FUTILITY AND THE PROPER GOALS OF MEDICINE:

A CRITICAL CARE PERSPECTIVE

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ABSTRACT

Futility and the Proper Goals of Medicine:

A Critical Care Perspective

English

While the concept of medical futility has existed for as long as medicine has been practiced, it remains a controversial issue that has become more clouded as medicine has advanced. This thesis will explore futility in the most technologically rich and emotionally charged of settings, the intensive care unit. The complex interactions of biology, ethics and the law, with their competing and sometimes conflicting interests will be explored. Disputes between patients, families and health care workers over life-sustaining interventions occur most often in the ICU, and the factors that influence this dynamic, such as lack of communication, time constraints, media-driven misconceptions and value-conflicts, will be examined. Attempts to address futility through advance health directives and conflict resolution policies will be critiqued. But most importantly, this thesis will explain, by appealing to the proper goals of medicine, why limitations should be placed on end-of-life care, and why physicians have an important role to play in making these determinations.

French

Malgré que la notion de la futilité existe depuis la pratique de la médecine elle-même, elle demeure une notion controversée qui est encore plus confuse avec l'avancement médical. Cette thèse explorera la futilité dans un des milieux les plus technologiquement sophistiqués et émotivement tendus, les soins intensifs. La complexité des interactions entre la biologie, l'éthique et la loi, avec leurs propres intérêts, souvent en compétition, sinon en conflit, sera examinée. Les conflits entre patients, familles et les professionnelles de la santé vis-à-vis les interventions artificielles se présentent le plus souvent aux soins intensifs, et les facteurs contribuant à cette dynamique, soit, les problèmes de communication, le manque de temps, les erreurs conceptuelles véhiculées par le média, et les conflits de valeurs seront examinés. Les tentatives d'adresser la question de la futilité médicale, soit par testaments biologiques ou politiques de résolutions de conflits, seront critiquées. D'autant plus, cette thèse fera appel aux objectifs appropriés de la médecine pour justifier certaines limites aux traitements en fin de vie, et pourquoi les médecins ont un rôle important dans ces déterminations.

Natalie Bandrauk, M.D.
McGill University, 2002

Preface

Over the last ten years, my journey through medical school, residency and a critical care fellowship has given me the tools to make good diagnoses and provide competent medical care to patients. But there remained a void; a sense of discomfort with how we do what we do, and why we do what we do, that keeps resurfacing.

On a personal and professional level, every phase of my life has evoked new existential questions. Unfortunately, the path to and through medical school these days often precludes any foundation in the Humanities, and the time commitment and focus on the "science" of medicine, do not allow much room in the curriculum for teaching young doctors how to become better thinkers and better decision-makers. I regretted not having acquired a formal framework to think about these questions.

As a daily battleground between life and death, I see the intensive care setting as being the epitome of where Ethics and Medicine meet. I cannot ignore this fact. I am particularly concerned with end-of-life issues, medical futility debates and resource allocations within the ICU, but also at the level of hospital policy. Despite considerable exposure to these issues, I remained troubled because I had received little guidance on how to address them.

I have had many different role models in the ICU, from the authoritative paternalist, to the defensive *laissez-faire* caregiver; one extreme seemingly motivated by ego, the other by the fear of litigation. I have found it difficult to reconcile my own opinions in ethical debates, with such opposing philosophies of care. I have also seen many physicians get into trouble because of their decision-making style, or lack thereof.

My greatest disappointment with respect to my training has been that the primary motivation for any ethical discussion, or for taking the time to make the 'best' decision, was the threat of legal action; 'damage control' ethics if you will. I appreciate that some decisions will never be easy to reach, but I would like to think that by learning, adopting and eventually teaching a proactive ethical approach to medicine, care will improve.

Many of my colleagues and students complain that ethics rounds only open the door to more questions and confusion, with no pragmatic endpoint and no plan of action to take to the bedside. Medical practitioners want a user-friendly approach. I want a user-friendly approach. Sometimes in medicine it is hard to see 'the forest between the trees'; I believe the answer lies in learning to ask the right questions.

If I had to describe what Ethics training represents for me, it was a chance to fill in some of these gaps; a chance for clarity.

I hope that my Ethics training, combined with my clinical experience, and my interest in and commitment to making it all make more sense, has provided me with the tools to identify the important questions and develop a framework where effective clinical decisions can be made. I hope to share what I have gained, to help my patients, my students and my colleagues think clearer and make better decisions. This thesis has set the groundwork for this task.

Acknowledgements

I wish to thank Dr Walter Glannon for his continued support and interest not only during the preparation of this thesis but throughout my Master's experience. His dedication and commitment to education, and in particular to opening the world of philosophy to the scientists in our group through supplementary tutorials was invaluable. He is a true mentor.

I also wish to thank my dear husband and 'coach' Dr Roger Avery for his patience and encouragement throughout this process. His insights and feedback were often instrumental in moving my reflections forward.

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Introduction

Medical futility is a concept that is quite controversial and often poorly understood. It is nonetheless frequently applied in the provision of patient care, particularly life-sustaining technologies including cardiopulmonary resuscitation (CPR). In order to understand the futility debate, one must appreciate the factors that inform the physician's assessment before he considers invoking medical futility to justify withholding or withdrawing certain types of treatments. Medical knowledge and experience, professional norms, patient and family preferences, societal and cultural influences, may all affect the physician's decision. The physician's task is further confounded by the lack of current ethical and legal consensus to guide such judgements, and the varied expectations different patients and families may have of the physician's role in medical decision-making.

While the concept of medical futility has received more than its share of attention in the bioethics and medical literatures over the last decade, the discourse will likely expand and take on even greater importance in the years to come. As internet access to medical information becomes widespread, patients will no doubt become more sophisticated and seek to push the boundaries of autonomy even more; as the voices of multiculturalism gain strength they too will demand special attention; as the push for cost containment increases, society will need to address and possibly limit the availability of certain medical resources; and hopefully physicians will strive to restore some of their professionalism that has been eroded over time. Because of these growing forces, disagreement over appropriate levels of care will become more frequent in the physician-patient relationship, and unavoidable on institutional and societal levels.

The goal of this thesis is to review the perspectives of these different interest groups and how the futility conversation has evolved among them. It is also to try and illustrate how complex and incommensurate this interaction can be, and that value judgements are an inescapable part of this task. Furthermore, the current circumstances of the futility debate will be explored and critiqued. This will include an analysis of the proposed strategies for dealing with claims for inadvisable treatments. Finally, this thesis will propose a different approach, one based on common sense values of both medicine and society, which will reflect not only what we can and cannot do, but also what we should and should not do.

BIOPSYCHOSOCIAL CONSIDERATIONS

IN

LIFE-SUSTAINING INTERVENTIONS

The Biological Realities of Life-Sustaining Treatments

The Paradigm of CPR

People's hearts stop beating every day, and for many different reasons. Rapid recovery of a spontaneously beating heart produces the best chance of achieving the ultimate goal of the Advanced Cardiac Life Support protocol, namely, "…a thinking, feeling, healthy human being."[1] In other words, promptly re-establishing brain perfusion is the most important objective. Cardiopulmonary resuscitation is the application of a combination of manoeuvres when the heart stops, in hopes of restoring the blood flow to vital organs and limiting permanent damage resulting from oxygen deprivation. Mechanical ventilation, initially through a bag and mask device, then following intubation, via an endotracheal tube, is used to restore oxygenation of the blood passing through the lungs. External chest compressions are administered to compensate for the loss of pumping of this blood by the heart. Intravenous access is sought to administer fluids and medications, that will help fill the heart and stimulate its pumping function, which in turn will restore circulation of blood to other organs. Finally electrical shocks are sometimes applied to the chest to 'jump-start' the heart when certain aberrant cardiac rhythms are noted. These manoeuvres, either alone or in combination, and other treatments such as transfusions and dialysis are considered life-sustaining interventions.

Although the resuscitation scene may be familiar to the public from its frequent re-enactment on television, it is neither an organised nor a dignified process in real life. Despite patients' lack of awareness of the procedure including any immediate suffering, they are

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[1] RO Cummins (ed), Advanced Cardiac Life Support (Dallas: American Heart Association, 1997), p1-1.

systematically invaded by the physical acts of health care workers and frequently left burdened by the results of these efforts. Ribs are broken, airways are traumatised, patients frequently vomit or become incontinent, and inevitably, unexpecting families and other patients are often witness to such displays. These efforts are frequently delayed, often involving many minutes of circulatory arrest and oxygen deprivation before attempts at resuscitation are even initiated. Thus outcomes are rarely favourable, even when a beating heart is restored, except when in monitored settings where prompt and rehearsed responses are facilitated.

CPR was originally intended for the rapid treatment of witnessed disruptions of the heart's rhythm in highly specialised and monitored units.[2] Its application was however rapidly and enthusiastically extended to include any situation where a person was found without a pulse. The eager and uncritical adoption of this new technology in the sixties and seventies reflected, "the widespread belief in American culture that science and technology [could] remarkably delay the ageing process and death."[3] Because all illness ultimately ended with the heart stopping, CPR could by default be applied to every one of these 'dying attempts'.

The medical profession has since become more sophisticated and realistic about the effects of CPR, including the benefits and burdens of this procedure in various clinical settings and in different patient populations. Physicians have recognised that the technological advances that have made it possible to save the lives of many individuals for whom previous generations of physicians could only pray, have also created a growing number of patients who have survived to experience a prolonged and painful death. Physicians have become concerned that they could be harming some patients by indiscriminately offering and attempting resuscitation

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[2] GL Snider, "The do-not-resuscitate order: ethical and legal imperative or medical decision?", *Am Rev Respir Dis* 143 (1991): p129.
[3] Ibid., p129.

for all patients. To a large extent even the public has come to realise the strengths and the limitations of such treatments, and there is frequent agreement that non-beneficial care should be forgone. Regardless, it remains standard practice to administer CPR to any patient found 'pulseless,' unless a Do-Not-Resuscitate (DNR) status has previously been established.

A decisive threshold for recovery and survival following cardiac arrest is impossible to define, for no two cases are exactly the same and no single variable can be reliably reduced to a statistic that is independent of the other factors. Nevertheless, attempts to define criteria that could predict favourable and poor outcomes after CPR have been studied. Statistical data in terms of success of resuscitation, survival to discharge and quality-of-life after CPR are available in the literature (see appendix A).

Despite continuing advances in cardiology, overall survival rates to discharge following CPR remain in the 50% range for the originally intended coronary care population.[4] Similar prognoses are noted for reversible conditions such as transient airway obstructions, electrolyte imbalances, and drug toxicities. For other non-cardiac etiologies, the outcomes after in-hospital cardiac arrest are poor, and in the few successfully resuscitated patients, the post-resuscitation course is dominated by the nature of the contributing disease process and the time to resuscitation. Patients with underlying illnesses such as metastatic cancer, sepsis, acute neurological syndromes and single or multi-system organ failure, particularly renal failure, appear to have poor survival rates after in-hospital cardiac arrest, even in monitored settings.[5] Frequently, there is a concomitant decline in the quality-of-life of the few patients who do survive beyond discharge from hospital as well. These studies, and others like them, have

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[4] H Brody, "Medical futility: a useful concept?", in Medical Futility and the evaluation of life-sustaining interventions, ed. MB Zucker and HD Zucker (New York: Cambridge University Press, 1997), p4.

[5] AH Moss, "Informing the patient about cardiopulmonary resuscitation: when the risks outweigh the benefits", *J Gen Int Med* 4 (1989): p349-355.

greatly influenced medical practice. It is generally held that overall, "when carried out in a timely and expert manner, CPR is often useful in the prevention of sudden, unexpected death. However, …it should not be carried out when it merely prolongs life in a patient with terminal, incurable disease."[6]

Because predicted mortality rates are far from ever being 100% in any clinical situation, and the appropriateness of using 'group data' to predict individual outcome remains uncertain and controversial,[7] physicians frequently must rely on their clinical interpretation, experience and burden-benefit judgements when making recommendations and decisions about patient care, including CPR and other life-sustaining treatments. In the end, "many clinicians view futility the way one judge viewed pornography: they may not be able to define it, but they know it when they see it."[8]

Other Life-Sustaining Treatments

Although resuscitation is the predominant life-sustaining treatment discussed in the futility literature, there are others that are perhaps even more contentious. These include the provision of massive transfusions for uncontrollable exsanguination, tube feeding in progressive dementia, long-term dialysis, and permanent reliance on ICU technology and support to survive, among others. Many of these medical scenarios, however, blur the operational definitions and conflicting principles at stake by adding their own particular twists to the futility debate. They nonetheless present similar ethical concerns to those discussed with CPR, and as such can generally be considered together.

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[6] KJ Isselbacher, E Braunwald, JD Wilson, JB Martin, AS Fauci,and DL Kasper, Harrison's Principles of Internal Medicine-13th edition (Montreal: McGraw-Hill, 1994), p5-6.
[7] RD Truog, AS Brett and J Frader, "The problem with futility", *NEJM* 326 (1992): p1561.
[8] *Ibid.*, p1560.

Ethical Considerations in the Provision of Life-Sustaining Treatments

The Meaning of Futility

According to Webster's Dictionary, futility is defined as, "that [which] easily pours out." The term is derived from Greek mythology, and refers to, "the daughters of Danaus [who] were condemned to draw water in leaky buckets from which the liquid would inevitably spill."[9] The essence of this tale conveys the meaning of futility. "A futile action is one that cannot achieve the goals of the action, no matter how often repeated."[10]

There has been much debate over the proposed definitions and thresholds of medical futility. To avoid needless suffering from CPR and other critical intervention it would be helpful to have consensus on what, "no reasonable hope of recovery"[11] means. One such definition suggests that a treatment should be deemed futile when it has not been successful the last 100 times it was tried.[12] As some commentators have noted, no matter what it is called or where the line is drawn, there are limits to what medicine can do and thus at some point the blurred line of medical futility is crossed.[13] In this narrow sense, the provision of a life-sustaining treatment would be futile only when it could not achieve its intended goal. This begs the question of what the intended goal of critical interventions should be, and who should decide on this goal.

The provision of critical interventions, such as CPR, has extended far beyond their original purposes, and its objective is often viewed very differently by the provider and the

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[9] A Alpers and B Lo, "When is CPR futile?", *JAMA* 273 (1995): p156.

[10] LJ Schneiderman, NS Jecker and AR Jonsen, "Medical futility: its meaning and ethical implications", *Ann Intern Med* 112 (1990): p950.

[11] Canadian Medical Association, "CMA policy summary: joint statement on resuscitative interventions (Update 1995)", *CMAJ* 153 (1995): p1652.

[12] LJ Schneiderman, p951.

[13] JJ Paris, MD Schreiber, M Statter, R Arensman and M Siegler, "Beyond autonomy – physicians' refusal to use life-prolonging extracorporeal membrane oxygenation", *NEJM.* 329 (1993): p357.

recipient of care. Critics have argued that just because clinical experience and statistical data suggest that a patient will not survive, they do not guarantee that fact. The slightest probability of survival can provoke disagreement based on differences in the perceived value of the outcome.[14] Providers look at their patient and the outcome data, and make two sorts of judgements: the first is whether or not a treatment will have an effect – in the case of CPR, to restore a heart beat (a physiologic or quantitative assessment); the second is whether the benefit of the intervention justifies the burdens (a qualitative assessment). Physicians are also more likely to focus on the survival data to discharge rather than the immediate survival of resuscitation and thus run the risk of making value judgements about which goals are worth pursuing. The patient and family on the other hand may value any resultant quantity and quality of a 'short-term' survival following CPR, a judgement that is generally accepted to be theirs to make.[15] For example, a 5% discharge survival following CPR may be acceptable for certain patients compared to certain death. There can be no basis for agreement about the burden of a given intervention or the meaningfulness of benefit or lack of benefit, unless there is first agreement about the **goals** to be achieved.

Sometimes there remain unrealistic expectations about what medicine and science can accomplish, and how these accomplishments should be utilised. Debating the meaning of futility does not eliminate the real fact that conflicts can and do arise over the provision of end-of-life care. Thus, "it is not the meaning of a word but the moral basis for the actions of the participants that ought to be the focus of our attention."[16]

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[14] RD Truog, p1560-4.

[15] CMA, "Joint Statement on preventing and resolving ethical conflicts involving health care providers and persons receiving care", (1999), <http://www.cma.ca/inside/policybase/1998/12%2D04.htm>.

[16] JJ Paris, p354.

Medical Practice and Integrity

Medicine is largely an attempt to prevent nature from taking its course. While this objective is true for many disease states, medicine is far from being able to remedy every ailment of the body. The notion of futile medical treatment can be traced back to Hippocrates who allegedly advised physicians, "to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless."[17] It is thus generally accepted that physicians are not obliged to provide patients with care that is contrary to their professional values.

Since the time of Hippocrates, physicians have also been required to act in the best interests of their patients and above all, 'do no harm.'[18] In some cases, treatments may cause suffering which is disproportional to the expected benefits, and physicians must find a balance between the competing goals of beneficent and nonmaleficent care. CPR and other critical interventions should not be used to prolong life without thoughtful consideration of their other effects. However, because of cultural, religious, family and even legal pressures, physicians sometimes feel compelled to provide life-sustaining treatments against their own professional and moral judgement. The easiest and safest solution from a risk-management perspective would be to respect patient wishes and simply give in to these demands. However, such a *laissez-faire* approach can undermine the obligation to spare the patient unnecessary suffering. Providing life-sustaining interventions such as CPR sometimes offers hope, but sometimes offers only false hope, stripping dying patients of their last thread of dignity in the process. In his book, How

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[17] LJ Schneiderman, NS Jecker and R Jonsen, "Medical futility: Response to critiques", *Ann Int Med* 125 (1996): p673.

[18] TL Beauchamp and JF Childress, Principles of biomedical ethics-4th edition, (New York: Oxford University Press, 1994), p189.

We Die, Nuland recalls the death of his brother, and how it could have been easier, "without the added devastation of futile treatment and misguided concept of hope…."[19]

Paternalism has become a 'dirty word' in the modern world of medical ethics. It has become commonplace to distinguish between issues of scientific knowledge in which the physician can legitimately assert expertise, and questions of value, in which the physician has a duty to respect the wishes and preferences of the patient. Yet it remains unclear which way the pendulum should swing on the issue of medical futility. Most critics agree that, "physicians should not offer treatments that are physiologically futile or certain not to prolong life."[20] But beyond this there is division of opinion. Opponents of the futility debate argue that physicians should not make value judgements about which goals and qualities of life are worth pursuing. They fear that by allowing physicians the authority to invoke unilateral physiologic futility judgements in the clearest cases, such authority will inevitably extend to cases of qualitative futility and abuse will follow. There is also concern that such power will silence the patient in medical decision-making, and undermine the very dialogue the autonomy movement has tried to encourage over the last few decades.[21]

On the other hand, proponents of the futility debate believe that, "futility is so closely bound up with the critical concepts of professional integrity that medicine risks losing its moral bearings if it ignores the issue."[22] Medicine has its own internal moral standards. And ultimately physicians, to greater or lesser degrees, adopt these standards as their own values. "The moral basis of the physician-patient relationship is to attempt to do the patient some good.

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[19] SB Nuland, How We Die: Reflections on Life's Final Chapter, (New York: Vintage Books, 1994), p231.
[20] SJ Youngner, "Who defines futility?", *JAMA* 260 (1988): p2094.
[21] H Brody, p3.
[22] *Ibid.*, p1.

Actions that do not contribute to this end are not morally required."[23] Physicians make these sorts of determinations every day. They refuse to order CT scans for simple headaches. They deny requests for anabolic steroids from bodybuilders, even if the patients are aware of the risks and benefits of such treatments. They also refuse to perform surgery on patients in whom it will likely do more harm than good. These are all examples of value judgements that society empowers and demands physicians to make based on their own understanding of medicine's defining values, irrespective of the valued benefit as defined by the autonomous patient. Thus, "physician integrity includes an injunction not to perform actions that predictably fail to offer benefit and that could in some cases cause harm."[24] Such value judgements are inescapable in medicine, including those involving end-of-life care. It would seem inconsistent that society can place such confidence and responsibility in the medical establishment and even sanction it to self-govern, yet selectively reject medical opinions regarding the appropriateness of CPR and other treatments at the margins of life.[25]

Patient Autonomy and Related Interests

Over the last few decades, the ethical principle of autonomy and respect for persons has replaced paternalism as the governing force in medical decision-making. The Canadian Medical Association endorses this position, stating that, "the needs, values and preferences of the person receiving care should be the primary consideration in the provision of quality health care."[26]

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[23] T Tomlinson and H Brody, "Futility and the ethics of resuscitation", *JAMA.* 264 (1990): p1277.
[24] H Brody, p8.
[25] *Ibid.*, p5.
[26] CMA, <http://www.cma.ca/inside/policybase/1998/12%2D04.htm>, p3.

This shift is unfortunately viewed by some physicians as a directive to give up their role as moral agent, and to simply accommodate the patient's or surrogate's wishes.[27]

With respect to end-of-life care, autonomy evolved as a right to refuse and be protected from unwanted and inappropriate life-sustaining treatments.[28] [29] There is, however, no correlative consensus regarding the right to demand such treatments. Neither is the principle of autonomy an absolute. Its goal is primarily to encourage conversation between patient and physician, and promote informed participation of the patient in the decision-making process.

The physician has a duty to, "fully and honestly inform the patient of the nature of the disease, the prognosis, and the risks and benefits inherent in the various therapeutic options, so that the patient has the information on which to base his or her decision."[30] Patients and families frequently underestimate the burdens of resuscitation efforts. They often view such efforts as only life or death endeavours, which they are, but defer the quality-of-life assessment to a second-order consideration. Murphy examined the effect of CPR outcome data on patient preferences amongst the elderly. He found that the number of patients still desiring CPR if needed, dropped from 41 to 22% after they learned the 'facts.' This number fell even lower in the 86 and over age group, and those with chronic underlying illness.[31] Thus it appears that many patients are not well informed and would indeed forego critical interventions if they understood the full implications.

For many patients and providers, offering critical interventions when death is imminent and when such care would only prolong the dying process is inappropriate and inhumane. It

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[27] Paris, p354.

[28] *In re Quinlan,* 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom Garger v. New Jersey*, 429 U.S. 922 (1976).

[29] *Cruzan* v. *Director, Missouri Dept. of Health*, 497 U.S. 261, 110 S. Ct. 2841 (1990).

[30] GL Snider, p130.

[31] DJ Murphy, D Burrows and S Santilli, "The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation", *NEJM.* 330 (1994): p545-9.

may, however, be heartbreaking for patients and their families, and even for health care providers, to suddenly give up, after hoping against all odds, and for so long. For family members especially, the only power they have at the bedside is to pray and insist everything be done. Some do this out of love, some out of guilt, some out of religious conviction, and some 'knowing' full well that if they ask for the most, they will be lucky to receive the minimum appropriate level of care. Thus, communication and mutual understanding of the different agendas and relevant interests are important to ensure that common and realistic goals are chosen, that will both respect the wishes of the patient and are in his or her best interests. Admittedly, there will be situations where disagreement about the appropriateness of resuscitation will follow such discussions. Respect for patient autonomy and self-determination means that it is the patient who should decide what quality-of-life is worth pursuing. Still, reasonable patients expect doctors to be beneficent and only recommend, and ultimately provide, treatments that, "offer a benefit reasonably worth pursuing."[32]

As Youngner put it, "physicians are in the best position to know the empirical facts about the many aspects of futility."[33] The quality of life that might follow CPR is difficult for the physician to communicate to the patient and family. And it is even more challenging to ensure they have an accurate understanding of this. Some authors believe that offering a patient the option of futile treatment is misleading, and might even undermine autonomy rather than promote it. If the physician-patient relationship is understood to be a fiduciary one, then offering a treatment that cannot realistically be expected to achieve its goal, sends a mixed message to the patient who might latch on to any hope for life, and then only endure the burden of the

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[32] T Tomlinson, p1279.

[33] SJ Youngner, p2094.

intervention.[34] Similarly, routinely and indiscriminately informing all patients of their prognoses, and discussing options that cannot be expected to work might take away that little bit of hope, if not peace of mind, that, for at least some patients, ignorance provided. Thus, "the loss of power to limit the range of reasonable patient options may remove a tool that physicians need, to serve effectively as advocates for the patient's autonomy."[35]

There are sometimes religious and cultural considerations that inform the decision-making process. In this context, non-disclosure may not be a matter of paternalism, but a matter of cultural sensitivity. Some patients are more comfortable with waiving their right to information and decision-making to family members or health care providers; respecting the autonomy of such patients sometimes means accommodating such different 'models' of physician-patient interaction. In other instances the difference is not about the process but about the actual decision. Religious conviction and belief in the *Sanctity of life,* for instance, might dictate that all possible treatments must be provided on the grounds that all life, regardless of its compromised quality, is worth saving. Thus what the physician in particular and society in general judge to be of no benefit and perhaps even harmful, might be perceived to have value by patient and family. There is no ethical consensus on how such demands should be addressed other than to, "promote institutional mechanisms for mediation and dispute resolution, and encourage the participants,...to attempt to work together to reach mutually acceptable understandings."[36]

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[34] T Tomlinson, p1279.

[35] *Ibid.*, p1280.

[36] L Turner, "Bioethics and end-of-life care in multi-ethnic settings", (University of Toronto Joint Centre for Bioethics, 2000), [unpublished], p17.

Justice and Economic Aspects

Although the debate over futile care has primarily focused on the struggle between patient and physician rights, society has a stake in such determinations as well. Specifically, these interests fall under the rubric of Justice.

Where the duty of previous generations of physicians was to always put the well-being of patients first, some more contemporary Codes have added an injunction to, "use health care resources prudently."[37] This shift in the general responsibilities of physicians reflects the growing pressure on our struggling health care system to cut costs and use resources judiciously. This additional demand on physicians has confused the issue of futility and placed the doctor-patient relationship in an even more tenuous position.

For some, the notion of futility is a convenient way to cut costs. Many futile treatments are expensive. What is less clear, is if limiting such treatments would make a significant dent in the health care budget. According to Murphy, limiting futile care alone would not lead to significant savings considering the few cases per year that face each institution. However a less strict definition including inappropriate interventions (where burdens simply outweigh benefits) could, "save as much as 6% to 10% of the health care budget."[38] While this may seem attractive, critics argue that such solutions do not pertain to medical practice but to public policy; rationing is a social discussion about the just allocation of resources and should not take place at the bedside.[39] Futility involves, "moral judgements about right and good care."[40] Rationing refers to withholding efficacious treatments that are not cost-effective. Futile treatments may also not

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[37] CMA, "Code of ethics", (1996): article 32.

[38] DJ Murphy, "The economics of futile interventions", in Medical Futility and the evaluation of life-sustaining interventions, ed. MB Zucker and HD Zucker (New York: Cambridge University Press, 1997), p128.

[39] American Medical Association council on ethical and judicial affairs, "Medical futility in end-of-life care", *JAMA* 281 (1999): p938.

[40] PR Helft, M Seigler and J Lantos, "The rise and fall of the futility debate", *NEJM* 343 (2000): p293.

be cost-worthy, but not all non-cost-worthy treatments are necessarily futile. For instance, society may decide that dialysis in the elderly may not be a cost-effective use of this resource, but it is by no means ineffective or futile. In the end, it is generally agreed that discussions about the inappropriateness of futile life-sustaining treatments should be kept separate from issues of cost-worthiness.

Justice also refers to, "giving to each person that which is due or owed, and which can be legitimately or fairly claimed."[41] While the overall cost of futile interventions may not be great, the demands on scarce resources such as intensive care, by patients occupying one of a finite number of beds for weeks on end, might limit the admission of other more salvageable patients. Such resource issues are real and important in the day-to-day functioning of a hospital, and affect the population it serves. But decisions regarding a patient's medical worthiness for intensive care should be based on that patient's physiological status and potential to improve, and not on the number of beds available. If the patient does not meet admission criteria then their presence in ICU is inappropriate, even if beds are available. Thus decisions about futility and triage should also be kept distinct.

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[41] GL Snider, p130.

Legal Considerations

There are three legal concepts that govern medical decision-making. They are the Doctrine of Informed Consent, the Best Interest Standard, and Standard of Care. These are respectively based on the corresponding ethical principles of autonomy, beneficence and nonmaleficence, and professional integrity. With respect to futility judgements there is no clear consensus either ethically or legally of how these principles should be interpreted and applied. What follows is thus a synopsis of the relevant sources of law that contribute to the debate.

The Doctrine of Informed Consent

The values behind the Doctrine of Informed Consent are mirrored in many sources of law. The Civil Code of Quebec stipulates that the, "person is inviolable," and that, "no person may be made to undergo care of any nature except with his consent."[42] These statutes reflect the Charter rights of *liberty* and *security* that all individuals hold.[43] In Common Law, failure to obtain consent for medical acts constitutes battery, whereas inadequate consent is a basis for negligence. The specific elements required in the process of informed consent derive from a number of legal holdings, in particular *Reibl v. Hughes*.[44] These include an adequate disclosure of information according to an objective view of what a reasonable person in the patient's position would want to know ('reasonable patient standard'), and capacity of the patient to make a decision. There are however exceptions to these requirements, namely, emergency care, patient waiver, incapacity and the notion of therapeutic privilege.

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[42] The Civil Code of Quebec, (1994), articles 10 and 11.

[43] Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, (1982). (specifically s.7 & s.12).

[44] *Reibl* v. *Hughes*, [1980] 2 S.C.R. 880, 114 D.L.R. (3d)1.

Some of these exceptions are relevant to our discussion of futility judgements. For instance, patients can waive their right to information and leave the decision in the hands of others, including the physician and family members. Alternatively, the notion of a therapeutic privilege can be appealed to by the physician, with the understanding that disclosures regarding prognosis or some treatment options may harm the patient, or not be in his best interests. The duty to obtain informed consent is also expressed in the standards of professional organizations such as the Quebec Code of Ethics of Physicians,[45] where, "except in an emergency, a physician must before undertaking an investigation or treatment,...obtain informed consent from the patient or his representative."(art.2.03.28) The therapeutic privilege clause is also addressed in this policy. "Except for valid reason the physician shall not conceal a fatal or grave prognosis from a patient who requests that it be revealed to him."(art.2.03.30) This exception, however, has not been challenged by the futility debate and the courts would likely interpret it very narrowly.

Another facet to the doctrine of informed consent is the issue of incapacity. In such cases physicians are still required to obtain consent, but from a surrogate decision-maker. In Quebec this person is identified according to the following order: the patient-appointed mandatary, the spouse, or a close relative or person showing special interest.(art.15 CCQ) This person's role is also legally determined.

> A person who gives his consent or refuses care for another person is bound to act in the *sole interest* of that person, taking into account as far as possible, any wishes the latter may have expressed. If he gives his consent he shall ensure that the care is beneficial notwithstanding the gravity and permanence of certain of its effects, that it is *advisable* in the circumstances and that the risks incurred are not disproportionate to the anticipated benefit.(art.12 CCQ)

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[45] Quebec Code of ethics of physicians, (1996).

However, the law does not stipulate by whose standard words like 'benefit' and 'inadvisable' and 'risk' should be interpreted. Ostensibly, if such a conflict made its way to court the 'reasonable patient standard' may be applied.

Best Interests Standard

When the wishes of the patient are not clear, physicians must appeal to the principles of beneficence and nonmaleficence. Patients have *Charter* rights, which include the right to life(s.7), but also the right, "not to be subjected to cruel and unusual treatment."(s.12) As such, "a physician must refuse to participate in acts that are not in the patient's interest."(art.2.03.23)[46] This view is supported by the holding in the *Quinlan* Case which states that if there is concern that, "a person's suffering would make the administration of a life-sustaining treatment inhumane, a 'pure-objective' [best interest] standard could be used to terminate [or forego] treatment."[47]

When health care providers have reason to believe that a surrogate decision-maker is not acting according to the wishes and values of the patient or, if these are not known, contrary to the best interests of the patient, arbitration may be appropriate. The courts can be petitioned to assess and decide if the proxy's decisions are justified. In one case, the Manitoba Court of appeals approved a DNR order in the 'best interests' of a battered child against the wishes of the alleged abusive parents, stating that, "it is no one's interest to artificially maintain the life of a...patient who is in an irreversible vegetative state."[48]

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[46] Quebec Code of ethics of physicians.

[47] *Cruzan* v. *Director Missouri Dept. of Health.*

[48] *Child and Family Services of Central Manitoba v. Lavallée* (14 Nov 1997), (Man, CA) [unreported].

It is however more common for the courts to support the opinion of the surrogate decision-maker unless, as above, it is believed that this person's efforts are clearly misguided.[49] For instance, in the case of *Helga Wanglie*, the courts agreed that the husband was in the best position to know and uphold his wife's wishes.[50] It is important to understand the position of the court, specifically its subjective perception of responsibility in such judgements. Prospectively, the burden in 'sentencing a patient to death' is seen as far greater than the imposition of continued treatment on an impersonal medical system.

Standard of Care

Physicians object to the seeming bias of the courts in supporting patients and their representatives in the name of autonomy.[51] There is genuine concern that this trend will one day include the right to demand care that is beyond the standards of the medical profession to provide. Because medicine is a self-regulating body, to date, the rules of conduct that the law looks to when judging physicians, 'the standard of a reasonably skilled practitioner', are found in the professional codes, in the consensus statements or policies on the different medical issues and on expert testimony. Nowhere in these standards, including those related to informed consent, is there a duty to provide care that is against the agreed-upon standard of practice. Furthermore, most of these codes of conduct and consensus statements are purposefully vague to allow for some flexibility and discretion in the individual physician's practice of his profession, and also in the implementation of related policies and guidelines by institutions.

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[49] In the Manitoba case, the presumed motivation of the parents was to keep the child alive to avoid criminal responsibility for the death.

[50] *In re Conservatorship of Wanglie*, No.PX-91-283 (Minn. Dist. Ct. Hennepin Co. July 1991).

[51] *In the matter of Baby K*, 832F. Supp. 1022 (E.D. VA. 1993), & *In re Conservatorship of Wanglie.* In the highly publicised US 'futility' cases of *Baby K* and *Helga Wanglie*, the courts sided with the surrogates forcing physicians to provide continued treatment.

The Canadian Medical Association (CMA) Joint Statement on Resuscitative Interventions affirms that,

> there is no obligation to offer a person futile or nonbeneficial treatment…. In some situations a physician can determine that a treatment is medically futile or nonbeneficial [if] it offers no reasonable hope of recovery or improvement or because the person is permanently unable to experience any benefit. In other cases the utility and benefit of a treatment can only be determined with reference to the person's subjective judgement about his or her overall well-being.[52]

The CMA code of ethics advises physicians to, "provide for appropriate care" and to, "recommend only those…therapeutic procedures that [are] considered to be beneficial."[53] The Quebec code adds that, "a physician must avoid …acts that are unsuitable or contrary to current medical science."(art. 2.03.17)

In addition to supporting a physician's decision not to offer or provide treatments that are ineffective and nonbeneficial, and possibly even harmful, these policies mandate that, "the physician must, where his moral or religious convictions prevent him from prescribing or dispensing a treatment that *may be appropriate*, acquaint his patient with these factors. He may however send the patient to another physician", but he may not abandon the patient in the meantime.(arts. 2.03.05, 06, 10)

Thus it would seem that there is some legal support to withhold futile treatments, purely on medical grounds. The problem however, is that what is disputed in most futility cases is whether they are actually futile. In situations where there is doubt about the value of a treatment, the law allows the physician to recuse himself, but only once care is assumed by another physician.

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[52] CMA, "Joint statement on resuscitative interventions".

[53] CMA, "Code of ethics", articles 3 & 14.

Looking For Real Options

In the search for guidance on how to balance the sometimes competing ethical principles that influence the provision of end-of-life care, physicians are left in a 'Catch 22.' Sometimes physicians are faced with the difficult task of having to choose between respecting the autonomy of the patient, and upholding or not violating the principles of beneficence and nonmaleficence, and their own professional integrity. "The art of medicine still lies in making the correct decision on the basis of incomplete information, and in finding an appropriate balance among the often conflicting principles that guide medical practice."[54] The dilemma is really about how to **balance** patient autonomy with the integrity of medical practice when both goals are desirable but mutually exclusive. How are doctors to reconcile their duty to respect their patient's wishes and their duty to secure beneficent and nonmaleficent care, particularly when they should not abandon their patient, and no one else is likely to assume responsibility either? There remains no consensus, but only an ongoing debate over the morally acceptable options.

In the end there are three options. To give autonomy moral supremacy, to give medicine the last word, or to give the power to neither and assess each case on its individual merits. To a large extent, the discussion of 'ethical considerations' has already addressed the first two options. There are obviously serious concerns with the debate resting on either of these.

Clearly, this conflict cannot be resolved by appealing to either autonomy or professional integrity alone. It has been wise of the medical bodies to keep their policies and position statements vague, because there is no one right moral solution, and flexibility is the best way to provide for the differing roles patients can and wish to play in their care. Undoubtedly, even with

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[54] GL Snider, p132.

the best intentions conflicts can arise. The current strategy is to address such disputes by adopting conflict resolution policies, where communication, mediation and perhaps even arbitration are sought.

WHERE WE ARE NOW AND WHY

Communication Breakdown

After a decade of debating it became clear that this controversy could not be resolved by appealing to either autonomy or professional integrity alone, and that no agreeable definition and threshold for futility could be reached. The reason was trust. The greatest obstacle, and the reason why these earlier attempts failed, was the loss of trust in the doctor-patient relationship.[55]

Consider the following case. Mrs. C. was a fifty-year old woman who was admitted to the ICU with pneumonia and respiratory failure. After multiple attempts at weaning from the ventilator, it became clear that her lungs had been significantly damaged. Her course in hospital was further complicated by antibiotic-induced renal failure necessitating dialysis and a waxing and waning neurological picture. Multiple investigations and consultations failed to find an explanation for her condition. As the months advanced, Mrs. C. slipped into a deeper coma. Despite this, her husband insisted that she maintained contact with him – the slightest movement was interpreted as having significance. He believed that if there were any chance of recovery, she would want to continue supportive care indefinitely. However, all involved physicians believed that even without a diagnosis, her condition was irreversible and her prognosis very poor. In their opinion, her situation was futile and they recommended withdrawal of life support.

This difference of opinion led to animosity between the health care providers and the husband. He was of the opinion that his observations were being dismissed and that optimal care was not being provided. To support his position, he would stimulate his wife repeatedly in an attempt to demonstrate her movements to the heath care team. He also began taking notes of all the irregularities in his wife's care, and criticising any action he felt was inappropriate. He was

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suspicious of any changes in the care plan, and felt that all the doctors were 'conspiring' against him. He no longer wished to speak to them because they were always trying to convince him to withdraw therapy.

In turn, the doctors stopped talking to the husband because the conversation was always the same – he wanted to know the diagnosis and without this information he would refuse to consider cessation of life support. As a result the patient's bedside would be skipped during rounds to avoid another pointless discussion.

After months of being at the bedside, the husband developed a superficial understanding of critical care. Although he talked to his wife and assisted in some of her care, much of his time was spent watching and listening to the events around him. He learned many of the catch-phrases that are used daily, and was quick to offer his 'expert' assessment of what needed to be done. This antagonised health-care providers and further impeded constructive communication. After ten months of a progressively deteriorating environment, an ethics consultation was requested to help remedy the situation.

ICUs are Setups for Disaster

One might ask how so much time could go by without reaching some sort of compromise. This is of course one of the extreme and difficult cases, one of the few cases per year that confronts every institution and which disheartens and perplexes all those involved. But at its heart it is a human story, and it teaches us a lot about what can go wrong among the different parties at the bedside.

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[55] AL Caplan, "Odds and ends: trust and the debate over medical futility", *Ann Int Med* 125 (1996): p689.

Our model of hospital care does not encourage trust between the patients or their surrogates and physicians. One problem is that increasingly the system is one of rotating physicians, often on a weekly or monthly basis. Just when you get to know your doctor's name, it is already time for a change in the duty roster. This lack of continuity of care makes trust a fragile and sometimes elusive element in the modern doctor-patient relationship. This reality is nowhere more magnified than in the ICU. Unlike the slow and gradual development of trust that matures over years in the family doctor's office, the ICU encounter introduces strangers at the bedside at the most critical of times. In many cases, before the patient even gets to the ICU the views of the family may already be influenced by the perception that something went wrong with patient care to precipitate this crisis.

Physicians barely know their patients. And what they know is from the charts, the medical facts and little more. They are not well trained to address the psychological and social needs of patients and their families, and this is even more true in the ICU where physiology is the basis of all care plans – social concerns take a back seat. Their understanding of a patient's goal can often be reduced to 'the patient is here to get better'. And in all fairness, this is also the proper objective of the ICU for the two or three days most patients spend there getting stabilised. But when this goal is threatened, a host of factors can contribute to the potential rift between doctors and a patient's family. Physicians are uncomfortable with discussions about end-of-life issues and do sidestep them,[56] in part because of the emotional nature of these conversations, and

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[56] SUPPORT Principal Investigators, "A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)", *JAMA* 274 (1995): p1591-8.

in part because there are no clear ethical and legal bearings for them to rely on. They are thus unsure of the legitimate scope of their role.

Time is perhaps the greatest pitfall. Families have too much of it, and physicians not enough. The ICU is a very stressful and emotionally charged environment for family members, especially when facing the death of a loved one. They are in crisis, they have no control, and they feel they have nowhere to turn. They have questions, and they want answers. Yet the doctors are often too busy. Because the setting is so foreign to them they are often not sure how to behave or how to ask for help. They feel alone. So they sit at the bedside for hours, worrying, hoping, and looking around, buying into all the technology and its promise. And when the situation abruptly changes, as happens all too often in the ICU, they have difficulty keeping up emotionally.

The doctors, for their part are so busy they do not always appreciate the family's angst. Often they do not even know who the family is. The priority is the medical care of the patients. Family members are generally not invited to the bedside during procedures or when doctors make rounds. Furthermore, with family visits often clustered in the evenings when only on-call services are provided, the paths of decision-makers on both sides of the equation are less likely to cross. And when they do meet, doctors share bad news.

Perception is the next hurdle to building trust. There are many misconceptions that can threaten the relationship between health care providers and recipients. First, there is a very real misunderstanding of what medicine can and cannot achieve. The media and its miracles colour the views of the public by depicting primarily the success stories. Furthermore, not only do these fictional patients survive incredible odds, but they also recover completely. This perpetuates an exaggerated sense of hope when a patient is admitted to the ICU. Thus families come in expecting miracles, and are reluctant to acknowledge the more common, yet real outcomes of diminished quality of life, prolonged death and suffering.

Doctors on the other hand are all too familiar with the limitations of their trade. They face death everyday, and see the reality of patients dying despite the best of care. They understand that up to twenty percent of patients admitted to the ICU never leave.[57] They are familiar with the limitations of the technologies used to sustain life. Statistics and probabilities are a reality in medicine, and are a driving force in guiding care. For families, statistics are not important, only the individual is.

Another difference is over the reality of care. Families often do not appreciate the amount of care provided to patients, or the nature of that care. Much of the hands-on attention that patients receive is behind the curtain and out of the family's view. For a variety of reasons, privacy of the patient being the most important, this is how medicine functions and how it gets the job done. Not everything that is said and done in the provision of medical care is appropriate for the eyes and ears of visitors. For instance, where healthcare workers struggle with turning and cleaning a totally dependant and comatose patient who is incontinent of urine and stool, and whose only responses day after day are grimacing or groaning, the family returns to find their loved one peacefully

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[57] HS Rafkin and T Rainey, in "Medical futility: a legal perspective", in Medical Futility and the evaluation of life-sustaining interventions, ed. MB Zucker and HD Zucker (New York: Cambridge University Press, 1997), p24.

'asleep' and neatly tucked in. Rarely are families witness to the chaotic and often undignified display of resuscitation efforts, not infrequently punctuated by cracked ribs, blood and other bodily fluids. Success or not, the tubes are all neatly repositioned or removed, and the mess cleaned away before visitation is allowed. Nothing on television can prepare a family member for viewing the burdens of such treatments on their loved one. When possible it is therefore avoided. Consequently, families cannot appreciate and weigh the true impact of these burdens. They do not see the suffering that goes on in their absence. Furthermore, when there is conflict developing between the family and health care providers, little things like being asked to leave the bedside for bath time can be construed as 'there is something to hide'.

Communication itself can be problematic. Physicians often are perceived as the bearers of bad news. The picture is invariably painted in a sombre light, often emphasising the gravity of the situation. Patients are in the ICU because they are very sick, and doctors want families to be prepared for the worst. This is perhaps a compassionate strategy. If the patient improves then the family is relieved, and if death ensues then the family is ready.

However, families may not respond favourably to this technique. They sometimes project their anger and frustration onto the doctor and equate the physician with the disease. By over-stressing the seriousness of the situation physicians also open themselves up to being proven wrong. This may put their credibility into question with the family, especially if the patient has a tumultuous course.

Another point of contention is that different medical specialists and personnel may paint either slightly or radically different pictures of the prognosis. While the oncologist tells the family the patient's cancer is in remission, the intensivist states that the heart is now failing from the chemotherapy. As a result families are not sure whom to believe and often end up believing no one. These mixed messages create a rift that is very difficult to repair.

Patients and families have difficulty understanding the jargon used in medicine. Too often, families are told the patient is, "critical but stable." The meaning of this statement may be obvious to a physician, but to the family it is almost an oxymoron. How can a patient be so sick, yet stable? While families often learn and repeat the catch phrases used in the ICU, there is often only a rudimentary understanding of what they mean or their significance. One family member may tell the other they have, "gone up on the levophed," but does not really appreciate its implications. Health care workers may then continue to talk to families on this more 'sophisticated' level without true comprehension on the part of the listener. This is the issue of incommensurability. Families and health care workers are often, at odds in their understanding of what was discussed and over their respective perceptions of how and what they communicated to the other party.[58]

Factors external to the interaction between families and health care workers can have an enormous impact on communication. In our modern world, family members are sometimes distant or estranged. At the end of a loved one's life they may be desperate to

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[58] M Schecter, Physician – Jewish family communication about futile medical treatment: a qualitative approach, (Montreal, Concordia University, 2001), piii.

make amends. Fuelled by love, hope and guilt, they may second guess the treatment plan and feel they need to fight. After years of not being there, this is the opportunity to right a wrong. This agenda is often not consistent with either the wishes or the best interests of the patient. Nor are doctors necessarily aware of these motives.

Families are aware of the fiscal constraints placed on the health care system, and worry that this may impact upon the quality of care delivered. This is another reason to fight; after all if the family does not ensure optimal treatment for the patient, then who will? If they insist on everything then at least they will get their fair share. They often suspect that physician's motives for withholding care are based more on management of finite resources than on patient interests.

This can be perpetuated as families in similar situations bond in the waiting room. They share their stories, their hopes, their fears. This can be very therapeutic, similar to a support group. But it can also fuel the fire of mistrust. They share incidences of when the doctor was wrong, when a medication was erroneously given, what they overheard the doctors say, or when the cold truth was just cold. This primes the situation for communication breakdown.

When patients are very ill, there is little for family members to do in the ICU beyond looking at the monitors and pumps at the bedside. The ICU can be a very interesting place once the initial intimidation has dissipated, often being one big room with lots of hustle and bustle to distract the weary. They observe this strange environment they are in and cannot help but scrutinize its energy and the activities of its players. It is difficult not to envy the patient and family in the next bed who are a success, especially when you are the 'futility' case. How can the doctors and nurses laugh and talk about vacations or what happened on television last night, when they are mourning? It is understandable that health care workers are judged for their detached coping mechanisms and dark humour, and simply going about their jobs and lives. But there is nowhere to hide in the ICU, the emotional charge is inevitable and may deepen any existing conflict.

In the end, a large number of 'futility' cases are really about denial, guilt, grief, misconception or misunderstanding of information, and particularly about poor communication. Often there is no real conflict about what is in the patient's best interest. But there remain those few cases that despite the best of intentions and efforts will continue to baffle and discourage the moral bearings of those involved.

Rebuilding Trust

Ultimately the players, be they patients, families, health care professionals or philosophers, have acknowledged the pointlessness of such a debate, and have sought more constructive rather than divisive solutions. Attempts to rebuild this trust have inspired the most recent chapter of the futility debate. There has been a shift away from thinking in terms of principles to looking for solutions through an understanding of the process. Efforts have been twofold.

Advance Directives

On the one hand there has been a push for preventative ethics[59] - an attempt to resolve such disputes in advance by encouraging conversations about end-of-life preferences and care in the trustworthy doctor's office.

Although advance directives in form of living wills are important tools, only a minority of patients have them. An even smaller number of family members are aware of these advance directives and remember to bring them in to help address the goals of care. The directives themselves are not always helpful either. They are generally quite vague, using blanket statements such as 'I would agree to reasonable care' and are therefore open to different interpretations by physicians and family, particularly when discussing the goals and benefits of a disputed treatment. It is also often argued that the value of such directives is uncertain as, "patients' views about care before they are sick may be quite different from their views when they are ill."[60] Still, they represent an important effort on the part of primary care physicians to educate their patients and sensitise them to the realities of end-of-life issues.

Conflict Resolution Policies

The second strategy to rebuilding trust has been to adopt a framework or mechanism whereby open communication and negotiation could help eliminate the tensions and conflict over disputed treatments - a sort of damage-control ethics. As Caplan has suggested, "the greater the trust between physician and patient, ...the more

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[59] PR Helft, p294.

[60] *Ibid.*, p294.

willing patients will be to refrain from pursuing long odds to achieve bad ends."[61] Conflict resolution policies have become an alternative avenue for health care workers and patients or their families who cannot agree on what is a reasonable, beneficial and advisable care plan. This strategy emphasizes an open process, with patients and families participating in decision-making, and not who holds the trump card or the right definition.

There are a growing number of examples of these policies in the literature. Two of the frequently cited model policies on the appropriate use of life-sustaining treatments are included in Appendix B, namely from the Houston City-wide Task Force, and from The University of Toronto.[62] Three general principles are echoed in these policies: patients have a right to quality end-of-life care; patients have a right to receive the 'standard of care' (just as physicians have the right to refuse care beyond this standard) as delineated by professional and institutional codes; and patients have a right to an open and fair process in negotiating the details of this care.

Beyond these principles are algorithms for dealing with conflicts over disputed treatments or interventions. They generally include the following steps: assuring medical consensus with respect to prognosis and advisable care options; fostering communication and understanding between the different parties; sometimes offering compassionate compromises in the form of treatment trials or simply the provision of more time; patient transfers; and mediation and arbitration (at the institutional or legal level). Ultimately,

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[61] AL Caplan, p689.

[62] A Halevy and BA Brody, "A multi-institution collaborative policy on medical futility", *JAMA* 276 (1996): p573, &, PA Singer *et al.*, "Hospital policy on appropriate use of life-sustaining treatment", *Crit Care Med* 29 (2001): p189.

the objective is to withhold or withdraw the inadvisable and disputed treatment if conflict persists beyond this process.

Progress has been made on this issue. In an attempt to promote fairness and transparency in end-of-life decision-making, more and more hospitals and institutions are developing policies on the appropriate use of life-sustaining treatments and policies on conflict resolution.[63]

Albeit a good idea, this procedure is not new. Negotiation, mediation and arbitration are what doctors and patients, and indeed all disagreeing parties do when conflicts arise. It just happens to now be in writing, thus making it a standard to be followed.

Impact of Policies

Obviously these policies have done some good. They have granted families time to digest the information, time for a trial period to be convinced of the futility of the disputed efforts, time to grieve, and time to say goodbye. The various steps of the policies have also given families a sense of involvement and control that can be so elusive in a time of crisis. Following a study of the process, Schneiderman confirmed that there was, "strong agreement among family members...that the ethics consultation helped to identify, analyze, resolve, educate, and was responsive to personal values."[64] The process has shown families that healthcare providers have compassion, have the

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[63] LJ Schneiderman and AM Capron, "How can hospital futility policies contribute to establishing standards of practice?", *Camb Q Healthc Ethics* 9 (2000): p524–531.

[64] LJ Schneiderman, T Gilmer and HD Teetzel, "Impact of ethics consultations in the intensive care setting: a randomized, controlled trial", *Crit Care Med* 28 (2000): p3922.

patient's best interests at heart, and are willing to listen. It has fostered dialogue, and with it, trust. The policies have also achieved their second desired outcome - a reduction in the number of inappropriately maintained, suffering patients.[65]

There are, however, serious concerns with these policies. Many institutions have had some form of end-of-life care policy for years,[66] which is updated and distributed on a regular basis. Yet few physicians outside the ICU are aware that such policies even exist. Schneiderman has noted that, "despite efforts to circulate the policy, most physicians and other healthcare providers were not familiar with the details of this policy when they needed it."[67] Doctors simply do not have time to sift through every notice that comes across their desk. Invariably the twenty-page paper describing how to deal with difficult families falls to the bottom of the pile. These algorithms are also not posted on walls for everyone, including patients and families to see. Someone remembers that such a policy exists and drags it out of a folder only once the conflict has already reached a critical point. This is much like considering the assistance of an ethics consultation after 10 months of silence. So although a good idea, and admittedly still in its infancy, there is a long way to go to ensure the awareness and implementation of the process.

Physicians remain doubtful of the legal ramifications of these institutional policies, and rightly so. These policies have not been tested in front of the courts and physicians are therefore still uncertain of their jurisdiction to implement the last step of treatment withdrawal, even after due process. The University of Toronto authors have admitted that they, "do not know how well

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[65] RL Fine, "The Texas Advance Directives Act of 1999: politics and reality", *HEC Forum* 13 (2001): p70, & LJ Schneiderman, T Gilmer and HD Teetzel, p3924.

[66] Most McGill hospitals have variations of such policies, often in the form of DNR policies.

[67] LJ Schneiderman, T Gilmer and HD Teetzel, p3923.

this step will work from a legal or institutional perspective." They add that institutions looking to adopt their policy model should decide for themselves the risk-benefit of such a final step.[68] In conjunction with the Texas legislature, the Houston Hospitals have arranged for immunity of health care workers and institutional committees in executing their policy. Although this seems to afford them protection, and to date has not been challenged,[69] "a petitioned court could [still] find the manner in which the Procedure was implemented to be inadequate or negligent."[70]

These situations can get ugly. No one wants to go to court. Those who witnessed the highly publicised Krausz case inquest[71] will remember that there were no winners. For the family, the patient who died was still dead. For the health care team, in addition to time in court and lost wages, there was personal and professional scrutiny and distress. Everyone watched Dr. Spanier pay the price for trying to uphold his notion of medical virtues and professional integrity. His death was certainly an unusual and tragic outcome, one related primarily to his poor underlying health, but the stress of such proceedings certainly did not help.

Unfortunately most physicians believe that the risk of litigation is too high a price to pay to uphold their integrity.[72] Many feel that, "life is too short to get in the way of a moving bus." As callous as this may sound, physicians have a right to protect themselves, their reputations and their livelihoods. "Many healthcare professionals do not feel they will be supported by their institution if they act according to what they

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[68] PA Singer, p188-9.

[69] RL Fine, p70.

[70] AL Flamm, "Texas takes on futility", *ASBH Exchange* Summer (2000): p5.

[71] *Report on the Inquest into the Death of Herman Krausz*, File no.: 97345, Opinion no.: A-125446, Provincial Court of Quebec, November, (1999).

[72] JM Luce and F Lemaire, "Two transatlantic viewpoints on an ethical quandary", *Am J Respir Crit Care Med* 163 (2001): p819.

perceive to be their professional values."[73] Furthermore, institutions have been all too eager to dissociate themselves from the physicians who are acting not only in the patient's but also the organisation's best interest when such conflicts become litigious.[74] Hospital administrators would often rather support these few difficult situations, than face the public relations and legal nightmare of a highly publicised battle.

If doctors espouse this attitude, then they stop fighting for patients. In some cases, do physicians not have a duty to protect patients from themselves and their families? The notion that a given treatment is inadvisable is at its origins motivated by concern for the patient and promoting his or her best interests. Physicians are advocates for their patients; they have the knowledge base and training to analyse the patient's situation and determine the most appropriate treatment plan. If physicians no longer do this, then patients lose a very valuable support. When this role is usurped by either fear of litigation or the time required to implement these policies, physicians may fail their patients by allowing continued suffering. However, many authors are of the opinion that in end-of-life issues, where the line between personal and professional values is frequently blurred, the physician's role as patient advocate is less clear.[75]

What does this mean for the patient? One concern is the potential loss of providing the patient with a 'good death'. Consider the following example. An elderly independent man suffers a massive dominant hemisphere intracranial bleed. He is in a coma, with evidence of paralysis. Physicians recognise the significant neurological deficit that will remain if he survives, and explain to the family that as the brain

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[73] LJ Schniderman and AM Capron, p525.

[74] *Report on the Inquest into the Death of Herman Krausz*, p1, (of note, Hospital and Physicians sought separate counsel).

[75] SJ Younger, p2094-5.

transiently swells over the following days, that his condition will worsen and they recommend not intervening but letting nature take its course. As predicted, the patient's situation deteriorates. Not being ready to accept this fate, the family asks for more time. The physicians reluctantly place the patient on a ventilator to protect his airway, and provide various treatments to reduce brain swelling. He survives this acute, life-threatening phase and is condemned to a devastating neurological state that neither he nor his family wished for, or could appreciate. He survives for months, with a tracheostomy and a feeding tube, alert and aware, unable to communicate, and totally dependent. This example shows how sometimes providing these compassionate treatments for the family's benefit, allowing for more time until all parties agree, can be a moral trap that hinders the opportunity to give patients what they really would have wanted - their chance at dying peacefully and with dignity.

This case also illustrates that patients and families are not always equipped to confront these life and death situations. These conflict resolution policies place more of the decision-making into the hands of the families, which may be detrimental to the patient. Most patients and family members cannot have the same appreciation for what is medically possible and probable. This knowledge is paramount to making a good decision; a value judgement about the facts cannot be sound if the very facts are not sufficiently understood.

If only one in twenty will survive a given illness with a good outcome, then 19 others will also have to undergo the treatment and endure all of its side effects without achieving the desired result. Potential outcomes may not be strictly limited to life or death either, but rather to some gray zone with diminished quality of life and suffering on the path to death. Hope makes 1 in 20 look pretty good, until the outcome is one of the statistically more likely 19 in 20.

Families may also be overcome by the complex combination of grief, fear, hope and guilt.

> Even if what family members aim to achieve through 'doing everything' is to convey their unfailing love, which is morally impeccable as an aspiration, this does not vindicate the use of futile treatments. Much less does it establish that 'doing everything' is the best means of realizing this aspiration.[76]

Families do not always appreciate that saying "no" to futile treatment is not saying "no" to continued caring for the patient. Furthermore, they often emotionally equate letting die with killing. The finer points of substituted judgement may become lost under such circumstances, calling into question their suitability for advancing the patient's best interests.[77]

What has all this done to the integrity of the medical profession? Many practitioners acknowledge that the family has much more at stake whenever conflicts over end-of-life care arise. While this is true on an individual level, the cumulative effect of these cases on the health care team is undeniable. Many members of the team become disenchanted with medicine, feeling their skills are being used to promote more suffering. Rather than utilising their knowledge and abilities to the benefit of the patient, they are reduced to mere technicians working their way through the policy algorithm against their better judgement. This sense of

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[76] NS Jecker and LJ Schneiderman, "When families request that 'everything possible' be done", *J Med Philos* 20 (1995): p151.
[77] RL Fine, p 71.

impotence and frustration, particularly for the nursing staff, leads to burnout. It affects not only the quality of care provided to the specific patient, but to all patients in that ICU.

While the policies admittedly provide an escape clause in the form of 'patient transfer to a different physician' if a stalemate persists, doctors know that in reality this is impracticable. It looks good on paper that doctors can recuse themselves if they disagree with the goals of the family or patient. But if doctors have good reasons for this opposition, it will often be difficult, if not impossible, to find someone who is willing to provide the demanded treatment. The principle of not abandoning one's patient further muddles the matter as it ultimately means that the attending physician may be forced to act against his will.

Physicians respond to this moral angst and loss of professional autonomy in different ways. Some physicians simply yield to families' wishes in order to limit further conflict. Others seek alternate means to provide for the patient's best interests while at the same time giving the illusion of aggressive treatment in keeping with the family's wishes. These covert forms of paternalism are derived not out of malice, but out of recognition that some patients and families need to believe that 'everything' is being done. The classic example is the 'slow code', going through the motions of resuscitation in a half-hearted manner. If a family insists their 98-year old comatose relative be resuscitated, it is done. The code team just takes longer to get things started in expectation that survival will be unlikely. This is bad medicine for sure; but it may be an adaptive response to the feeling that physicians must comply with this untenable requirement of their profession.[78] One might argue that such strategies are sometimes justified because they protect patients from themselves and their families. A little

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[78] G Gazelle, "The slow code – should anyone rush to its defense?", *NEJM* 338 (1998): p468.

'healthy' paternalism can be good, as some families cannot make these difficult decisions, yet refuse to defer to the physician's judgement. In the end, however, these tactics probably do more to tarnish the integrity of the medical profession, hindering whatever trust has been salvaged.

Another concern with the widespread acceptance of the conflict resolution approach is that the futility debate has been silenced. The responsibility for solving the problem of futility cases has been deferred on the hope that these policies will resolve the conflicts. This is illustrated by *The New England Journal of Medicine* article documenting 'the rise and fall' of the futility movement. "The most recent attempts to establish policy in this area have emphasized processes for discussing futility rather than the means of implementing decisions about futility."[79] This is further echoed in the reduction in futility literature that has followed: from 134 articles on futility in 1995 to 31 in 1999.[80] Justifiably, the establishment had shifted its efforts away from a principle-based attempt to resolve the problem of futility disputes, to recommending increased dialogue and due process once this point is reached. There has been success in eliminating the cases that were caused by poor communication. In the study by Schneiderman reviewing the impact of ethics consultation and mediation in futility disputes, it is suggested that they, "may lead to a reduction in non-beneficial treatment, particularly days spent in the ICU and hospital by patients who die."[81] But the true ethical conflicts have not gone away.

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[79] PR Helft, p294.

[80] *Ibid.*, p293.

[81] LJ Schneiderman, T Gilmer and HD Teetzel, p3924.

There are limits to the kinds of care patients and families can legitimately request. These treatments are bound by the 'standard of care' of the medical profession. This is a standard to which the practice of appropriate medicine is held; it is the bar against which medical bodies and the courts measure physicians' actions. In the case of futility judgements, the standards set forth have been particularly vague and leave much room for interpretation. It has been unclear if doctors can present a list of options from which patients can choose, or if physicians must provide treatments demanded by patients and families that may have an effect, but no justifiable benefit from the doctor's perspective. "Patients do not have a right to treatment that falls outside the bounds of standard medical practice. Such treatments need neither be offered to patients nor be provided if demanded by them."[82] Ultimately, physicians are likely to be held to the standard of their peers in such situations.

The concern is that this standard of care is shifting. As a physician, it becomes very confusing to know what the standard of care is at the margins of life. Medical bodies and the law have remained vague on these issues, and different textbooks and articles have espoused very different thresholds of appropriate medical conduct on the issue of futility conflicts. The ethics chapter in one critical care textbook states that, "if family members or legal surrogates for the patient want every possible measure taken to keep the patient alive, professionals should comply with this request."[83] Statements like this become almost gospel when found in such authoritative manuals. Medical bodies and the courts may then quote these references to support the standard. They incite a

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[82] C Weijer and C Elliott, "Pulling the plug on futility", *BMJ* 310 (1995): p684.

[83] TA Raffin, "Perspectives on clinical medical ethics", in, <u>Principles of critical care</u>, (New York: McGraw-Hill, 1992), p2185-204.

self-fulfilling shift in the standard of care, when they are mere opinion in an ongoing debate. At the same time, the law has also been reluctant to commit to upholding any one view, and sidesteps the issue of futility by focusing on less contentious elements whenever it can.[84] [85]

It has become so confusing to sift through all the ethical deliberations, that many doctors simply do not know where to stand. They are uncomfortable saying "no", so they acquiesce. Sometimes physicians yield out of respect for the non-medical goals of the patient and family. Other times, physicians compromise as they feel it is not worth the emotional and legal struggle to protect the patient and family from 'themselves'. The rationale is that the patients are so ill that in most cases they do not survive the time required to resolve such issues in court. So for reasons of ethical and legal uncertainty, out of compassion or a sense of defeat, more and more physicians are yielding to such demands for inappropriate treatments.

Institutional policies further complicate matters by reinforcing these attitudes. They practically oblige physicians to provide care contrary to their professional judgement for the several weeks required to work through the algorithm. They promote the idea of using the courts for conflict resolution when the legal system has been fence-sitting for years.

> The courts have usually espoused the view that all parties should err on the side of continuing life support. Physicians should not expect the courts to give them prior permission to forgo futile treatment because the

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[84] In the *Helga Wanglie* case the hospital petitioned the court to replace the husband as surrogate – the court held that he was best placed to know his wife's wishes, without specifically ruling on his wish to continue the disputed ventilator support. The court did not respond to the futility issue, only to the narrow question.

[85] In the *Baby K* case, rather than comment on the futility of the disputed intervention, the courts ruled on the issue of discrimination, holding that failure to provide care to a patient in an emergency was discriminatory.

> courts will want the opportunity to examine all the facts *after* the action is completed in order to judge the rightness or wrongness of that action. Indeed, "physicians are likely to get better legal results when they refuse to provide nonbeneficial treatment and then defend their decisions as consistent with professional standards than when they seek advance permission to withhold care."[86]

Furthermore, in those cases where no internal consensus can be reached, doctors are forced to concede to families, as most institutions want to avoid the negative publicity of a legal battle anyhow. This creates the perception that the family has been right all along. Thus, giving in to demanding families becomes the *de facto* standard of care.

The policies themselves can be unworkable in a practical sense. Rather than complete the time-consuming protocol, many physicians will give up, as they cannot foresee how it will achieve the desired outcome beyond enhancing communication. This sense of defeat also contributes to the shift in standard of care. It leads to the understanding that if communication has failed, families should not be challenged when conflicts persist.

If a respectable minority of peer practitioners would indulge families, does this mean that the courts can force an unwilling doctor's hand? This is an interesting question that has not been tested. A clever retort, however, was proposed by Schneiderman:

> Most of the futility policies...agree that physicians are not obligated to continue life-sustaining treatment of patients who have reliably been determined to be permanently unconscious. If this standard were urged on the...courts, it would need to be acknowledged that at the very least a "respectable minority" of hospitals have not adopted such an explicit policy statement. These latter hospitals, however, should consider the obligations and actions associated with their position. Is it a position or merely the absence of a position? Specifically, are these hospitals willing to accept the transfer of a permanently unconscious patient or others for whom another hospital has deemed further life-sustaining treatment futile?

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[86] LJ Schneiderman and AM Capron, p528.

> If so, disputes over end-of-life treatments could be resolved without requiring hospitals to go to court.[87]

He calls the bluff of physicians and their institutions to accept such patients in transfer if they do not dispute the demanded care. While this is a valid argument, the adoption of policies by institutions does not guarantee full implementation. That is, while it is easy to comply with such policies and transfer patients to another facility, it is a different matter to bring the issue before the courts and unilaterally withdraw care. This is a stand most institutions will not take.

Do these changes in philosophy not affect the expected standard of care? How can doctors say "no" when the boundaries of standard of care are so ill-defined? What does this mean for patients and practitioners? What about the impact on society?

Without question, conflict resolution policies have resulted in a decrease in the number of inappropriately maintained patients. But perhaps the most important achievement of these policies has been to remind physicians to talk to their patients; it has made them more transparent and more aware of the need to engage in dialogue. Communication, in and of itself, likely contributed the most to reducing the number of 'futility' cases and disagreements. This begs the question of whether they were indeed futility conflicts or simply examples of communication breakdown. These policies have separated the true ethical dilemmas from the failures of communication and bought some time for the cases where denial and grieving needed to precede acceptance and agreement. But the true cases of conflict still exist, policies notwithstanding. And they

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[87] *Ibid.*, p529-530.

often leave the true ethical disputes with no viable approach, with no one discussing options or informing greater society of the need for solutions.

With or without these policies there is room for compassionate flexibility in the provision of life-sustaining technologies. This allows time for all parties to get used to the realities of the situation, instead of engaging families in a battle of who is right. Do we really need these quasi-legal policies to open up the lines of communication and rebuild trust between patients and their families and the medical profession? Probably not, but they have contributed towards this admirable goal. While they have been an important steppingstone in the evolution of the provision of end-of-life care, much more work is needed before we as a society can truly say we have found a solution to balancing the claims of autonomy, beneficence and justice.

IN DEFENSE OF SAYING "NO"

> *Most of the working truths on this earth are humble, not heroic; and there have been times in the history of mankind when the accents of heroic truth have moved it to nothing but derision.*
>
> Joseph Conrad

Drawing a Line

According to Caplan, the concept of medical futility is, "expected to bear more weight than it can reasonably sustain."[88] In its present form perhaps this is true. It lacks clarity and guidance. Despite this, there is a misconception that the issue of futility has been put to rest. Physicians, policy-makers and institutions look at the current conflict resolution policies and advance directives as solutions – 'the problem is fixed, we can stop debating, what a relief.' But there remain significant concerns with this approach. Is process preferable to principles? Certainly it is more democratic. Do we not however risk making ethically problematic decisions by agreeing to compromise the goals and limits of modern medicine?

To a large extent the debate and solutions that have come before have laid the groundwork for a more important task. Beyond the conceptual debate of futility there should be limits to the goals to which medicine's treatments and interventions, and indeed a physician's knowledge and skill can be applied. Discussion and re-negotiation of the goals of medicine can no longer be avoided. Our society will need to draw a line in the realm of end-of-life care. I believe it is not as much about where we draw the line or who draws the line, but that we **should** draw the line.

But why do we need to draw a line? If most 'futility' cases have been solved through a policy of communication and negotiation, is this not good enough? The answer is an emphatic, "NO," for one simple reason: patients are still suffering.[89] The role of physicians has been undermined over time and under the pressure of uncertainty, to the point where the whims of autonomy have superceded a fundamental principle of medicine, to alleviate suffering.

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[88] AL Caplan, p668.

[89] R Tong, "Towards a just, courageous, and honest resolution of the futility debate", *J Med Philos* 20 (1995): p178.

"Over the years the practice of discussing CPR has degenerated and we are now expected to extract a 'consent' to no CPR. To extract a consent to withhold a useless treatment."[90] It is time to come back to a common sense notion of beneficial care as the way to promote autonomy rather than the perversion of offering what cannot work.

Another reason to draw the line is, if we do not do so, it will be drawn for us.

> For if limits to physicians' obligations are not defined, end-of-life outcomes are likely to be determined less by medical circumstances and justifiable standards and more by individual healthcare providers' tolerance for risk, patients' and families' varying degrees of knowledge and rhetorical skills, and economic considerations.[91]

Hopefully society and the medical profession will not wait for financial issues to force our hand but will proceed by analysing what medicine can and cannot achieve, tempered by what medicine should or should not try to achieve. Just because we can, does not mean we should. Defining the scope of patient rights and the contemporary goals of medicine will go a long way to helping draw that line.

Although most debaters have focused their efforts on definitions and the struggle between patient and physician autonomy, few have touched on the more compelling arguments: the notion of the right to health care and the proper goals of medicine. This is where I believe the discussion must go next: restoring common sense, and restoring a realistic grasp of the power and limits of medicine.

Perhaps a decade ago society was not ready to consider the concept of medical futility. Even doctors needed time to consider and sort out their position. But medicine has been moving towards consensus. It has searched for new avenues to make the stalemate go away, and in so

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[90] B Eaton, "Glad to be alive", *MUN Med* Spring (2000): p16.

[91] LJ Schneiderman and AM Capron, p528.

doing has improved patient-doctor relations. But no system is perfect and the difficult cases have not gone away. And a stronger more united stand will be required to ensure the best interests of both patients and society.

Seeing the big picture

"Paradoxically, the advances that have allowed a high survival rate have also created an increase in the number of individuals who survive in a state of chronic persistent illness."[92] A significant section of society is cognizant of the strengths and weaknesses of health care and there is frequent agreement that heroic efforts that will likely confer greater burdens than benefits should be forgone. Similarly, "physicians have become more sophisticated about the limitations of medical care and about the suffering that can result from invasive, yet unfruitful, therapy and are now less willing to administer care that they consider of no benefit."[93]

"Supportive care in a modern ICU can maintain a critically ill patient in a state of limbo for weeks."[94] While the technology may ward off death for a while, the disease process may be irreversible and progressive. This should signal a change in the goals of care. A shift in priority from curing to caring. Indulging in heroic efforts beyond this point often only prolongs the dying process. However, there is sometimes a misconception that medicine can fix everything, an optimism that because technology can postpone that last heart beat, it can also fix the reason the heart wants to stop.

If the treatment cannot work then the patient will likely die quickly. If however the treatment has an effect but the effect is only to prolong the current suffering, was this

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[92] HS Rafkin, p24.
[93] *Ibid.*, p24.
[94] *Ibid.*, p31.

specifically understood to be part of the deal? Many families cannot anticipate or appreciate the quality-of-life considerations they are asked to judge. They are often so caught up in advancing their cause that they lose sight of the bigger picture. They only understand life versus death, keeping the quality-of-life distinction secondary.

Many diseases in critically ill patients have very high mortality rates, often upwards of 50%. As the condition evolves it becomes clearer on what side of these statistics a patient will fall. Furthermore, with every deterioration patients auto-select themselves towards mortality rates approaching 100%. What these statistics do not convey, and what families often do not appreciate beforehand, is that beyond surviving the given odds is the burden to endure the resulting morbidity. Cost-effectiveness - the number that must be treated to obtain one successful outcome[95] - is not only measured in dollars but also in terms of suffering of those with the less favourable outcomes.

Admittedly, "behind medical judgements of inappropriateness are the dual concerns that resuscitation sometimes would not work and sometimes would not be worth it."[96] This is the essence of the debate. Who can judge quality of life?

What does not come through in most writings on the futility debate is the reality and time frame of the actual cases - the plight of patients, of families and of caregivers. What it actually means for all concerned to have to experience the day to day, the week to week; the hope, the frustration, the animosity. This predicament is seldom visible to the general public until a loved one is critically ill.

There is also a lack of public awareness of the scope and suffering of chronically debilitated patients, many of whom bear the side effects of heedlessly applied medical

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[95] DJ Murphy, p123.

[96] SB Rubin, When doctors say no, (Bloomington: Indiana University Press, 1998), p17.

treatment. Most members of our society have been relatively sheltered from chronic illness and the dying process. They often know more from television than from any personal source. As such they expect patients to either make a full recovery or die quickly and painlessly. Few are aware of the magnitude of our chronic care facilities with floors and floors of people who cannot contribute to life or enjoy it. It is not sexy, not uplifting; there is no telethon for these patients.

Perhaps it is not fair to generalise. However, the point is that the plight of these 'warehoused' patients should sensitise us to the fact that theirs is not always a desirable existence. It certainly is not one any of us would wish for. How many of us would settle for such a life, however, is less clear. Perhaps with a little foreknowledge and warning many would have refused the treatments, or shared their wishes with family members and avoided the prolonged journey to death.[97] As discussed earlier, education will go a long way towards increasing public awareness of the importance of such advance directives and also towards improving their usefulness.

Unfortunately, there will always be cases where end-of-life care was not addressed, where poor outcomes could not be visualised and where disagreements over the goals and value of different treatments prevailed. I am not advocating that we draw a line to deal with the chronically critically ill, but rather to reconsider our approach to life-sustaining treatments so that we limit the reasonably predictable cases that will have these poor outcomes. Ultimately, the premise for futility judgements is to protect patients from these bad outcomes and the associated suffering.

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[97] DJ Murphy, D Burrows and S Santilli, p545-9.

Debunking the Fact-Value Distinction

Ostensibly, the debate would dissolve and care at the end of life would all make sense if we could all only agree on what is suffering, what is harm, what is benefit, what is reasonable and indeed what is futile. This of course will never happen.

This has led to a search for a way to overcome the value struggle of futility judgements. Many authors insist that only a very narrow definition of medical futility is value-free and thus morally acceptable. The idea is that, on medical grounds, a futile intervention is one that will predictably fail to produce its desired **effect**. Physiological futility is one thing, quality-of-life assessments are another; doctors are best positioned to judge the former, while the latter should be left to patients and their families.

This is a misleading and flawed distinction, since most, if not all, judgements by physicians about which treatments should or should not be given to a patient are in fact value-laden and therefore inherently involve quality-of-life considerations.

> The popular practice of making an exception of physiologic futility has been bolstered by the contention that judgements of physiologic futility are purely factual claims devoid of any evaluative content. This understanding of physiologic futility, and the sharp distinction that it presumes to exist between facts and values, has its roots in an older, but now generally repudiated, conception of science.[98]

According to Popper, the objectivity of knowledge is a social construction.

> The old ideal of *episteme* – of absolute certain, demonstrable knowledge – has proved to be an idol. The demand of scientific objectivity makes it inevitable that every scientific statement must remain *tentative for ever.* It may indeed be corroborated, but every corroboration is relative to other statements which, again, are tentative. Only in our subjective experiences of conviction, in our subjective faith, can we be 'absolutely certain.'[99]

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[98] SB Rubin, p99.

[99] In, LJ Schneiderman, (1996): p671.

Information must pass through the various hands of scientists, clinical researchers and clinicians who each in turn and in their own way digest and selectively restate the 'relevant' elements of this information.[100] The 'certainty' of medical facts rests on a cumulative number of assumptions and data approximations that through convention become accepted truths. There is nothing value-neutral about this process. The clinical conclusions derived from these facts are consequently value-laden as well.

In this respect, medical futility judgements are no different than any others in medicine. They are in essence value choices because they depend on data that is perhaps ambiguous and uncertain. They involve the subjective integration of clinical outcome data and statistics with the particulars of a given patient. Physicians in turn must make decisions with this information. Thus even physiologic judgements have a qualitative aspect. While it is true that the scope of the notion of physiologic futility is far within the confidence intervals of 'certainty', it remains on the continuum of possibilities. It is inherently value-laden and cannot logically provide doctors the proposed value-free defense to say "no" to patients and families.[101]

Paradigm scenarios classically used to illustrate physiologic futility include ventilator support for patients with metastatic lung cancer and CPR for patients with progressive unrelenting heart failure.[102] However, the outcomes of these examples are not so absolute. Supporting a patient with metastatic lung cancer for a few days to overcome a superimposed pneumonia is not so hopeless an option. It is also not so clear-

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[100] RM Veatch and WE Stempsey, "Incommensurability: its implications for the patient/physician relation", *J Med Philos* 20 (1995): p266.
[101] T Tomlinson, p1278.
[102] WC Weijer *et al.*, "Dealing with demands for inappropriate treatment", *CMAJ* 159 (1998): p817-21. See also McGill Hospital Policies on Critical Interventions.

cut that providing CPR to patients with heart failure will not restore a heart beat. Sometimes reversible causes lead to rapid but treatable cardiac arrest, even in the seriously ill. It is however very different to intervene in a witnessed arrest as opposed to finding someone blue and cold in the middle of the night. Not all cases befitting the classic scenarios are created equally; the details are important. They too fall on a continuum of 'futility'.

Under the pressure of the debate, however, many policy-makers have in fact adopted these limits as their own.[103] To advocate such cases as 'physiologically futile' in policies is flawed and risky. They become seen as the truth, when they are really just another shade of qualitative futility. The ambiguity confuses and paralyses those who try to apply them, as they do not help physicians decide which patient fall into this category.

Furthermore, all treatments have effects. Treatments that are deemed 'physiologically futile' are not futile then because they fail to produce any physiologic effect, "but rather because [they] fail to produce a physiologic effect that is deemed worthy of desire by the individual measuring the effect."[104] This begs the question of whose yardstick should determine which effects are worth pursuing, a value judgement in itself. Resting futility decisions on this line of argument leads us back to the value struggle we started with.

If the premise of 'physiologic futility' is that if a given treatment will not work based on a strictly medical assessment, then the treatment is not morally required; and if

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[103] The Society of Critical Care Medicine *de facto* adopted the quantitative/qualitative futility distinction in their 1997 Consensus statement, and that only quantitative futility can be used. Hospital policies routinely use the paradigms of metastatic cancer and heart failure to illustrate quantitative or physiologic futility applications (see McGill hospital policies).

[104] SB Rubin, p102.

these medical assessments cannot be value-neutral as previously explained, then in fact physicians are also allowed to make value-choices.

In fact, in many aspects of medicine it is accepted that physicians can make value judgements in providing appropriate care. They are entrusted by society to make these sorts of judgements every day. The role of physicians is to combine their training, knowledge base and experience to benefit the patient. Pellegrino and Thomasma have argued that medicine is best understood as the application of scientific principles to individual cases with the goal of promoting, "a right and good healing action."[105] For instance when a patient presents with chest pain, the responsible physician will consider the symptoms, the past history, the physical findings and the overall psycho-social context in deciding on a plan of action. Any one of these variables can influence the treatment plan. Furthermore, different physicians seeing the same patient may make different judgement calls depending on the information gathered. This reinforces that these interactions are value-laden, and that medicine is far from an exact science.

When patients request treatments that doctors judge unreasonable, they are permitted and indeed expected to refuse. It is ethically appropriate for doctors to refuse to indulge patients who request antibiotics for the common cold, as they are known to be ineffective. Similarly it would be unethical for a physician to engage in sexual acts with patients even at their request, or perform surgery when the disease for which the procedure is indicated is not present.[106] These are the types of value judgements that society requires of physicians based on their own understanding of medicine's defining

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[105] ED Pellegrino and DC Thomasma, A philosophical basis of medical practice. (New York: Oxford University Press, 1981), p211.
[106] H Brody, p7.

values and moral standards, irrespective of the value perceived by the autonomous patient. "To admit that physicians should have the power to refrain from doing harm is to concede that they have the moral authority to judge not just the harms, but also the benefits, of medical interventions."[107]

It is inconsistent of society to trust the medical profession to use its moral authority with respect to these scenarios but selectively reject its judgements in end-of-life care. While the environment is more emotionally charged, and the outcomes more final, physicians still have that same capacity to judge reasonable benefits and harm. They understand that at the margins of life there is a greater burden for certainty, but must also still consider potential benefits to and anticipated suffering by the patient.

Even within futility, it would seem that physicians are permitted to make some types of value-laden decisions. In the case of CPR, doctors do not ask families if resuscitative efforts can be stopped after 5 minutes or 10 minutes or 30 minutes, nor are they expected to. If society is so worried about physicians making unilateral determinations that certain life-sustaining treatments would be futile, then they should be equally worried about physicians unilaterally deciding when to terminate CPR efforts. It is a quality-of-life judgement based on reason and common sense that the more time goes by the poorer the outcome. It is inconsistent to allow doctors to make the latter sort of value judgement but not the former. If physicians have moral credence then they can make futility judgements, too.

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[107] T Tomlinson, p1278.

Ultimately there is a need for a practical working definition of when it is reasonable to stop. While some authors have claimed that the term futility serves no useful purpose, most medical professionals, patients and their families have an intuitive understanding that certain types of medical treatments have crossed that line. Medicine may not have a crystal ball, but it is not ignorant about probable outcome either.

It then comes down not to whether, but what sorts of value judgements physicians can legitimately make. The distinction between physiologic and qualitative futility is a fallacy. By definition all medical judgements are value-laden to varying degrees, so this line that needs to be drawn must rest somewhere within the continuum of 'futile' care at the margins of life. And it will by definition be a quality-of-life assessment, not simply a burden-benefit judgement.[108]

In addition, whether this 'line in the sand' is value-free is not as important as whether it is rests on defensible values. It is not about who has authority, but who has the best moral justification. "Moral justification requires giving and defending reasons for preferences, and by doing so relying on methodological ideals of clarity, impartiality, consistency, and consideration of all relevant information."[109]

In the end, the difficult cases will always be difficult no matter where the line is drawn. Furthermore, in controversial cases more than one ranking of the important values is defensible leading to more than one defensible course of action.[110] Such rank ordering of any principles is also a value judgement - one that society will have to make.

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[108] Arguably one cannot 'harm' a patient in a persistent vegetative state; CPR can thus only confer benefit in prolonging life. As such we must also rely on quality-of-life assessments to apply futility claims.

[109] LM Kopelman, "Conceptual and moral disputes about futile and useful treatments", *J Med Philos* 20 (1995): p117.

[110] *Ibid.*, p118.

The Right to Health Care

The notion of autonomy, as related to end-of-life care, evolved as a patient's right to die. Yet somehow it has become perverted into *the right of the dying to live.* There is a misconception that restricting available choices to someone is an infringement on their right to autonomy. Does respect for autonomy mean their demands must be met?

Kant proposed that there are perfect duties and imperfect duties. Perfect duties are absolute. Individuals have a negative right not to be harmed and others have a perfect duty not to harm them. Individuals also have a positive right to be assisted. This entails a correlative duty or moral obligation of beneficence from others. This is arguably an imperfect duty, for we must, "endeavour, so far as we can, to further the ends of others,"[111] and to promote their general happiness. This means that being helped is not an absolute right.

Negative rights are those that afford citizens a sphere of protection from government interference, such as the rights of liberty and privacy. Positive rights by comparison are those requiring affirmative obligations of the state to provide social goods such as education, due process, and health care. The scope of these positive rights is not only the ideals to which a society aspires, but also what society is willing and able to provide. While health care in Canada is a right, it is not an absolute right - like many other socially sanctioned rights, it is subject to being limited by public consensus.

Negative rights are the sorts of rights that allow patients to refuse life-sustaining treatments.[112] Physicians have a perfect duty to respect such decisions and not interfere.

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[111] J Rachels, The elements of moral philosophy – 3rd edition, (Toronto: McGraw-Hill College,1999): p134.

[112] The *Quinlan* case (patient in a coma on life-support) held that life-support could be discontinued under the right to privacy. The *Cruzan* case (patient in PVS with feeding tube) held that the request to withdraw a feeding tube was within the scope of one's liberty right.

It does not follow however that patients have a right to medical treatment and physician the correlative duty to always provide it. In simple terms it is the difference between patients saying 'don't touch me' and 'you must touch me.'[113] Doctors must respect the former, but they have a certain amount of choice with regard to the latter. The obligation to provide health care is thus an imperfect one.

Likewise, physicians have rights. Specific to the futility debate, they also have negative rights, or autonomy. According to Mill, "so far as self-regarding actions are concerned, the individual should be *autonomous*…the state should have no power to force an individual to act for the public good."[114] This means doctors are similarly free from restraint, and, can practice as they see fit within the bounds of their professional standards. While there is a fiduciary responsibility towards patients, there are limitations to the obligation to provide care. Physicians decide to what ends their skills can be applied. They cannot be forced to act. To do so would harm physicians and their professional integrity. Because physicians are also actors in these treatments, consideration must be given to their morality and interests.

For most types of medical care doctors can and do say "no" when they disagree over requested treatments. Arguably, if a patient needs to rely on an ICU to be alive there comes a point where that life is reduced to mere existence, where every vital function is dependant on the efforts of others. At such a point there is presumably no more private sphere, where only the individual patient's interests matter. When others

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[113] W Prip, p139.

[114] GE Pence, Classic cases in medical ethics, (Montreal,: McGraw-Hill, 1995), p54-55.

become affected, morality becomes important.[115] Thus health care workers should be able to legitimately say "no" because their negative rights carry more moral weight than the patient's positive ones.

Is there something different about life and death situations that the moral stand of the autonomous physician changes? If doctors truly have negative rights then they should be free to refuse. If however, as Veatch and Spicer have argued, physicians lose this negative right, "as a condition of the monopoly privilege of licensure,"[116] it does not follow that the correlate to the patient's positive claim to medical assistance becomes a perfect duty. It still remains an imperfect one. This means the disputed care must rely on the socially sanctioned standard of the profession; society endeavours to provide patients with the standard of medical care, the determination and limits of which are deferred to the judgement of the medical profession. As discussed earlier, however, given that the standards for such care have become muddled under the pressure of the futility debate, and the lack of consensus amongst physicians, the question must be decided at the next level. It becomes society's imperfect duty to fulfill. Society decides where to draw the line, and which claims it wants to support. It seems intuitive, however, that the more controversial a treatment option, the lesser the obligation to provide it.

Another way to verify the legitimate moral position of physicians regarding these life and death claims can be found by looking at the nature of fidelity, "the obligation to act in good faith, to keep vows and promises…."[117] The promise of medicine is to care, not necessarily to cure. Therefore, where the physician may have a perfect duty not to

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[115] *Ibid.*, p7.
[116] RM Veatch and CM Spicer, "Medically futile care: the role of the physician in setting limits", *Am J Law Med* 18 (1992): p28.
[117] TL Beauchamp, p430.

abandon, it does not follow that this promise is to do more than provide 'care.' While caring for the patient may be included in this pledge, honouring all his goals may not. Thus the physician should be able to stand up and say "no" to certain treatments without fear of abandoning a patient, as long as the standard of care to be provided is clear.

If other physicians are willing to accept the patient in transfer, it means there is at least a respected minority of the profession that would agree to provide the disputed treatment. However, if no one else would provide this treatment, a court would be hard-pressed to force the attending doctor to do so and *de facto* turn the obligation to treat into a perfect one. Forcing one to do what the rest refuse would violate the negative rights of all physicians. Despite this being a sound argument, it must be remembered that no right is absolute, and this is as true for patient autonomy as it is for professional integrity. Society can decide to override any of these rights in the interest of public good. However, the moral harm would be greater in thwarting a negative right than a positive one. Forcing this as a perfect duty on physicians would only be defensible if it supported a positive right to a good that society had an interest in protecting.

So in the end, whether it is because society should not violate the medical profession's integrity and 'negative' right to define itself and its limits autonomously, or because society itself delimits the scope of positive rights patients can legitimately claim, a line can defensibly be drawn.

Common Sense and the Proper Goals of Medicine

"A futile action is one that cannot achieve the goals of the action."[118]

Much of the conflict in the futility debate can be reduced to disputes over the goal of a particular treatment or intervention, and who decides if this goal is justified. Many treatments exist, but from different points of view may not always be beneficial and appropriate. The perspective of some patients is that they are **entitled** to all that medicine has to offer. The response of many care providers is that they are not merely technicians and wholesalers of medical care where patients can simply custom pick from existing treatments. Who should decide to what end an intervention or the efforts of an individual can be directed has been a matter of controversy throughout the futility debate.

Medicine has changed profoundly in the last few decades. In solving old problems, the technology has created new ones. Consider the example of using an intervention such as mechanical ventilation for the treatment of severe pneumonia. A ventilator can do many things. Primarily it breathes for the patient when the patient cannot adequately do so alone or at all. It is a tool used in medicine to keep patients breathing transiently during anesthesia when the breathing muscles are paralysed. It is commonly used as a bridge to support respiratory function that has failed until antibiotics can control infection and independent function can be restored. For doctors the goal is to support patients **transiently** so they can return to prior independent life. The machine is simply a tool to achieve this end. If this goal is not possible the tool's use is no longer appropriate. But for families the ventilator may be seen both as a means to allow the medicine to overcome the illness, and also as a way to preserve life. If the former goal is no longer possible they sometimes settle for the more basic goal, life itself. The personal and

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[118] LJ Schneiderman, (1990): p950.

psychological make it more difficult for families to separate these two ends. Although modern technology can to a certain extent support this second objective, there is conflict over what specific goals are not within medicine's mandate to provide. As Schneiderman astutely summarises, "means are confused with ends, effects are confused with benefits and available technologies are confused with obligatory medical therapies."[119]

The old adage, *just because we can, does not mean we should* also lies at the heart of the futility debate.

> Consider the questions that now arise about some commonly accepted goals of medicine. One traditional goal has been the saving and extending of life. But what does that goal mean when machines can sustain the bodies of those who would, in earlier times, simply have died? How far should medicine go to extend faltering individual life?[120]

The traditional position and goals of medicine have become clinically unreliable as they have failed to find a good balance between care and cure, between conquering disease and improving quality-of-life. They are also socially confusing, "stimulating false and unrealistic public hopes and creating expectations about the transformative powers of medical progress that cannot be achieved, or achieved only at costs that are too high economically, socially and ethically."[121]

What we need is, "a medicine that seeks, simultaneously, to be honorable, temperate, affordable, sustainable, and equitable, [and such a medicine] must reflect constantly on its goals."[122]

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[119] LJ Schneiderman, (1996): p671.
[120] The Hastings Center, "The goals of medicine: setting new priorities", *HCR* special supplement (1996): p3.
[121] The Hastings Center, p6.
[122] The Hastings Center, p23.

One rational attempt at redefining these goals in the realm of futile care is the common sense patient-centred notion of the goals of medicine. Schneiderman urges,

> the medical profession not to banish the "language of futility" but to examine that language more deeply and to look at the roots of the practice embedded in that language. Words that are central to health care, such as "heal" (which means "to make whole") and "patient" (which comes from the Latin "to suffer"), suggest that the goal of medicine is not merely to achieve a means, such as restoring heart-beat, unless that means leads to the end of healing the patient.[123]

When redrawing our line we should move towards the idea of regarding the patient as a whole rather than the current situation that yields to the goals of fixing body parts and treating numbers and assuring physiologic activity without regard to the bigger picture.[124] The premise is that none of these ends are worthy goals of medicine if the overall goal of improving the **whole patient** is not possible. As Sir William Osler said, "the various organs, the diseases of which they are subdivided for treatment, are not isolated but complex parts of a complex whole…when one member suffers, all members suffer with it."[125] Only when we talk about the whole patient can we presume a benefit as opposed to simply physiological effects on some body part.

A ventilator can sometimes be used in highly motivated spinal cord injury patients to perform the work of breathing indefinitely so that they can carry on with some aspects of their prior life outside a critical care setting. Much like dialysis, a ventilator in this setting replaces the functioning of one organ system, and allows individuals to pursue their other life goals. However, when used for pneumonia and the infection progresses despite medical efforts, the medical premise of reversal is no longer present. This is why,

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[123] LJ Scneiderman, (1996): p673.

[124] *Ibid.*, p671.

[125] From the motto of the Canadian Society of Internal Medicine.

when the treatment of pneumonia has failed to confer improvement in the patient, the continued use of a ventilator is no longer supporting a medical goal. Similarly, "any treatment that merely preserves permanent unconsciousness or that fails to end [a patient's] total dependence on intensive medical care should be regarded as nonbeneficial."[126] The 'value-free' notion of physiologic futility would mean that doctors should care only about treating numbers and not the whole patient, and is one that the medical profession and society should reject.

This common sense view of the whole patient may be a quality-of-life assessment, but one that is on the right track of what society should consider as reasonable and just.

Existence in a critical care setting is not a goal to which any physician, patient or family member should aspire. And medicine and society should not foster this goal. Yet modern medicine has somehow lost its way by 'complicating' the dying process and care at the end of life.

> The appropriate goal of medicine in such cases is to promote the welfare of the patient, to sustain life where possible and *reasonable*, but to recognise that because of its necessary place in the human life cycle, death as such is not to be understood as the enemy. It is death at the wrong time (too early in life), for the wrong reasons (medically avoidable or treatable *at a reasonable cost),* and coming to the patient in the wrong way (full of relievable pain and *suffering and excessively prolonged*) that are the appropriate enemies.[127]

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[126] LJ Schneiderman, (1990): p952.

[127] The Hastings Center, p14, (emphasis added).

The Hastings Center has worked extensively to review and develop modern priorities for medicine, specifically:

1-the prevention of disease and injury and the promotion and maintenance of health.
2-the relief of pain and suffering caused by maladies.
3-*the care and cure of those with a malady, and the care of those who cannot be cured.*
4- *the avoidance of premature death and the pursuit of a peaceful death.*

Dealing with Difficult Claims

There will always be requests for exception to a line drawn by medicine and society. And it is important to be able to justify refusing to honour such claims. To do so, physicians and society must rely on **principles**, such as the limitations of positive rights which are not absolute, on realistic and relevant goals and limits of medicine, and on fairness. Beyond this, different societies will have to decide if what the patient is requesting is of sufficient enough value **to that society** that it is willing to protect and promote that interest above others.

Dealing with Uncertainty

As discussed earlier, uncertainty is an inescapable fact of all decisions in life, and medicine is no exception. All standards of care for different treatments assume some **reasonable** level of uncertainty in deciding what goals are achievable and appropriate. Society has already shown that it accepts and endorses these standards even when life hangs in the balance. It has done so for brain death, and it has done so for physiologic futility. It has done so despite the fact that there is no guarantee that the next patient to meet the 'Harvard Criteria for brain death' will not wake up.

> The notion of **reasonableness** is [also] accepted in another major sector of society where a person's life may be at stake: courts of law. A jury in a criminal trial may find a defendant guilty and subject to the death penalty if the evidence is persuasive beyond a reasonable doubt, not beyond all doubt.[128]

Thus medicine and society agree that they must accept some 'workable' truths. Otherwise they would be paralysed by uncertainty. Society has determined that certain levels of success are reasonable to pursue, and anything falling short of these levels is

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[128] LJ Schneiderman, (1996): p672.

not. "This change in direction signifies a turn away from *individual* conceptions towards *social* conceptions of reasonableness."[129]

When family members are faced with the uncertainty inherent in end-of-life care, claims of denial and distrust in the medical assessment and prognosis are not uncommon. As such, physicians will frequently offer a time-limited trial of therapy, a second opinion or a transfer of care. But when these good faith efforts still support the initial conclusion, these claims remain subject to the socially sanctioned standard of care.

Dealing with Life as a Goal of Medicine

In 1996, The Hastings Center proposed new priorities for medicine for the 21st century. Among these was the reframing of a time-honoured goal. The ideal of, "preserving life," was replaced by, "*the avoidance of premature death and the pursuit of a peaceful death.*"

> The struggle against death in many of its manifestations is an important goal of medicine. Yet it should always remain in a healthy tension with medicine's duty to accept death as the destiny of all human beings.[130]

Rhodes argues that most people, "would still list "preserve life" as one of the legitimate goals of medicine…[and that] given this broadly shared social understanding, it does not yet seem legitimate to claim that the goals of medicine have been revised to exclude treatment that would merely preserve life without accomplishing any other of the accepted goals."[131]

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[129] T Tomlinson, p1278.
[130] The Hastings Center, p13.
[131] R Rhodes, "Futility and the goals of medicine", *J Clin Ethics* 9 (1998): p200-1.

It is, however, simplistic and shortsighted to say that life itself is a goal of medicine and therefore should be provided for upon demand. This idea is not in keeping with the evolution in medicine and technology, and what has been achieved in terms of averting death. Life should be more than just a beating heart. And The Hastings Center has made a good attempt at drawing this line.

One hurdle to redefining the goals of end-of-life care is that most citizens are ignorant of the realities of 'futile' care, and have unrealistic presumptions of what medicine can and cannot achieve. Ongoing education will contribute to a better understanding of the limits and proper priorities of medicine.

Dealing with Religious Claims

No medical or religious perspective that came before could have predicted and prepared us for how this capacity to sustain a heart beat would have fit into the said goals of medicine and society. Historically, the preservation of life was so important because it was so elusive. But this has changed dramatically in the last century. "Nothing less than a profound transformation of human life has taken place. It has changed the way human beings think about the ancient threats of disease, illness and death."[132] Where before the path was short between health and death, it can now be very long between incapacity and disease, and death. The artificial block of medicine in the dying process, the ability to ward off that last heart beat...this is a different enemy from the diseases that led to premature deaths in past centuries. This metamorphosis has outrun and disturbed the missions of our world religions. Their laws were centuries in the making; our technology has come and upset this equilibrium almost overnight.

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[132] The Hastings Center, p2.

In addition to the goals of medicine and the goals of society evolving with the new capacities and limits of technology, so too must religion. Fortunately, this shift is already happening. In 1999, The Vatican Council issued a statement that physicians are not required to offer or pursue useless treatments.

> When the doctor is aware that it is no longer possible to impede the death of the patient, and that the only result of intensive therapeutic treatment will be that of adding suffering to suffering, he must recognize the limits of medical science and of his personal intervention, and accept the inevitability and ineluctability of death. At this point, the respect due to the dying person demands more than ever that one avoid any sort of "therapeutic obstinacy" and that one encourage the acceptance of death. The work of the doctor and of other health care workers must continue, however, in the attentive and efficacious application of so-called "proportionate therapies and palliative treatments."[133]

But there are still religions that value life above all else.

The notion of *Sanctity of life* is a different type of argument. The difference between the *Sanctity of life* and *life as a goal of medicine* lies in the religious nature of the first claim. It appeals to society rather than to medicine proper. The goals of society and the goals of medicine are not mutually inclusive; not all goods that society wishes to promote are proper goals of medicine. Religious freedom and fulfillment are goals of society that go beyond the duty of medical care. When did medicine acquire the responsibility for religious fulfillment?

Certainly as a result of achieving health, people can pursue other socially desirable goods. But, the goals of religion are not equivalent to the goals of medicine. Society on the other hand wants people to achieve these goods. It promotes and provides health care to allow its citizens to be healthy so they can in turn enjoy life and their own

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[133] Pontificia Academia Pro Vita, "Dignity of the Dying Person." *L'Osservatore Romano*, (8-9 March 1999): p10.

life goals. But it does not follow that medicine should skip the intermediate objective of health and be responsible for these other goals.

Where medicine may draw a line, which society endorses, that a certain quality of life (for instance, mere existence in an ICU) is not within its bounds to support, the assertion of *Sanctity of life* as an exception to this limit should have no claim on medicine. If medicine decides that it is not within its standard of care to keep patients alive for the sake of life itself, then this limit applies to everyone in that society. Religious freedom is not an excuse for exemption.

Another similar claim is the hope for a miracle. Is it really medicine's duty to support such hopes? Unquestionably, if science and medicine never pushed the envelope for these seemingly hopeless cases then where would we be? But this claim appeals to the goals of research, and is therefore outside the standard of therapeutic medical care.[134] While the belief in Divine intervention may be very important for patients and families in moments of crisis, it is not a goal of medicine either. Physicians may empathise and believe in the need for hope, but they have no duty to provide time for such miracles to occur. Compassionately they are not against this end, but there are good reasons not to indulge it, primarily nonmaleficence. Providing time for a 'miracle' to occur in many cases would prolong suffering, violating a fundamental tenet of medicine. Even in the Bible, a true 'miracle' relies on the notion that, "things that are impossible with men are possible with God."[135]

While an ICU can allow for the fulfillment of a specific religious edict, surely its modern application cannot reflect the spirit in which it was intended. The extension of

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[134] The proper goal of research is to gain new knowledge, and not offer cure to the research subjects *per se*.

[135] LJ Schneiderman, (1996): p673, re: Luke 18:27.

'life' at the expense of prolonging of suffering is a perversion of any religious teaching and should be reconsidered. The goal of creating an ICU did not include a way of life but rather a **bridge** to resuming one's life.

Religions must come to terms with the technological advances and reinterpret their laws, understanding that death is no longer the enemy it once was, and that a new evil - prolonged dying - needs addressing, as death itself will never be cured. So the notion that life is supreme in and of itself is perhaps still true, but must be tempered by this new unforeseen gap created by modern medical efforts.

In turn, society, rather than individuals must decide not only what goals and what thresholds of success are worthy of pursuit, but also which symbolic values are worth recognising. The free practice of religion is not an absolute, yet for some reason society affords it an enormous amount of weight in our daily living compared to other rights. No one wants to confront it. But as pointed out in a landmark Jehovah's Witness case, freedom of religion, "embraces two concepts – freedom to believe and freedom to act. The first, is absolute, but in the nature of things, the second cannot be."[136] When religion must rely on the state and its institutions for individual fulfillment, its rights must be balanced against the other competing and sometimes conflicting interests that society wishes to promote. If society feels that *Sanctity of life* is an interest worth protecting, the medical profession may have to acquiesce. But as discussed earlier, if the medical profession has reached internal consensus that such a claim is outside its mandate to provide, it would be very difficult for society to force medicine's hand. While this

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[136] *Cantwell vs Connecticut*, 310 U.S. 296 (1940).

struggle between patient and physician rights may be unpredictable, society's interests will always prevail over this positive right.

> The unrestricted claims of an individual to common resources raises issues that by their very nature transform the conflict between religious views and medical judgement from a clash between individual patient and physician values into a matter of public concern. It is no longer merely a question of competing patient versus professional norms but a public assessment of the relation of an individuals goals to the common good.[137]

Such a right is thus subject to the limits and leeway different societies can, and are willing, to provide. Autonomy is therefore best understood as the freedom to choose **within** these parameters.

While society has some interest in just providing majority opinion, it also has an interest in supporting and not dismissing minority claims. Each society must ask itself if it is in its best interest to preserve freedom of religion or a right to life and ultimately a right to certain kinds of medical care, against other important social interests such as the common notion of quality-of-life, the common notion of a good death, the integrity of the medical profession, the just allocation of scarce resources, and the financial cost of such care to society.

Consider the example of brain death. Medicine proposed a line whereby the irreversible absence of brain activity equaled death. In **time**, and through **education**, society agreed to this line and passed legislation allowing death to be declared if the specified criteria were met – even if the patient's heart was still beating. Although the medical community and western societies have formally adopted the notion of brain

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[137] JJ Paris and M Poorman, "When religious beliefs and medical judgments conflict: civic polity and the social good", in <u>Medical Futility and the evaluation of life-sustaining interventions,</u> ed. MB Zucker and HD Zucker (New York: Cambridge University Press, 1997), p90.

death, there have been requests for exception and continued treatment of such patients on religious grounds. Some religions still refute this definition and claim that, "one whose heart still beats still lives."[138]

Does society want to provide the means for the few who want this existence? This is a difficult question that different jurisdictions have provided for differently. For instance the courts of New York and New Jersey maintain exception clauses for such claims even though they recognise these patients as legally dead.[139] It is perhaps more compelling to realise that Canada and the other 48 American states, offer no such concession. They drew their line and stuck to it.

Furthermore, it should be noted that in the case of brain death, such an exemption is a compassionate gesture that is short-lived, as, "the maintenance of cardiovascular homeostasis for more than a few days under these circumstances would be unlikely, and traditional cardiovascular death criteria would soon be met."[140] The risk assessment is that the few days for each of the few patients or families who seek this exemption is a reasonable compromise, and not worth the fight.

If, however, society draws a broader line, this sort of exception clause will be much less agreeable. Patients can survive for a long time with ICU care. How would these societies then chose to balance such requests against their other important interests? Would they still indulge these religious requests for 'futile' care knowing that such patients could artificially exist for months or even years in a critical care setting? This sort of policy would quickly become unsustainable emotionally, financially and ethically.

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[138] *Ibid.*, p88.

[139] NM Lazar, *et al.*, "Bioethics for clinicians: 24. Brain death", *CMAJ* 164 (2001): p836.

[140] *Ibid.*, p836.

Dealing with the Slippery Slope

The slipperiness of empowering doctors and the medical profession to make decisions in the clearest of cases of 'futility' is that such judgements may progress to include less legitimate ones. But this is a speculative argument, not an ethical one. By definition, these arguments are constructed broadly and emphasise the worst fears that may be realised. In so doing they appeal to the moral indignation of society in hopes of preventing any steps towards the 'slope'.

Slippery slope arguments are difficult to counter because generally they are only conjecture and their validity is felt to be tenuous at best. Most advances in civilization, however, have come at the risk of plummeting down the slippery slope. All changes involve risk. It is only by weighing the desired outcome against the perceived risk, and proceeding with trepidation that society evolves. "If, before every action, we were to begin by weighing up the consequences, thinking about them in earnest, first the immediate consequences, then the probable, then the possible, then the imaginable ones, we should never move beyond the point where our first thought brought us to a halt."[141]

Despite the weakness of this sort of argument, it reminds us just how fragile the doctor-patient relationship can be, and that we must endeavour to protect the trust in this bond. This is achieved by implementing a framework whereby doctors justify their position for refusing to provide disputed treatments. It appeals to the notion of professional integrity, where moral codes are in place to promote and safeguard the ethical practice of medicine. Enlisting physician integrity should start rather than silence the proper dialogue. As such, patients should be able to present their wishes and

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[141] J Saramago, Blindness (Montreal: Harcourt-Brace, 1997), p 78.

preferences, and physicians allowed to limit the kinds of care they are willing to provide, as long as they explain why. Such physician judgements could be either quantitative or qualitative as long as they are transparent, and reflect the need for a greater burden of proof when quality-of-life is at stake.

> In futility conversations, physicians state clearly what power they propose to exercise, on what authority they feel entitled to exercise it, and what checks and balances ensure that these exercises of power do not constitute abuses. The physicians also remind the patients, as a part of the conversation, about the countervailing sources of power they possess (such as a right to a second opinion, ethics committee review, and so on). Under these circumstances, it seems hard to imagine how the power to determine futility could be abused on a regular basis.[142]

Dealing with Cost-Containment

"The concept of futility is unavoidable or can be avoided only by paying far too high a price."[143]

No discussion of the futility debate would be complete without addressing the need for cost-containment and allocation of scarce resources. The idea behind managed care is to reduce escalating health care costs by restricting nonbeneficial treatments. Yet, the reality is that in order to truly cut, let alone contain costs as the population ages and technology gets more expensive, managed care will also need to eliminate treatments that are not futile but of marginal benefit.

Rationing shifts the focus towards who is most likely to benefit. It is a utilitarian solution to scarce resource allocation. Futile care may not be cost-worthy, but non-cost-worthy care is not necessarily futile. They are of course not mutually exclusive considerations, but they should be separated at the level of thinking about patient care. Decisions about futility should rest with

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[142] Brody, p13.
[143] *Ibid.*, p.

moral judgements regarding whether we should provide certain treatments just because we can. Even if we had endless resources, there are some things we simply should not do. And harming patients by keeping them alive indefinitely and thwarting all efforts their bodies make towards death is one of them.

However, some critics have compelling statistics to justify drawing a line on the basis of economics. "Expenses for care during the last year of an average [US] Medicare beneficiary's life are approximately 24% to 30% of the total Medicare budget. More than 60% of these expenditures are in the three months before death."[144] Some feel that it is, "better that health care dollars be spent where, on average, they have a better chance to provide true benefits than to pour the large percentage we now do into the final days and weeks of life."[145] While there is some truth to these claims, is it not better to decide this issue on moral grounds before society is forced to decide because of financial constraints? Unfortunately, the public debate is even less likely to separate these two issues.

At least physicians want to say what should and should not be done. Society may on the other hand decide on the basis of what it can or cannot afford to do unless it is sensitised to the importance of this difference. If doctors leave it solely to public debate and insurance companies, it will come down to money. And no one will have a say… not patients, not doctors. The subsequent cutoffs may ultimately be much less palatable as they will likely be based on age, not prognosis, and on capacity to pay, with little attention to the merits of each claim. Money should not decide this. It should be about the right and good use of medicine, the provision of beneficent and nonmaleficent care.

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[144] DJ Murphy, p129. (citing McCall 1984, Lubitz and Riley 1993, Scitovsky 1994).

[145] AM Capron, in Medical Futility and the evaluation of life-sustaining interventions, ed. MB Zucker and HD Zucker (New York: Cambridge University Press, 1997), pxii.

Conclusion

Much work needs to be done to resolve many of the issues surrounding medical futility. This process must be based on the fundamental ethical principles of beneficence, nonmaleficence, respect for persons, compassion and justice. Physicians need to work together so that the shift in standard of care can be redressed and clarified. Rather than giving in and allowing the shift in standard of care, physicians should also take an active role in educating patients and the public. The erosion of the doctor-patient relationship must be mended through ongoing communication and mutual understanding. The debate, which has stagnated in recent years, needs to be reopened, so there can be education and social discourse on this important issue. Through education, society's understanding will evolve and reach consensus. Change in ethical attitudes and public opinion happens slowly. "We need to make the transition…to a more communitarian ethic that will help us survive (an perhaps thrive) in the next century."[146] This will require an understanding of not only what we can and cannot do, but also what we should and should not do. The line in the futility debate should also be based on morality, not money, on common sense rather than common cents.

It would be premature to dismiss the concept of futility because no consensus was reached at the peak of its debate.

> "Achieving consensus is a gradual and evolving process. It begins with public awareness of an issue, proceeds to understanding by working through the issue (which in the case of medical futility will require changing unrealistic expectations about what medicine and science can accomplish), and finally leads to resolution on cognitive, emotional, and moral levels. It is worth remembering that achieving nationwide consensus on a universal definition of death according to whole-brain criteria took approximately 20 years."[147]

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[146] DJ Murphy, p123.

[147] LJ Schneiderman, (1996): p671.

Lack of consensus in the futility debate is an issue that must be resolved; at its heart are real people dealing with real suffering. "Asclepius recognised this and revealed the art of medicine for the benefit of people of sound constitution who normally led a healthy life, but had contracted some definite ailment.... But where the body was diseased through and through, he would not try, by nicely calculated evacuations and doses, to prolong a miserable existence...."[148]

Perhaps modern medicine must revisit some of the sage advice of its forefathers.

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[148] FM Cornford, The Republic of Plato, (Oxford: Oxford University Press, 1941), p97.

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Appendix A

Studies on CPR Outcomes

- RB McGrath, “In-house CPR-after a quarter of a century”, *Ann of Emerg Med* 16 (1987)

  Retrospective review of 12961 in-hospital resuscitation attempts
  Mean survival to discharge of 14.6% (range: 3-27%)
  Patients resuscitated in specialised care areas did significantly better than the non-monitored ward patients (14.9 vs 11%)
  Younger patients (< 60 years old) did better than older patients (18.3 vs 12%)
  Patients with ventricular tachycardia did better than those with asystole (19.8 vs 3%)

- MW Peterson *et al.*, “Outcome after CPR in a medical ICU”, *Chest* 100 (1991)

  Retrospective study of CPR in the ICU
  Showed an initial resuscitation rate of 70%
  Followed by an 11% survival to discharge from hospital
  Low BP, sepsis, severe disease and prolonged CPR were poor prognostic variables

- FJ Landry *et al.*, “Outcome of CPR in the ICU setting”, *Arch of Int Med* 152 (1992)

  Retrospective trial of CPR in ICU patients with underlying medical illnesses
  Close to 50% survived initial CPR
  None of the patients with sepsis or malignancy survived the initial CPR
  Only 6 of the 114 (5%) patient survived to discharge
  Only 2 survived an additional year, and were significantly disabled

- DR Miranda, “Quality of life after CPR”, *Chest* 106 (1994)

  Prospective Dutch ICU study
  Showed that 47% survived initial CPR, but only 3% survived to discharge
  Survivors had cognitive impairments and a decreased capacity in pre-ICU activities

- K Rockwood *et al.*, “One year outcome of elderly and young patients admitted to ICU”, *Crit Care Med* 21 (1993)

  Prospective study of ICU patients
  No difference in outcome associated with age alone
  Outcomes worse with severe underlying illness, length of ICU stay and respiratory failure
  Elderly proved to be psychologically more accepting of their resultant impairments
  Only 7% of older versus 15% of younger survivors, felt their ICU stay was not worthwhile

Appendix B

1-University of Toronto
Hospital Policy on the appropriate use of life-sustaining treatment

2-Houston city-wide taskforce on medical futility
Guidelines on institutional policies on the determination of inappropriate interventions

1-PROCESS FOR DECISION MAKING

This section describes the steps that should be followed when there is disagreement between patients/substitute decision makers and health care providers about the appropriateness of initiating or continuing life-sustaining treatment including intensive care. This process should commence as soon as the health care provider becomes aware of potential for future conflict. Although the steps are presented in the order they will most likely occur, the order of steps 1-8 may be varied and several steps may occur simultaneously. The patient's condition may not permit completion of this process.

1. Interprofessional team consensus -- The health care team should reach consensus regarding the range of appropriate treatment.
2. Communication -- In collaboration with other members of the health care team, the most responsible physician should:
   a) as early as possible, discuss with patients while capable, their prognosis and wishes for treatment
   b) explore why the patient or substitute decision maker wishes treatment to be continued and address these issues directly
   c) discuss with the patient and/or substitute decision maker the rationale for withholding or withdrawing life-support treatment
   d) describe palliative care measures which emphasize patient comfort and dignity
   e) offer hospital resources such as social work, chaplaincy, or bioethics to assist the patient/family with their psychosocial, cultural, spiritual, and informational needs
   f) document pertinent details of this communication in the patient's health record
3. Negotiation -- The most responsible physician or other designated member of the health care team should attempt to negotiate a plan of treatment that is acceptable to both the patient/substitute decision-maker and the health care providers actively involved in the care of the patient.
4. Intensive care consultation -- If intensive care admission may be required, a consultation from an intensive care physician should be obtained as early as possible.
5. Second opinion -- The patient or substitute decision-maker should be given an opportunity to request a second opinion, and assisted by the health care team to obtain one.
6. Trial of Therapy – A time-limited trial of therapy may result from the negotiation described in step 3 above.
7. Patient Transfer – The patient or substitute decision-maker should be given an opportunity to identify another provider willing to assume care of the patient, and assisted by health care team to do so.
8. Mediation -- A person designated by the hospital for this purpose should meet with the patient/substitute decision maker and health care team to attempt to mediate the disagreement.
9. Arbitration/adjudication -- If mediation fails, the hospital's lawyer should be consulted regarding the appropriateness of an appeal to the Consent and Capacity Board (under section 37 of the *Health Care Consent Act*), arbitration, or court proceedings.
10. Notice of intention to withhold or withdraw life-sustaining treatment -- If the health care team intends to withhold or withdraw the disputed life sustaining treatment, the patient or substitute decision-maker should be informed, given an opportunity to challenge this decision in court, and assisted by the hospital to do so.
11. Withholding/withdrawal of life-sustaining treatment – If all the procedures in this policy have been followed, the health care provider may withhold or withdraw the disputed life-sustaining treatment including intensive care.

Guidelines on Institutional Policies on the Determination of Medically Inappropriate Interventions

Policy

The traditional goals of medicine have been to heal and to relieve suffering and pain. In recent years, the goal of respecting autonomous patient choices has motivated the establishment of policies which permit patients (or surrogate decision makers) to exercise that autonomy by refusing or limiting an unwanted intervention. These policies are limited to situations in which patients (or surrogate decision makers) refuse an intervention. This current policy, designed to supplement rather than to supplant currently existing policies on limiting life-prolonging therapies provides a conflict resolution mechanism to follow when a patient (or surrogate decision maker) requests, rather than refuses, an intervention which the responsible physician* assesses to be medically inappropriate (commonly referred to as medically futile).

This policy affirms both the traditional goals of medicine and the moral value of physician and institutional integrity in discerning the limits of medical interventions. Respect for this integrity provides the basis for the right to refuse to provide a medically inappropriate intervention. It complements the right of patient determination that must be given both voice and effect in any forum for medical decision making. This appeal to integrity is generally rooted in a combination of concerns such as avoiding harm to patients, avoiding provision of unseemly care, and just allocation and good stewardship of medical resources. This policy affirms this value of integrity so long as appropriate institutional review supports the determination of medical inappropriateness.

After following the procedures set forth in this policy, a medically inappropriate intervention may† be withheld or withdrawn without obtaining the agreement of the patient (or surrogate decision maker).

Procedures

1. When the responsible physician determines that an intervention is medically inappropriate but the patient (or surrogate decision maker) insists that it be provided, the responsible physician should discuss carefully with the patient (or surrogate decision maker) the nature of the ailment, the options including palliative care and hospice care, the prognosis, and the reasons why the intervention is medically inappropriate. The responsible physician should explain that not providing the intervention in question does not mean abandoning appropriate medical care and humane care designed to promote comfort, dignity, emotional, and spiritual support.
2. The responsible physician should address with the patient (or surrogate decision maker) the options of patient transfer to another physician or to another institution and of obtaining an independent medical opinion concerning the medical inappropriateness or medical futility of the intervention in question. The responsible physician should also provide the patient (or surrogate decision maker) with a copy of these guidelines.‡
3. The assistance of institutional resources (such as nursing, patient care representatives, chaplaincy, social services, or the biomedical ethics committee) shall be made available to the patient (or surrogate decision maker) and to the responsible physician.
4. If, after reasonable effort by the responsible physician using the available institutional resources, agreement is not reached between the responsible physician and the patient (or surrogate decision maker), the responsible physician who still wishes to limit the intervention must obtain a second medical opinion from a physician who has personally examined the patient and must present the case for review by an institutional interdisciplinary body and must provide to that body clinical and scientific information pertinent to the determination that the intervention is medically inappropriate.
5. The responsible physician must notify the patient (or surrogate decision maker) that this process has been invoked, what it involves and what are its possible outcomes, when and where the review will take place, and that the option of transfer before the meeting exists, but that arranging such a transfer is the responsibility of the patient (or surrogate decision maker). Absent patient (or surrogate decision maker) consent to an earlier time, the meeting cannot take place for at least 72 hours after the patient (or surrogate decision maker) is notified.
6. During the institutional review process, the responsible physician and the patient (or surrogate decision maker) are encouraged to be present together to express their views for consideration including alternative plans of care.
7. If a finding of medical inappropriateness is affirmed§ by the institutional review body, medically inappropriate intervention may† be terminated and a plan of care established that addresses comfort care and the preservation of patient dignity.‖ If, however, the institutional review body does not concur with the responsible physician's determination of medical inappropriateness, then orders to limit the intervention will not be recognized as valid without patient (or surrogate decision maker) agreement.
8. If the institutional review process agrees with the determination of medical inappropriateness, intrainstitutional transfers of the care of the patient to another physician to provide palliative care are allowed. However, intrainstitutional transfers to another physician to provide the intervention that has been judged by the institutional review committee to be medically inappropriate will not be allowed.
9. The procedures set forth in this policy may be invoked only by the responsible physician or as otherwise authorized by the hospital's medical staff by-laws. Concerns on the part of other health care providers, hospital officials, or family members should be addressed through already existing institutional mechanisms.

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*The term "responsible physician" should be defined by each institution.

†Institutions may wish to substitute ". . . must be terminated even though the agreement of the patient (or surrogate decision maker) has not been obtained."

‡Each institution may insert the title of its policy.

§Each institution should determine the voting requirements for its review mechanism affirmation.

‖An institution may impose a finite grace period after the determination that an intervention is medically inappropriate or medically futile but prior to the termination of the intervention.