

# **MEDICAL FUTILITY**

## **Strategies for Dispute Resolution when Expectations and Limits of Treatment Collide**

**A report for the Harvard Ethics Leadership Group  
by the Community Ethics Committee**

**January 2013**

The Community Ethics Committee was created under the auspices of the Harvard Ethics Leadership Group and functions as a part of the nonprofit Community Voices in Medical Ethics, Inc. The Committee was developed to serve both as a policy-review resource to the teaching hospitals affiliated with Harvard Medical School and as an educational resource to the varied communities from which the members come.

The volunteer members of the Committee are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Committee members, during all or part of this study, included:

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## **COMMUNITY ETHICS COMMITTEE REPORT to the HARVARD ETHICS LEADERSHIP GROUP and interested others**

### **Medical Futility – Strategies for Dispute Resolution when Expectations and Limits of Treatment Collide January 2013**

#### **SETTING**

Medical Futility is an inscrutable phrase. Some parents know it, at least conceptually, from the experience of being denied antibiotics for their child's horrible virus. Antibiotics do not work on most viruses; that is, they are medically futile, although sometimes the prescription is written anyway – to ease the parents' state of mind more than to treat the child's virus. In such a case, the treatment might be futile but any harm could seem, in context, to be minor. In care of a patient at the end of life, however, Medical Futility takes on a darker cast. Medical Futility becomes something of a "catch-all" phrase encompassing a confrontation with impending mortality. It is a situation that highlights the limits of a doctor's ability to treat and cure; a family's trust and faith in the doctor's intentions or ability to "know"; struggles of accepting our own dying or that of a loved one; where the phrase "do everything to save him" holds entirely different meaning to the person "saying" and the person "doing." In end-of-life care, situations of Medical Futility demand as much art as science and can transform loving care into nightmarish harm. It exists in the space between the heroic ("Don't just stand there, do something") and the Zen ("Don't just do something, stand there"). Medical Futility is, in some respects, a "know it when you see it" kind of thing, but because so much of medical care is provided behind closed institutional doors, both literal and figurative, we in the community generally do not see it. Rarely do we know of the "hard cases" where patients with no rational hope of recovery and no audible voice are having decisions made for them by those with different and competing agendas; where bodies only negligibly alive are tended by nurses who must bear the stench of decaying flesh; where doctors and families make decisions in hallways and conference rooms seemingly far removed from the patient in the bed.

Awareness of Medical Futility in end-of-life situations began for members of the Community Ethics Committee during research for our study *Withholding Non-Therapeutic Cardiopulmonary Resuscitation* (2009) and was a background theme throughout the study *Palliative Sedation – Continuous Deep Sedation as Comfort Care until Death* (2011). Over the past two years, the CEC has heard narratives of these hard cases – both medical professionals and family members came to us to share their stories of Medical Futility. We were given many examples of patients whose last days and hours were spent enduring medical interventions that either family members or health care staff believed were medically futile. We bear witness to the fact that these cases leave deep and lasting scars on family members as well as medical staff. This Report on Medical Futility, especially on the intractable disputes that sometimes arise from such situations, is necessitated by those narratives – they are compelling, disturbing, and, in the end, they are the result of a society that denies death and does not see the damage that such denial can cause. We begin with a story, in composite, to illustrate what we have heard.

"Mom is not that old in the whole scheme of things – 78 isn't old anymore! She had a few episodes of sickness before, but her primary care doctor always got things stabilized and she was always able to come home. There was one time when she ended up going to a big fancy Boston hospital - she had pneumonia and was on a respirator for a time, but she got better and

came home. Our minister came to the hospital every day and we are convinced she was healed because of his prayers. And, all this time, Dad has been taking care of her just fine. That is, up until now. She fell and these past few weeks, she's been at another Boston hospital and we had high hopes she would be discharged soon. They are the experts - her primary care doctor said - they are the best of the best! But it isn't looking so good – nothing seems to be working and the doctors aren't talking. Or at least they aren't telling us much. We admit she has been sick for awhile but nothing deadly – along with her diabetes came heart disease and some lung problems. She's on a respirator now because her breathing got so bad. Of course that means she can't move much and there are horrible bed sores. The skin on one of her legs is gone – you can see all the way down to the bone! She's in and out of consciousness and when she is conscious, she does nothing but thrash and moan. The nurses are upset because they think we need to let her go – they think they are hurting her when they change the dressings and suction her lungs. We don't stay in the room when they do their work – it's a courtesy to them since we don't want to interfere. We've decided we want Mom to have surgery to fix the open sore – once that's done, we know she'll feel better and she'll be able to come home again. We've talked to a plastic surgeon who thinks an operation can help her. But the ICU folks want it all to stop – they want us to disconnect Mom from the respirator and let her die. We don't want that - we want her to come home. Everything will be okay if we can just get her home. She's a fighter and now that she can't fight anymore, we're going to fight for her. She needs to have the surgery and then we'll take her home. It doesn't matter what they say, we know what is best for our mother and that's what we are going to do. She needs us now more than ever – we aren't going to abandon her at her greatest hour of need.”

This Report addresses the intractable disputes that develop for reasons which include distrust, poor communication, or outright denial, when the care team and family cannot agree what measures should be taken to care for the patient. These disputes, increasingly common in the Intensive Care setting, prolong the dying process and create a situation where a basic principle of medical ethics – Do No Harm – is turned on its head. That is, harm is done daily, and repeatedly, to patients by medical professionals who believe that it serves no therapeutic purpose. Why do they do it? Because we demand it.

It is noteworthy that in none of the cases we heard and read about was the patient a dying physician. In the essay “How Doctors Die: It's Not Like the Rest of Us, But It Should Be,” Ken Murray, physician and professor of family medicine at the University of Southern California, wrote: “What's unusual about (doctors) is not how much treatment they get compared to most Americans, but how little. For all the time they spend fending off the deaths of others, they tend to be fairly serene when faced with death themselves. They know exactly what is going to happen, they know the choices, and they generally have access to any sort of medical care they could want. But they go gently. Of course, doctors don't want to die; they want to live. But they know enough about modern medicine to know its limits. And they know enough about death to know what all people fear most: dying in pain, and dying alone. They've talked about this with their families.”

It is perhaps each human's most profound challenge to accept that we are mortal, and those we love are mortal, and despite remarkable advances in cures, treatments and technologies, we will all reach a point where life-prolonging efforts become futile. Determining that point is as individual as is each one of us.

## **INTRODUCTION**

The Community Ethics Committee (CEC) is a group of volunteers living in the Boston metropolitan area who are members of the various populations served by the Harvard-affiliated teaching hospitals. The CEC provides reports and opinions on topics brought forward by members of the Harvard Ethics Leadership Group – representatives of the various ethics services within the Harvard teaching hospitals. The need for such a consultative group has been evident for a long time, since the few community members on hospital ethics committees are unable to represent multiple communities. Solicitation for membership on the CEC has been cast widely through community, business and religious groups, with a specific application process to ensure selection of a dissimilar but effective working group.

CEC members are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Ten members are women and eight are men; we range in age from our teens to seventies. Some have advanced degrees, some have high school diplomas, others are in high school now. Among members past and present are a high school administrator, and a high school teacher; a rabbi, an imam, a Muslim female attorney, and a professor at a Protestant seminary. Some of us are individuals with disabilities and parents with disabled children. Two are retired, one from a large Boston law firm. We are students and writers and small business owners. We volunteer in our communities, including on an Institutional Review Board and in local health care facilities. We belong to eight different religious traditions, including atheism, and we are fluent in seven different languages. Most of us have attended the annual Harvard Clinical Bioethics Course, where the original members first met in 2007 and began the conversation as the Community Ethics Committee. Since 2011, the CEC has been part of the nonprofit corporation, Community Voices in Medical Ethics, Inc., which was established in order to enhance the CEC's mission to bring the issues of medical ethics into the community as well as to include the community's voice in the dialogue already occurring in health care institutions, government, and academia.

## **PROCESS**

The CEC came to the topic of Medical Futility with no preconceived notions of what it is, which stakeholders were the primary obstacles to good decision-making, or what was the best approach to make something that is intractable, tractable. We met throughout the Spring and Summer of 2011 and returned to the subject in the Fall of 2012. As community members, we had no real understanding of the phrase “medical futility” and no understanding of the difficulties faced when medical interventions are continued on, in essence, a mechanically sustained corpse. We had no sense of how difficult the task would be that lay before us.

Throughout the Summer of 2011, the CEC met with numerous staff members from Boston area hospitals – they came to share with us their narratives of challenging situations where medical interventions were continued even though they were without therapeutic effect and only served to cause pain and suffering on an unimaginable scale to a vulnerable dying patient. The CEC heard story after story of patients subjected to painful interventions at the end of their lives; families tragically unable to move on from destructive grief processes; and caregivers traumatized by the demand to provide “bad care” that seemed to them to approach outright medical torture. The CEC also heard from family members who shared the enduring effects of this kind of care, causing profound pain long after the death of the loved one.

In addition to our monthly meetings, CEC members corresponded by e-mail and shared articles we had found and information we had gathered on Medical Futility. As part of our process, the CEC reviewed existing hospital and hospice policies which deal with this subject. Perhaps most important, the CEC members spoke about these issues with our own families, friends and colleagues – the community. Monthly meetings were held at the Harvard Medical School and, although scheduled to run for three hours, discussions often continued much longer (more than once members stood in the parking garage until late in the night doggedly trying to sort out these issues).

More than any other topic the CEC has addressed to date, the issues raised by Medical Futility are so broad and multi-faceted that we recognized any observations we made would be woefully inadequate to “solve” the problem. Sometimes these situations are truly intractable, without a solution ending in consensus. We recognize that we will revisit this issue many more times during our Committee life together. This Report is, therefore, an admittedly unfinished product. Nonetheless, the CEC wanted to respond because we were uniformly moved by the narratives we heard and the willingness of caregivers and family members to share with us these most difficult of life’s decisions. With a need to respect their time and transparency, we are providing this Report knowing it is only a beginning.

## **DEFINING THE TOPIC, FINDING A FRAMEWORK**

The CEC has found the first step in any review of a topic must involve defining our terms. The lack of a consistent and uniform understanding of futile medical care made the concepts we were wrestling with even more troubling and difficult to clarify. We concluded that clarity in the words we chose to describe this kind of medical care and the structure we gave to our discussion would be crucial to ensuring the ultimate usefulness of this report to caregivers, patients and families and the public.

If the term Medical Futility is inscrutable, it also is subjective. One person’s sense of futile medical treatment is another’s handle of hope. Hence, use of this label may hasten polarization and the formation of intractable disputes. Similarly, the word “ineffective” as it is applied to medical treatment options is colored by the subjective values – religious, cultural, ethnic and moral – each participant brings to the discussion. Again, the phrase “quality of life” is defined by the varied values of those involved in decision-making for and caregiving of the patient.

Medical Futility itself describes treatment with no reasonable possibility of cure or therapeutic benefit to the patient. The context of Medical Futility at the end of life centers upon the moment when a medical team, the family, and sometimes the patient, either together or individually, conclude that interventions are no longer of benefit to the patient and may in fact be harmful; that the dying process is active and irreversible; that comfort care is the recommended course of treatment; that continued or additional therapies, rather than providing care for the patient, are inflicting harm.

Medical Futility itself does not imply dispute. In most cases considered futile, when further medical interventions are determined to be neither therapeutic nor curative, the patient or surrogate agrees with the determination that further aggressive care will be of no benefit and, based upon the patient's best interests, such interventions are withheld or withdrawn. In those

cases, often with the hospital's ethics service playing a key role in coming to agreement, the patient's comfort becomes the primary goal of care and the dying process is not prolonged.

When futility disputes occur, at the core of conflict is disagreement over the best interests of the patient or the value of treatment. Sometimes it is the patient or surrogate who comes to that moment of declaring futility and declines a recommended treatment option, as when a terminally ill cancer patient forgoes additional chemotherapy or when a frail elder refuses aggressive resuscitation measures. More often, however, it is the medical team that comes to the moment of declaring futility, concluding that further aggressive interventions are not accomplishing the patient's goals of care, and often that additional medical interventions will only cause pain and suffering. When the family disagrees and insists that treatment continue, dispute arises.

The dispute becomes intractable when the surrogate and family believe the medical team does not have the patient's best interests in mind, but instead is abandoning the patient in a cold and utilitarian way. Difficult questions about quality of life and religious and cultural values arise, as does the volatile issue of cost of care. Lack of trust, poor communication, different world views, all contribute to the makings of an incendiary dispute where surrogates and families are not ready to "let go" and the medical team is perceived as "giving up" prematurely. The dispute can become intractable in a flash or over time.

In these situations, the potential for conflict arising upon declaration of futility grows with the number of persons involved. The patient, often unconscious, is accompanied not only by a surrogate decision-maker but also by a contingent of family and friends, often with differing agendas and histories of grief and loss. The medical team is also diverse, coming to the encounter with varying communication skills and professional duties. In contrast to the patient/family and physician decision-makers, nurses are most often the ones with little decision-making authority but with the substantial burden of performing medical interventions that cause, rather than relieve, pain and suffering.

Medical Futility, when it results in intractable disputes, is a horrible state of affairs. In addition to stories told in confidence by palliative care physicians, intensivists and other specialists, nurses, chaplains, social workers and ethicists, the CEC was privileged to hear from family members who came to believe their grief was prolonged and complicated by disputes over futile care and who "wish they knew then what they know now." This report would be of little value without their courage and honesty in revisiting difficult memories.

In the care of a dying patient, arguably there is no one involved who knows that patient in the bed, and the specific realities of what that patient is experiencing, better than the nurse. Indeed, it is a distressing irony that in disputes over care at the end of life, the two human beings at the very center of that care, the patient and the nurse, often have no decision-making capacity.

While a patient's surrogates argue with the attending physician over whether stopping treatment means killing the patient or allowing a natural process of dying, perhaps the only thing that patient will feel all day, at least as can be perceived, will be in reaction to extreme pain caused by continuing medical treatments - necessary and merciless changes of dressing, repeated attempts to access a vein, and suctioning fluids from lungs. And the person performing these procedures -- inflicting is arguably the more accurate verb -- is usually the nurse. If there is some hope of benefit to the patient, if continued treatment is seen to be in the patient's best

interests, then even pain-causing procedures should rightly be performed by the nurse, for however long necessary, especially in a critical care environment. Simply put, it is part of the job. But take away that benefit to the patient, and the nurse is left inflicting harm. And harm is done not only to that patient but to the integrity of the nurse (in the form of moral distress) and to the ability to care for the next patient (in the form of compassion fatigue), both of which lead to burn-out and grief.

A mother who told the CEC the story of her child's death after months of aggressive treatment (that retrospectively seemed futile, even to the mother) still remembers the chilling feeling upon learning that several nurses had declined to care for her child because to do so would compromise their commitment to do no harm. The mother wishes she had known this while choices to continue interventions were being made, and yet acknowledges there were things she could not hear at the time. One particularly devoted nurse --a nurse beloved by this mother -- had stayed with this child's case through to its completion -- the baby's death -- and then promptly quit her job. In these situations, harm is being done to many.

## **STRUCTURE OF OUR ANALYSIS**

Faced with this many-headed hydra of Medical Futility, the CEC adopted a deliberate structure in our attempt to make headway. We divided our inquiry into separate areas of focus, and although there is overlap, each looks at a single aspect of Medical Futility. Subcommittees were formed to address these separate areas, which we described as:

- BIOS** – the **biology of futility**, sometimes described by terms such as physiologic, qualitative and quantitative futility;
- LOGOS** – the **words used among stakeholders** when faced with challenging end-of-life decision-making, communication that is often incomplete and biased;
- PATHOS** – the **heart issues** framed by culture, religion, and personal history; and finally,
- ETHOS** – the **societal challenges** found particularly in judicial or less formal procedural approaches to solutions, and **cost concerns** raised by any limitation of access to care at end of life.

This Report will mirror that structure so that we can present our perspectives about Medical Futility in the only way we could discern would make any significant contribution to a discussion of this topic.

Finally, based on our group discussions and in order to obtain everyone's viewpoints, our CEC leadership developed a survey that elicited individual members' views on the dilemmas raised by the medical community and family members. Comments from that survey inform this Report.

### **BIOS – Physiology at the end of life**

The CEC examined whether physical attributes of a patient's medical situation made continued treatments automatically futile. Is dialysis for a terminally ill cardiac patient always biologically futile? Is chemotherapy for a terminally ill cancer patient always futile? Such a

determination may be based upon qualitative futility criteria – the harm done to the patient by the medical intervention far outweighs the benefit of an extended period of life, often days or weeks, in a significantly compromised physical state.

Or such a determination may best be based upon quantitative futility criteria – is the probability of more time so insignificant as to not warrant further medical interventions? The biological benefits are not in balance with the burdens of the medical interventions being considered. Are end-of-life treatment decisions enhanced by these kinds of biological approaches? The CEC heard about clinical situations where the staff felt they were essentially caring for a corpse – necrosis had already begun and bones were exposed much like a cadaver's. Is there a point at which there is a biological mandate to stop treatment? How does one decide, and how is a physician to communicate the meaning of a complex terminal diagnosis as it relates to a loved one's treatment options?

The perspective of the stakeholders here is skewed by the fact that the physicians' knowledge of the biology of the situation is far more extensive than the patient's and their family's. The urge toward internet research and social media connections is an effort to equalize that disparity of knowledge. But information alone does not provide the sole basis for making the best decision. The biological basis for a decision does not often stand alone as grounds to pursue or to terminate medical interventions.

Nevertheless, biological markers such as a diagnosis of multiple irreversible organ failure, shared with patients and their families, might help them understand that a moment of Medical Futility may be on the horizon. Fair warning should be given. A sudden proclamation of the patient's imminent demise is defeating and devastating to any sense of hope. Physicians can and should communicate that biological markers are present indicating the end-of-life may be approaching.

Those biological markers alone are not sufficient to enable patients to make good medical decisions. The medical staff must take the time to ask questions to elicit the patient's overall goals of care in the context of those biological markers -- "Given your current condition, what are you expecting or hoping for?" With a focus on what can be done to meet those goals of care and a reasoned and compassionate response to those goals that cannot be met, the physician might provide the patient and family a basis for good decision-making that can avoid a futility situation that ends in an intractable dispute.

### **LOGOS – Words used at the end of life**

Good, clear and compassionate communication is perhaps never more important than in end-of-life discussions and decisions. Amid recent research strongly linking early communication with less aggressive treatment during a patient's final days, the CEC was struck by the fact that poor communication is central to the development of intractable disputes. Loss of trust is a primary component of these disputes and deficient communication skills are a clear precipitant to that loss of trust. Even though much has been written about the need for enhanced patient/physician communication, frequent and repeated observations prove that, especially at this most crucial juncture, many physicians are abysmal at communicating with patients. And yet such "personal work" is as important as any technical skill learned in medical school. For a poor communicator, the collaborative approach, or team approach, is crucial.

Any limitations at good communication on the physician's part can be compounded by an inability to comprehend on the part of the patient and family, who can exist in an "alternate reality," a combination of conflicted emotions, fear, grief and loss of control over what is transpiring. The patient's and family's inability to process impending death can create an additional barrier to rational discussion and understanding. Sometimes it does not matter what a physician says, or how compassionately or well. Hard things may not be heard.

Poor communication renders the ethical concept of autonomy moot; unless patients, surrogates and families are well-informed, with understandable and usable information, they cannot make autonomous decisions, and informed consent is not possible. Patients become subject to the power disparity inherent in the medical encounter when one stakeholder knows so much more than the other. This power disparity exposes meaningful flaws in the paradigm of "shared decision-making" (in which doctors and patients are partners in the decisions based on evidence and the patient's values and circumstances). Perhaps a new paradigm of "supported decision-making" (in which the patient's decisions are supported by a designated circle of advocates and, as needed, a representative) could better help avoid Medical Futility disputes. In all events, enhanced patient/physician communication at the end of life is a recommendation easy to make and difficult to accomplish.

Even when speaking the same language, cultural influences can make what is *said* and what is *heard* two different things. Some CEC members have the privilege of working with religious groups with a substantial population of ethnic minorities, primarily African-American and Hispanic. These two ethnic groups have been the focus of empirical studies that address issues of health-care disparities with respect to ethnicity and socioeconomic status, high end-of-life medical costs, and the role of spirituality/religion in shaping decisions.

Spiritual care does not necessarily lead to less aggressive medical care at the end of life. According to Michael J. Balboni and colleagues researching the religious and spiritual dimensions of life-threatening illness: "Cancer patients whose spiritual needs are well-supported by their religious communities have higher medical care costs in the final week of life as compared to those less supported, particularly among racial/ethnic minorities and (patients whose beliefs most strongly influence decision-making). Higher costs are known to be driven by greater aggressive medical care at the (end of life)."

And yet a related study of spiritual needs of cancer patients, led by Dr. Tracy Balboni of Dana-Farber Cancer Institute, found "patients reporting that their spiritual needs are not well supported by the health care team have higher end-of-life costs, particularly among minorities (highly religious)."

It is not true that all ethnic minorities who are African-American or Hispanic have a religious view of the world. However, the discussion here highlights important implications for those from these ethnic groups who do.

Among many African-Americans and no doubt other ethnic minorities, there is widespread mistrust of institutional health care and lingering worry that medical professionals do not have the minority patients' best interests in mind when certain treatments are stopped or when hospice or palliative-only care are recommended. Paradoxically, there seems to be a disproportionate number of individuals from these ethnic groups who receive more aggressive end-of-life treatment, oftentimes seen as futile by health-care providers. Given the lack of health

care resources among some ethnic minority groups, the perception can be that their lives are not considered valuable enough to expend such resources. Hence, they may feel compelled to insist on these treatments for loved ones or themselves, sometimes leading to situations of intractable dispute.

A few recommendations merit greater emphasis in addressing these communication issues. The medical profession should intentionally reach out to leaders in various religious communities for the purpose of “cross-pollination” education. In other words, the religious communities have much to learn from the medical community concerning end-of-life care, and health care professionals have much to learn about the internal logic of how faith informs patients’ decisions. If this dialogue is encouraged, some CEC members believe, less aggressive therapies will be found to be consistent with many religious/spiritual traditions. Perhaps then health care providers may be more sensitive in presenting care recommendations and patients and their surrogates/families may be able to make more informed decisions about life-sustaining treatments and end-of-life care.

A model for this is found at Gunderson Lutheran Hospital in LaCrosse, Wisconsin, where a thoughtfully designed system emphasizes understanding and honoring a patient’s treatment preferences. Gunderson has a record of increasing continuity of care, quality of life and respecting patient wishes, while matching services with patient preferences and reducing unwanted treatments. In particular, Gunderson’s Respecting Choices program for advance care planning offers an effective model for minimizing intractable disputes through patient-centered communication and teamwork. At Gunderson, social workers, nurses and clergy are trained in end-of-life conversations, and the cost of care in a Gunderson patient’s last six months are roughly a third less than the national average. Similarly, two related programs of the Institute for Healthcare Improvement - the Conversation Project and Conversation Ready - provide useful tools for engaging these difficult conversations within the community and among health care providers.

In addition to such institutional measures, the medical profession should take the initiative to win the trust of particular ethnic minority groups by working in more intentional and collaborative ways within the broader community that it serves. Such interactions can only help to improve communication and trust.

### **PATHOS – Heart issues at the end of life**

A patient’s perspective on treatment is shaped by a unique combination of cultural, religious, and moral beliefs which often appear in bold relief when facing mortality and are at the core of end-of-life decision-making. In addition to one’s cultural and religious views of death, we are each influenced by our individual narratives -- our history -- of grief and loss occasioned by the dying and death of family members and loved ones. We are also influenced by our encounters with the unexpected. Sometimes the reverse holds true - belief that a past “miracle” defied a dire medical prognosis may influence future responses. Intractable disputes are more likely to arise when these personal histories are filled with distrust, with fear, and a sense of despair.

Other participants in a Medical Futility dispute – the surrogate, family, friends, physicians, nurses, other medical caregivers, chaplains, social workers -- also come with

their personal histories and cultural and religious world views. At a minimum, each participant, aided by robust dialogue, should be given the tools to identify their own world views and understand how others' world views inform the difficult decisions that arise at the end of life. The entire multidisciplinary team of medical caregivers has a special responsibility to develop the acute listening skills needed to foster understanding and lead to resolution.

In addressing this issue of pathos and cultural differences among all the parties involved, Committee members disputed the phrase "cultural competency" -- no matter the good intentions, one cannot enter another's cultural and religious reality. "Cultural literacy" is perhaps attainable and certainly "cultural sensitivity" is mandatory. Information and programs fostering such cultural sensitivity exist in abundance and include increased knowledge for the interdisciplinary medical team, counseling, spiritual guidance, or community support for patients and their families. Such interventions addressing these heart issues are absolutely necessary to avoid or minimize the damage done in Medical Futility disputes.

There also is the matter of spiritual or theological convictions of the deeply religious. Among particular religious communities, there can be an insistence on preserving life indefinitely to give the Deity time to work a miracle. Or followers believe their stewardship of life calls them to preserve life at all costs despite the circumstance or situation. To do otherwise would be "playing God." Clergy, wittingly or unwittingly, reinforce these beliefs. However, in the experience of some CEC members, religious leaders do not share views of life-sustaining treatment and end-of-life care uniformly or with the same fervor. Perhaps there is a disconnect between the teachings of their traditions and their application. While some clergy recommend aggressive treatment, others hold religious convictions that inform them not to recommend certain kinds of life-sustaining treatment altogether, even when the professional health-care team does not consider the treatment futile. Although less common, such beliefs can be the source of an intractable dispute "in reverse" when death is greeted prematurely. Such decisions are sometimes based on certain notions of an afterlife, varying with respect to religious teaching, as with philosophical views.

Clergy well-trained in their particular tradition, but also with understanding of end-of-life medical issues, would be in a better position to help both patients under their care and the medical community lessen the frequency of intractable disputes, whatever their source.

In the realm of Pathos' "heart issues," possible measures to avoid falling into an "intractable dispute" include:

1. Time - health care teams should offer objective arguments for the treatment recommendations they are making and then allow patients and families time for reconciliation of their belief systems with the reality presented.
2. Suspend Judgment – health care teams should strive to avoid paternalistic value judgments of the patient's and family's decision-making model.
3. Use Tools – many communication tools have been developed to help further conversations about end-of-life wishes and values including sorting exercises such as

“Go Wish,” the tools of The Conversation Project, and decision trees to forecast treatment choices and consequences of those choices.

4. Advocate – if available, a “health system navigator” is helpful to voice the patient’s perspective and act as translator between hopes and desires and the medical realities being faced.
5. Redirect Hope - foster a conversation about “adjusted hope,” practical and spiritual, in the face of hope thwarted by current medical realities.
6. Robust Literacy and Sensitivity Training – all patient support groups, including medical teams, should be provided comprehensive training in cultural literacy and sensitivity regarding ethnic, religious and cultural belief systems of patients and families.

In sum, absence of trust is a major contributor to the breakdown in communication and to conflict regarding medical treatment and goals of care, both of which are components of an intractable dispute. Each patient brings to the conversation with caregivers particular religious, cultural and ethical value systems, as well as personal and family histories. Sensitivity to each patient’s heart issues will contribute to the building of trust. Also important is each medical caregiver’s awareness of their own personal heart issues. In a setting of openness and vulnerability, patients, families, and caregivers can build a mutual respect and trust that will go a long way in avoiding intractable disputes, even in the face of situations of Medical Futility.

### **ETHOS – Social structures affecting end-of-life care; and resolving intractable disputes**

When the Committee framed the subcategories of our inquiry into Medical Futility, we recognized that the “ethos” of our society made these disputes inevitable. We are a society that holds tightly to the denial of death and the rights both to life and to choice. Most recently, the specter of “death panels” silenced any constructive political discourse on the possibility of physicians getting Medicare or Medicaid reimbursement for discussions with their patients about values and wishes near and at the end of life. We are a society steeped in an ethos of avoidance – if I don’t talk about it, it won’t happen. Unfortunately, such an approach is at the zenith of futility – we are all dying and we will all die.

The CEC looked at two distinctly separate aspects of our social approach to disputes arising out of Medical Futility situations – financial, or the cost of care; and dispute resolution, whether that be judicial or other procedural paths to resolving intractable disputes.

### **Financial – Cost of care**

The CEC was convinced that consideration of Medical Futility disputes demanded a discussion of cost of care. Although physicians assured the CEC that considerations of whether a patient could pay for costly interventions were never factors in medical treatment recommendations, we were aware of the tensions caused by issues of justice and access that are heightened when a patient who is terminally ill and actively dying receives aggressive care. Any disinterest of front-line providers in cost cannot continue for long. With changes to health care reimbursements and cutbacks to hospital programs, the cost of care will necessarily be more manifest as a determining factor in choices offered and decisions made.

In addition, Medical Futility disputes seem to arise when the patient and family have or develop a deep distrust of the hospital and its staff. The issue of cost presents itself “front and center” when a family feels disenfranchised and distrustful of the system and its members are convinced they are not heard, respected, and cared for. Numerous studies support the conclusion that certain cultural groups enter the system feeling at a disadvantage, automatically making encounters with staff more confrontational and difficult than they might be otherwise. When there is any sense that decisions to forgo medical interventions may be based upon ability to pay, then all hope for effective and cooperative decision-making evaporates. The new and most volatile category of patient discrimination may well be the costly patient. Indeed, the very meaning of the phrase “cost of care” is perhaps relative to any individual’s ability to pay.

As is often the case, the solution is more difficult to describe than the problem. Just as the ethos of our society does not want to acknowledge death as an inevitability, neither does our society want to talk about money in this context. Yet these hard discussions must be had. We must ask ourselves as a society, how do we honor the elders among us and do what we can to enhance their longevity in ways that assure them of a good life and a dignified death? At the same time, how do we ensure funds are available to care for the youngest among us and to invest in their futures knowing dollars spent in early interventions yield extraordinary benefits over time? And how do we allocate funds in a manner that respects choice without subsidizing notoriously harmful choices at a cost we all must bear? The CEC recommends that we recommit ourselves to respectful and open-minded discussion of these topics. In this and earlier studies, the CEC has found, the solution is in the conversation.

## **Dispute Resolution**

As our system exists now, a patient’s life is supported at any and all cost. Many hospitals have futility policies on their books but such policies are rarely, if ever, invoked. The default is to honor the family’s demand for continued treatment, regardless of the medical team’s distress and disgust. The continuation of care that has become harm often is stopped only when the patient dies, in spite of all the interventions in place. Those interventions are continued because there are those who demand it, but the drive to continue is also fueled by fear of legal liability and by the lack of truly effective mechanisms for dispute resolution.

Some argue that the impact of Medical Futility disputes on the care team depends significantly on the size of the hospital. A large, well-funded hospital has both the human and other resources to shield staff from ethical compromise or legal vulnerability. At smaller institutions, staff may be more exposed and in greater need of governmental, institutional, and legal backing. It can be argued the same applies to the patient and families faced with a Medical Futility dispute. Those patients who have the financial means, whether from personal funds or generous insurance coverage, have more options for care, and may be more likely to pursue a legal confrontation more aggressively. The threat and cost of legal action necessarily affect the realm of decision-making in the context of Medical Futility, and the narratives we heard spoke of the caregivers’ cost in time lost and in the personal distress created by being forced to bring nuanced medical treatment decision-making into a courtroom setting.

No matter what structure may be provided to mediate these Medical Futility disputes, a troubling Catch-22 exists in the constitutional guarantee of due process. Due process as it unfolds in a judicial process is of little or no use to the imminently dying, their surrogate

decision-makers, or the medical team responsible for the patient's care. When judicial decisions must be made about end-of-life care, due process does not work in anyone's best interests unless a special provision is made by statute or court rules to shorten response times. Simply put, due process in our contemporary judicial system takes too long. A guaranteed day in court to resolve a dispute is a darkly comic idea when that day is nine months away and the patient will not live more than weeks. Setting a date for these disputes to be heard in a court of law becomes its own exercise in futility. The court date is rarely kept - the patient usually dies first.

Unless an effective and efficient Medical Futility dispute resolution mechanism is in place, our society will continue to suffer. And most importantly patients suffer – their dying process is prolonged for no apparent therapeutic or curative purpose with substantial harm done to caregivers, family members, and patient alike. No matter whether decisions are made by court or committee, even if all cases of Medical Futility could be decided reasonably and well, with the patient's best interests protected, efficient resolution by any authoritative institutional group may come at the potential expense of public trust and confidence. Decisions made by either courts or medical institutions' internal review boards are suspect because the stakes are high, core values differ, and the power disparity of the stakeholders is extreme. Rarely does anyone feel particularly comfortable when a court or authorized expert panel or ethics committee mandates withdrawal of life-support for a terminally ill child, for example, against the wishes, hopes, and demands of frantic and grief-stricken parents. Another approach must be found that includes safeguards and provides an open process that considers cultural, religious and patient values and welcomes participation by surrogates acting in the patient's best interest.

The CEC discussed a wide range of possible decision-making aids in Medical Futility disputes:

- a) skilled mediation using internal, trained facilitators;
- b) skilled mediation using external, trained facilitators;
- c) designating a specific Massachusetts court to hear these cases, such as the Probate court or a newly designated Medical Futility court, similar to courts designated to adjudicate business disputes;
- d) appointment of a qualified Special Master by specialized or non-specialized courts to make a recommendation to the Court, such as appointment of a guardian ad litem by the Probate Court to advocate for the patient/surrogate; and
- e) use of new or existing review panels or boards with statutory authority to make binding decisions and mitigate risks of malpractice claims.

We looked most closely at four existing approaches with certain attributes we believe essential to creating an acceptable process: decision-making that is reviewed outside the hospital; a process that includes consideration of non-medical factors, such as family, cultural and religious values; and a process that manifests fairness, being timely and independent of the economic or social circumstances of the patient or healthcare institution. Those four dispute resolution approaches are presented in more detail below.

## **1. Texas**

In the U.S., Texas has taken the most aggressive, even radical, steps to take Medical Futility disputes out of the courts by creating a completely different procedural solution. The Texas Advance Directives Act, or TADA, has in many ways proven to be an effective process for dispute resolution, protecting both the patient's best interests and the integrity of the medical profession. Other states have adopted aspects of TADA to address futility disputes, but none have provided such extensive legal protections to the medical team and hospital as has Texas. Our particular concern in that regard is the fact that TADA's resolution process never leaves the hospital - an internal ethics board serves as the decision-making authority.

Dr. Robert Truog of Harvard Medical School and Boston Children's Hospital has written extensively about futile care and the Texas law. In the *New England Journal of Medicine*, he wrote that TADA "has defined one very concrete approach to addressing these dilemmas. When families demand treatments that have an exceedingly low likelihood of success or that sustain life of such low quality that one might reasonably say it is of no benefit to the patient, Texas law allows physicians to refuse to provide such treatments. Under the Texas legislation, demands by families for treatments that appear to meet these criteria are adjudicated by a hospital-based committee, and if the committee agrees with the clinicians, and if other providers cannot be located who are willing to provide such care, then treatment may be withdrawn without the permission of the patient's surrogate."

## **2. Ontario, Canada**

The CEC has examined an alternative decision-making model found in Canada. Under the Health Care Consent Act established in the 1990s, the province of Ontario created a responsive appellate panel known as the Consent and Capacity Board, or CCB. The board consists of lawyers, psychiatrists and members of the general public appointed by the lieutenant governor. It considers a broad range of cases including mental health, consent, privacy, and substitute decisions, responds with a timely process respectful of the urgency of end-of-life disputes, and carries legal authority.

In resolving intractable disputes at the end of life, the CCB has an impressive record of protecting the patient's best interests. In one noteworthy case, the CCB agreed with the view that a patient's treatment had become futile, and yet ruled for the patient's family to continue treatment. The decision was based on the fact the physicians had not taken into account the patient's religious beliefs and had not considered how those values might influence care decisions. In essence, the physicians sought to make decisions without understanding the patient's values, and the CCB called them to task for it. In this case, the CCB passed the "best interests" test with flying colors – the patient's values, and one could argue the community's values, were protected.

## **3. External Review under the Massachusetts Cost Containment Law**

Interested in applying to Massachusetts the best aspects of TADA and the CCB, we considered the impact and possible adaptation and use of the external review already existing under the Massachusetts Cost Containment Law. Such review is available to individuals covered by a fully insured Massachusetts health plan who have been denied benefits by reason of

“medical necessity,” a defined term in the regulations. Although “medical necessity” is a narrower concept than what we have identified as appropriate to futility decisions, a large proportion of the patients at the institutions this report is addressed to will have these review rights, so the process, which is efficient as to cost, if not time, inevitably will have a major role in determining these disputes. Under the regulation, for \$25, a patient may obtain an external review of a denial of service from one of three external, independent review agencies. The reviews are conducted by independent, experienced physicians or other health care professionals from the US who typically treat the health care conditions under review. The decisions of this panel must be delivered in 60 days and are binding. The review is conducted entirely on the basis of the medical record and no testimony is asked for or accepted.

This Committee would have written the regulations slightly differently -- we would suggest an expansion of the external review board to include community members outside the medical profession; we would broaden the scope of review from just medical necessity” to include religious, ethnic and cultural views of the family; we would offer a face-to-face hearing; and we would offer expedited consideration of cases where death is the primary issue. Importantly, we would find a way to expand the program beyond Massachusetts-insured patients to all patients.

#### **4. Massachusetts’ Department of Children and Families (DCF) process for evaluating proposed withholding or discontinuing life sustaining medical treatment**

The Department of Children and Families has in place a process for reviewing hospital decisions about the appropriateness of foregoing or discontinuing life-sustaining medical treatment for minors under its jurisdiction. The process includes written recommendations by the treating physician; a written second opinion by a consulting physician from another institution; and a recommendation from the ethics committee of the treating hospital. The mandated DCF form for the ethics committee recommendation requires the hospital to determine whether the recommending physician has taken into account “ethically relevant information,” such as religious, cultural and ethnic views of the family and others involved with the child. The ethics committee must also respond in writing whether it has evaluated other treatment options and assessed quality of life issues. With this record, the matter is presented to a court for a decision. Conceptually, at least, the DCF model has useful elements for a policy and procedure covering all patients in Massachusetts health care facilities, whether or not covered by health insurance.

These existing precedents in dispute resolution offer encouragement that Massachusetts can develop a process to hear and decide cases of Medical Futility – intractable disputes at the end of life. Ideally the process would put the heaviest burden on the health care facility to support a written recommendation and careful consideration of religious, cultural and ethnic views of the patient and family would be taken into account. The medical decision would be supported by an independent second opinion. The final decision would be made by an independent court or legislatively sanctioned review panel that is completely unconnected to either the health insurance or medical institutional systems. Such a decision-making process should be the public’s voice, speaking to and deciding upon a particular patient’s end-of-life care while also addressing a societal good. Such a recommendation is based upon the CEC’s perception that these decisions involve the community as well as the individual stakeholders.

And it is based upon the assumption that such an independent review mechanism would be responsive in a timely way and effective in mediating and deciding these extreme cases.

With no effective or efficient Medical Futility dispute resolution mechanism in place, society suffers. And most importantly, patients suffer – their dying process is prolonged for no therapeutic or curative purpose with substantial harm done to caregivers, family members, and patient alike. No matter whether decisions are made by court or committee, even if all disputes over Medical Futility could be decided reasonably and well, with the patient’s best interests protected, efficient resolution by any authoritative institutional group comes at the potential expense of public trust and confidence. Decisions made by either courts or medical institutions are suspect because perspectives and core values differ, and the power disparity of the stakeholders is extreme. Rarely does anyone feel particularly comfortable when a court or TADA-authorized ethics committee mandates withdrawal of life-support for a terminally ill child against the wishes, hopes, and demands of frantic and grief-stricken parents. Another approach must be found.

Although certain segments of the general public clearly distrust the medical system, it is less obvious but no less real that certain segments of the medical community greatly distrust the general public. To grant decision-making authority to an independent review panel, allowing it to intervene in Medical Futility cases, would require an exercise in trust for both “sides.” Such a leap of faith is needed, however, and the CEC believes such a decision-making process would be a societal good – a step forward in developing an ethos of compassion for patients, their families, their caregivers, and our community as a whole.

Instituting such an independent review process serves the patient’s best interests. And yet the Committee wanted to be sure there were no procedural impediments to stakeholders resolving the dispute on their own. Committee members repeatedly brought the discussion back to the primary goal at hand – a patient who is suffering and who is imminently dying. Should anything stand in the way of providing relief to such a patient?

The CEC’s assumption was that, during the time when discussions among the stakeholders are clearly dissolving and the dispute about medical interventions is on its way to becoming intractable, all parties need to be made aware of this independent review process and discussions about taking that separate decision-making route should be initiated and encouraged.

The CEC recognized there are situations where the differing approaches of the family and medical team will never be reconciled and the dispute about medical interventions will become intractable. We acknowledged that there are situations where no amount of enhanced communication, no exercise of cultural sensitivity and understanding, no insight into a particular religion’s approach to death and no facilitated discussion can cross the divide. It is then that the patient’s interests must be made paramount and the suffering stakeholders must be protected. The CEC concluded that an independent review panel was the best advocate for that “patient in the bed.”

## **CONCLUSION**

In December 2012, before the Supreme Court of Canada, the attorney for a patient’s family refuted a medical assessment of futility with these simple words: “The treatment is 100 percent effective. It permits him to breathe.”

If only it were that simple. Terminal diseases of a generation or so ago have become treatable and sometimes even curable. And yet, we still die. We say we don't want to die hooked up to tubes and monitors in a hospital bed, but too often we do, in a state that the surgeon and author Atul Gawande has named "warehoused oblivion."

Sometimes dying can be a time of great clarity and meaning, especially when all parties involved acknowledge that the dying process is taking place and is not reversible. But acknowledgment requires acceptance of something we cannot know with absolute certainty. For some religious, this is like faith itself: belief in something unknowable. Death is certain; dying is unpredictable.

Perhaps no one is more aware of this than the medical staff of the modern Intensive Care Unit, who increasingly are asked to provide technological life support and to treat symptoms of unconscious and irreversibly dying patients at the request of family members who sometimes hope for divine intervention, sometimes hope for a miracle with a more scientific basis. The key word is hope. And hope, it has been said, is not a treatment plan.

The Community Ethics Committee wishes there could be a simple formula with a clear biological and spiritual threshold, beyond which therapy and life-sustaining technologies would be abandoned while suffering would be compassionately treated and the dying process would be allowed to proceed naturally to a peaceful end. Unfortunately, there is no such formula or threshold. There are only individual patients and their families and caregivers - mortals all.

But what do we as a society tell our physicians and nurses, the religious and non-religious alike, who are devoted to curing and caring for fellow humans, having committed themselves to doing no harm? How do we empower them to use their best judgment and to do the right thing? The determination to continue or stop treatment requires human judgment, flawed and error-prone as it is. Truly knowing the difference between hastening death and prolonging dying is impossible. And yet to whatever degree we can know this, it is important. It is vital in that word's purest sense. Perhaps the best we can do is to treat each case individually and compassionately with a deep respect for a human life that transcends the denial of death.

In those cases when Medical Futility results in intractable disputes, these were areas of special concern to the CEC: the compromised integrity and burnout of the care team, nurses in particular; the importance of protecting the vulnerable, of allowing for disagreement, and putting the patient first; and making certain there is someone with an empowered voice among the care team who is considering the "whole" patient, and not just symptoms and vital statistics.

The CEC encourages institutions to develop a strong palliative care specialty service, and not to wait until a patient is near death to make use of those services. The literature that the CEC has reviewed repeatedly makes the point that the care of patients at the end of life is immeasurably enhanced by the involvement of medical personnel trained in palliative care – both in their particular skill in conducting constructive dialogue with patients and families about end-of-life issues and in their expertise in pain management and in developing effective end-of-life care plans.

Palliative care is a relatively new specialty in medicine but has proven especially capable of knowing the "whole" patient, compassionately and respectfully treating suffering, and

ultimately allowing for the “good death” many of us say we want. But too often palliative care services are systemically marginalized, its specialized care delayed until “all hope is lost.” Palliative care needs to be brought into the mainstream of medical practice. And even though palliative care is increasingly available in mid-size to large hospitals nationally, it is significantly less likely to be available at the public and other hospitals where 47 million Americans who are either uninsured or geographically isolated get their medical care. We are encouraged that the Center to Advance Palliative Care at Mount Sinai School of Medicine in New York City has resources for building and sustaining effective palliative programs within a collaborative care model.

Advance directives are an imperfect means of giving voice to patients’ wishes and values when they can no longer speak for themselves, but they are an important tool for physicians in serving the best interests of patients who often arrive as strangers in need, especially in the emergency room setting. The MOLST system deserves full backing in Massachusetts. It is the CEC’s belief and experience that the more individuals and society discuss complex end-of-life questions, the less often disputes over medical decisions will arise.

Finally, when in those few but wrenching cases where decision-making over care of the dying results in intractable conflict, there must be a means for society to resolve the dispute both fairly and expeditiously. In Massachusetts, the Committee believes the most promising means of making this happen would be as a new and uniquely crafted component of the external review process for determining “medical necessity.” Such a dispute resolution process is needed not only for the sake of the medical care teams and for the families, but it is especially needed in serving the best interests of the patient.

## **RECOMMENDATIONS**

The four areas of focus that helped us to understand Medical Futility in end-of-life care might also inform approaches to minimizing such situations. As a summary to this Report on Medical Futility, addressing first the avoidance and then the resolution of intractable disputes in end-of-life care, the Community Ethics Committee recommends:

### **BIOS**

Sensitive to the inherent power imbalance in the patient/physician relationship, medical care teams must be collaborative and forthright in informing the patient of the likely path of their illness and in ascertaining goals of care. Medical staff must understand the importance of building trust relationships with patients and families. Palliative care specialists, including nurses, social workers and chaplains, are especially effective in providing care at end-of-life; their participation should not be delayed.

### **LOGOS**

If there is a solution to Medical Futility, it is to be found in better communication. Medical care teams must be able to communicate well, listening attentively and using words and manners that enable patients and their families to understand the medical treatment options available to them, and the likely course of treatment. Ethicists and palliative specialists should be invited to join these conversations early, with the understanding they have a significant role to play in enhancing communication.

## **PATHOS**

Medical care teams, patients and families all must be sensitive to the religious, cultural, and ethnic influences that affect understanding of life-sustaining treatment options and end-of-life care. Engagement and education are needed, within hospitals and the diverse communities they serve, regarding end-of-life wishes, advance-care planning, and Medical Orders for Life-Sustaining Treatment (MOLST).

## **ETHOS**

We recommend early involvement by ethics support services and palliative care specialists, at the request of either the care team or the patient/family. Ethicists and palliative specialists can provide wisdom and guidance as a Medical Futility situation unfolds. When disputes become intractable, a resolution mechanism is needed. Informed by such mechanisms in Texas and Ontario, the CEC recommends expanding the review powers under the existing Massachusetts Cost Containment Law to include review of Medical Futility cases so that recommendations of an ethics committee and consideration of religious, cultural, and ethnic concerns can be included. Such review outside the hospital might follow the existing Massachusetts DCF process regarding life-sustaining treatment for minors, and require separate written recommendations by both the treating physician and a consulting physician from another institution, and a formal review of the case by the ethics committee of the treating hospital. We also advise immediate action on the recommendations of the Massachusetts Expert Panel on End of Life Care.

## **A NOTE OF THANKS**

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