneficial. In this case, White and colleagues use the term "justifiable futility" to recognize both the benefit and the fact that physicians consider it not worth pursuing. At the same time, the authors recognize the inherent contradiction: "The term 'justifiable futile treatment,' containing, as it does, an internal contradiction, might be better rendered as 'appropriate treatment, all things considered.'"<sup>25</sup> The authors' alternative, appropriate treatment, may avoid conflict as long as physicians explain the reasons why they think a marginally beneficial intervention should not be pursued.

## MEDICAL FUTILITY IN PRACTICE

### The Courtroom

Examining legal cases is instructive for a variety of reasons. They provide well-documented examples of true futility, of misattributed futility, and of grey-area instances in which it is better to avoid futility language altogether. They show typical features of futility cases and articulate the reasons physicians often give for withdrawing interventions that have a marginal benefit and a weighty burden. Moreover, legal cases offer the opportunity to explore both the complex situations in which futility arises and the ethically meaningful distinctions that may help

resolve conflict. Finally, learning from legal cases provides realistic hope that sound ethical reasoning and strong attempts at honest, fair, and open communication may diminish the risks of litigation, of negative public reaction, and of damage to an institution's reputation.

The case of 28-year-old Carl Winspear provides a clear example of an intervention rendered immediately futile by the medical condition of the patient. Both family and medical professionals recognized that CPR would have been futile, but the family brought legal action because they were not informed of the DNACPR order (do not attempt CPR). Winspear suffered from cerebral palsy and spinal deformities that made CPR futile, presumably because these pathologies rendered his skeletal structure incapable of supporting the CPR procedure. Moreover, performing CPR would have been terribly distressing and painful for the patient and therefore extremely burdensome. His surrogate, his mother, recognized that CPR was futile, but objected to the DNACPR order placed without their consent.<sup>26</sup> The case illustrates futility in its strictest sense, the strong justification for declining the intervention, and the increased likelihood that surrogates will recognize futility.

In *Rotaru v. Vancouver*, the physicians correctly recognized that an advanced pathology, declining medical condition, and very poor prognosis left the patient with a number of interventions with little immediate benefit and made them futile for bringing about the healing required for discharge. However, the surrogate seemed to have the goal of prolonging life indefinitely and insisted on continuation. The patient, Alecsandrina Priboi, suffered from global vascular disease and presented at Vancouver General Hospital in December 2007 with right leg ischemia caused by a popliteal artery occlusion, which was treated. Subsequently, her medical condition declined, and court records summarize the physician's view:

Mrs. Priboi has global, irreversible vascular disease, with inoperable lesions resulting in compromised blood flow to vital tissues, particularly to the GI [gastrointestinal] tract. She has chronic ischemic colitis, with GI bleeding and inability to support enteric nutrition requiring TPN [total parenteral nutrition]. Her life currently is being sustained by artificial means. It is my opinion that she will not improve to the point that she will survive without these treatments, and I would expect that irrespective of our interventions that she will die. This is due to the burden of her disease state.<sup>27</sup>

The medical staff saw progressive multi-system organ failure that rendered dialysis, ventilation, and TPN futile for the goal of allowing the patient time to heal and return home. Family members never engaged the futility discussion, but insisted on continuing ventilation and TPN. These interventions provided some small immediate benefit, were not futile in that sense, and out of compassion for the family were continued as long as they did not increase the patient's suffering. Nonetheless, the family perceived the overall withdrawal of medical interventions as "death inducing actions" and sued for negligence.

In *Marsala v. Yale New Haven Hospital*, physicians also recognized that an advanced pathology, declining medical condition, and poor prognosis were progressively rendering interventions burdensome, marginally beneficial, or futile. In this case, the surrogate was not attempting to prolong life indefinitely, but did have moral objections to withdrawing ventilation, which remained immediately effective for prolonging life, yet futile for enabling the healing sufficient to return home. The medical record describes the declining medical condition of the patient, Helen Marsala,

a 76 year old woman transferred from Griffin Hospital for multiple medical problems for further management. She has an extensive past medical history, which included [diabetes mellitus], moderate aortic stenosis, hypertension, hyperlipidemia. . . . She has had a long hospital course, which has included prolonged respiratory failure and failure to wean, shock requiring vasopressors, Morganella bacteremia requiring treatment with Impipenem, volume overload, and GI bleeding thought to be due to ischemic colitis.<sup>28</sup>

Physicians repeatedly but unsuccessfully attempted to stimulate respiratory function by weaning the patient from ventilation. They recognized that continuing ventilation would offer marginal and declining benefit, with increasing burdens as the patient's medical condition deteriorated. Conflict arose when the physicians recommended changing her status to "do not re-intubate," but the surrogate, husband Clarence Marsala, considered re-intubation obligatory for preserving life. Notably, the patient's husband did consent to a DNR order because he believed his wife would not have wanted to be kept alive "at all costs." The physicians had a strong case that continued ventilation would be excessively burdensome, and could be withdrawn. Further, the physicians might have argued that continuing ventilation

was futile for the goal of discharge and would only slow the dying process. Invoking futility would have likely appeared counterintuitive to the family, because ventilation was immediately effective. In the end, the family brought numerous legal claims, including "negligent infliction of emotional distress, intentional infliction of emotional distress, wrongful death, loss of consortium, and medical malpractice."<sup>29</sup> This case illustrates that it may be better to avoid invoking futility even when one could make a good case for it.

In the case of Baby Joseph Maraachli, physicians invoked futility to withhold an intervention that was not actually futile in any sense. The baby's family requested treatment that physicians found excessively burdensome, but the family had a different view of the burdens involved, and legitimately pursued the intervention. The baby was born with a rare, neurodegenerative disorder eventually diagnosed as Leigh's disease. The ethical question was whether or not to perform a tracheotomy, which would have allowed the family to care for him at home until his death. The physicians called a tracheotomy futile because they thought it would cause much discomfort, increase the risk of infection and pneumonia, and impose arduous burdens of care on the family. They also thought that the baby had suffered enough and had no hope for recovery. But the physicians never claimed that a tracheotomy would not ease his breathing and realize the family's goal of caring for him at home. The parents recognized the burdens and the benefits because they had had a daughter with the same disease just a few years before. In her case, they had requested a tracheotomy, which was performed, and had cared for her at home until she died. With certain knowledge that a tracheostomy was not futile, the family brought legal action, and the conflict drew widespread media attention.<sup>30</sup>

### **Better Language at the End of Life**

Medical professionals need a broader set of ethical concepts and terms for legitimately withholding and withdrawing interventions. Futility does not apply when an intervention is capable of delivering its designed benefit. By contrast, the concepts "proportionate" and "disproportionate" describe the kind of reasoning that relates declining benefit to increasing burden and therefore that helps clarify when an intervention is not obligatory, even though not futile. A medical intervention is proportionate when its benefits outweigh its burdens. In such cases, the intervention is typically provided, and there may even be an expectation that the patient

accept the intervention if it is important for regaining health.

Disproportionate means that the burdens of an intervention outweigh its benefits, but benefits still remain. Achieving the benefit requires an excessively strenuous effort because the burdens are so heavy. Such burdens could include pain and suffering for the patient; psychological burdens on family and caregivers; and significant cost to the patient, the insurance plan, and the medical institution. Yet disproportionate treatment is *not* futile.

Disproportionate treatment should not necessarily be considered inappropriate. Although the recent ATS policy statement advocates “potentially inappropriate,” there are good reasons to avoid the term inappropriate altogether in conflictual, end-of-life cases.<sup>31</sup> Some families might mistakenly think that *they* are behaving inappropriately in requesting an intervention, when the physician is really saying that the *intervention* could be considered inappropriate. Moreover, the term inappropriate does not convey why a medical professional counsels against an intervention, for example, because it is excessively burdensome. In this context, disproportionate has the sense of “off balance” or “out of equilibrium,” describing a poor benefit-to-burden outcome that could be maintained with strenuous effort for a limited time. Patients are not expected to accept interventions with disproportionate burdens, but might request them in pursuit of specific, usually short-term, goals. Medical teams are not required to provide them, but often do for various reasons, especially to show compassion for patients and their families.

It is not always necessary to label an intervention as proportionate, disproportionate, or futile. These terms accurately convey the relationship between benefits and burdens, but can come across as overly technical for use with patients and families. Many people have never heard of them, and courts have had difficulty understanding and applying them. Local cultures might possess better language for communicating the meaning behind these concepts.

Generally, the most useful terms are probably “beneficial,” “burdensome,” and “ineffective.” Ineffective communicates the reason why an intervention is futile while avoiding the complications surrounding futility in today’s healthcare culture. Beneficial means that, on balance, the benefits outweigh the burdens of the intervention. Burdensome or perhaps “excessively burdensome” means that, on balance, the burdens outweigh the benefits of the intervention. As different parties to an end-of-life con-

flict express their views of treatment, using these terms naturally leads to a discussion about why each thinks the balance tends one way or another.

## CONCLUSION

It is better to avoid futility language in end-of-life conflicts, but some institutions have come to rely upon it, and the term has legitimate, although limited, purchase. Medical futility applies only to interventions and should be defined in terms of the benefit for which the intervention is designed. Medical futility occurs when the medical condition of the patient renders the intervention incapable of delivering its designed benefit, either immediately or in support of a reasonable goal of treatment. It should be properly related to goals of treatment. For example, ANH is futile if it cannot prolong life, but not because the patient will not regain consciousness. Nor does it apply whenever the medical team believes that the intervention should not be offered or continued, for example when it is excessively burdensome with marginal benefit. Although it may be difficult in practice to distinguish between futile and excessively burdensome interventions, in the latter case the patient or surrogate and family might legitimately state what that marginal benefit would mean to them. Physicians might still decline excessively burdensome interventions, but not on grounds of medical futility.

There is no guarantee that candid, compassionate discussion will prevent intractable conflict over end-of-life care. Many other factors, especially emotional states, influence end-of-life discussion more than the calculus of burdens and benefits. There is no language that automatically reconciles opposing views. Sometimes we can hope only that views are expressed and decisions are made with enough respect and transparency to avoid intractable conflict and promote resolution.

## NOTES

1. Legal scholar Thaddeus Pope maintains a very useful website that provides an excellent view of the scope of futility legislation, jurisprudence, and policy: <http://www.thaddeuspope.com/medicalfutility.html>.

2. J.L. Bernat, “Medical Futility: Definition, Determination, and Disputes in Critical Care,” *Neurocritical Care* 2 (2005): 198-205; E.D. Pellegrino, “Futility in Medical Decisions: The Word and the Concept,” *HEC Forum* 17, no. 4 (2005): 308-18; L.J. Schneiderman, “Defining Medical Futility and Improving Medical Care,” *Bioethical Inquiry* 8, no. 2 (2011): 123-31; L.J. Schneiderman, N.S. Jecker, and A.R. Jonsen, “Medical Futility: Its Meaning

and Ethical Implications,” *Annals of Internal Medicine* 112 (1990): 949-54; D.P. Sulmasy, “Medical Futility and the Varieties of Medical Judgment,” *Theoretical Medicine* 18 (1997): 63-78; see also E. Coonan, “Medical Futility: A Contemporary Review,” *The Journal of Clinical Ethics* 27, no. 4 (Winter 2016): 359-62.

3. See articles by Schneiderman et al., which propose quantitative and qualitative futility, in note 2 above.

4. *OED Online*, “futile, adj.” and “futility, n.,” <http://www.oed.com/view/Entry/75839>.

5. Schneiderman, “Defining Medical Futility,” see note 2 above.

6. P.R. Helft, M. Siegler, and J. Lantos, “The Rise and Fall of the Futility Movement,” *New England Journal of Medicine* 343, no. 21 (2000): 293.

7. M.R. Wicclair, “Medical Futility: A Conceptual and Ethical Analysis,” in *Biomedical Ethics*, 7th ed., ed. D. DeGrazia, T. Mappes, and J. Brand-Ballard (New York: McGraw Hill, 2011), 362.

8. G.T. Bosslet et al., “An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units,” *American Journal of Respiratory and Critical Care Medicine* 191, no. 11 (2015): 1320.

9. *Ibid.*, 1319.

10. Regarding physiological futility, see D. White and T.M. Pope, “Medical Futility and Potentially Inappropriate Treatment,” in *The Oxford Handbook of Ethics at the End of Life*, ed. S.J. Youngner and R.M. Arnold (New York: Oxford University Press, 2016), 72; regarding qualitative futility, see articles by Schneiderman et al., which propose quantitative and qualitative futility, in note 2 above.

11. Schneiderman, Jecker, and Jonsen, see note 2 above, p. 951.

12. Sulmasy, see note 2 above, pp. 73-4.

13. Schneiderman, “Defining Medical Futility,” see note 2 above, p. 127.

14. K.E. Lunsford et al., “Avoiding Futility in Simultaneous Liver-kidney Transplantation: Analysis of 331 Consecutive Patients Listed for Dual Organ Replacement,” *Annals of Surgery* 265 no. 5 (2016): 1016-24.

15. H. Petrowsky et al., “Liver Transplantation in Highest Acuity Recipients: Identifying Factors to Avoid Futility,” *Annals of Surgery* 259, no. 6 (2014): 1186-94.

16. *Ibid.*, 1191.

17. Lunsford et al., “Avoiding Futility,” see note 14 above, p. 7.

18. Royal College of Physicians, *Prolonged Disorders of Consciousness: National Clinical Guidelines* (London: Royal College of Physicians, 2013); Schneiderman, “Defining Medical Futility,” see note 2 above, p. 123.

19. J.P. Burns and R.D. Truog, “Futility: A Concept in Evolution,” *Chest* 132 (2007): 1987-93; C.J. Misak, D.B. White, and R.D. Truog, “Medical Futility: A New Look at an Old Problem,” *Chest* 146 (2014): 1667-72.

20. T.M. Pope and E. Waldman, “Futility: The Limits of Mediation,” *Chest* 134 (2007): 888 is a response to Burns and Truog, “Futility: A Concept in Evolution,” see note 19 above; T.M. Pope, “Procedural Due Process and Hospital Dispute Resolution Mechanisms: The Texas Advance

Directives Act,” *Saint Louis University Journal of Health Law & Policy* 93 (2016): 97-9.

21. J. Paris and A. Hawkins, “‘Futility’ Is a Failed Concept in Medical Decision Making: Its Use Should Be Abandoned,” *American Journal of Bioethics* 15, no. 7 (2015): 50-2.

22. B. White et al., “What Does Futility Mean? An Empirical Study of Doctor’s Perceptions,” *Medical Journal of Australia* 204, no. 8 (2016): 318e1-5.

23. *Ibid.*, appendix 1, “Interview Guide.”

24. *Ibid.*, 318.e2.

25. *Ibid.*, 318.e4.

26. *Winspear v. City Hospitals Sunderland NHS Foundation Trust*, 3250 (EWHC 2015), [http://www.thaddeuspope.com/images/Winspear\\_2015.pdf](http://www.thaddeuspope.com/images/Winspear_2015.pdf).

27. *Rotaru v. Vancouver General Hospital Intensive Care Unit*, 318 (BCSC 2008), <http://www.courts.gov.bc.ca/jdb-txt/sc/08/03/2008bcsc0318.htm>.

28. *Clarence Marsala et al. v. Yale-New Haven Hospital, Inc.* (Appellate Court of Connecticut 2016), <http://caselaw.findlaw.com/ct-court-of-appeals/1739065.html>.

29. *Ibid.*

30. *In re JM, CanLII 7955* (ON CCB 2011), <http://canlii.ca/t/2ftdh>. See especially the board’s ruling on pp. 19-20. “Baby Joseph, Just the Facts: Medical, Legal, and Ethical Issues,” London Health Sciences Centre, [http://www.lhsc.on.ca/About\\_Us/Baby\\_Joseph/](http://www.lhsc.on.ca/About_Us/Baby_Joseph/). For media coverage, see Joseph Maraachli case, [https://en.wikipedia.org/w/index.php?title=Joseph\\_Maraachli\\_case&oldid=775746549](https://en.wikipedia.org/w/index.php?title=Joseph_Maraachli_case&oldid=775746549).

31. Bosslet, “An Official,” see note 8 above.