

Medical Futility: Implications for Ethics, Public Health, Politics, and Policy

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Abstract: Since the time of Hippocrates, medical futility has been a concept that has been acknowledged, but which neither the medical community nor ethicists have been able to concretely define. This is because while the cardinal goals of medical care: “to relieve physical and emotional pain and suffering... enhance the quality and functionality of life... to extend the length of life” (Doty, & Walker, 2000) have remained constant, our preoccupation with the prolongation of life, fortified by the extraordinary advances in medical technology that make it possible, have skewed our perception such that the line between prolongation of life and prolongation of the dying process has been blurred. As a result, physicians and families faced with end-of-life decisions must navigate their own way. Ideally, public health officials will initiate a national discussion about medical futility and all of the demons it brings with it so we can achieve a more consistent, ethical health care system.

I. Introduction

The Merriam-Webster dictionary defines futile as “having no result or effect: pointless or useless”, “serving no useful purpose: completely ineffective”, and “occupied with trifles: frivolous” (“Futile - Definition and More from the Free Merriam-Webster Dictionary”, n.d.). Most of us use it to describe a variety of innocuous and mundane circumstances in everyday life (i.e. “This diet is futile, I love to eat too much to stick with it”, or “My efforts to convince my parents to let me go to Mexico on Spring Break unchaperoned were futile”); but those circumstances belie the gravity of the word when spoken in the context of medicine. “Medical futility” in this context is often referenced when a life hangs in the balance; when the question is whether to withdraw or withhold life-sustaining measures to a critically-ill or injured patient. It may be cited by medical staff or the patient (or his/her family) to make a case for the cessation or abstention of treatment; and because it is largely viewed as a value judgment rather than a medical determination able to be made on clear cut criteria, there are major ethical hurdles to overcome on both sides before any decisions are made or actions taken. Additionally, as a value judgment, the concept of medical futility has impacts the field of public health in terms of policy (i.e. unilateral implantation of standardized protocol versus case by case determinations), as well as ethical (patient autonomy versus professional integrity), and legislative implications (i.e. the need for actionable, enforceable legislation).

II. Discussion

What is Medical Futility?

The American Medical Association (AMA) fully recognizes the motivations for wanting to clarify the meaning of medical futility in the context of end-of-life care (“Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs”, 1999). A query on their website quickly offers up these motivations, which include the quality versus quantity of life conundrum, (i.e. advances in medical technology have enabled life to be sustained even in the event that “cognizant human life is no longer possible” and therefore bringing into question the value of such interventions) (“Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs”, 1999); the desire to avoid dependence on legal proceedings to determine the course of action when there is a conflict between the family and medical staff as to what should be done; as well as the cost involved in keeping persons alive by artificial means when there is no hope for such persons who have no reasonable expectation of returning to a normal life; and the ongoing debate regarding appropriate interventions for the growing elderly population, as well as the shift in the medical decision-

making paradigm from paternalistic to patient-centered. However, in their Code of Medical Ethics, of medical futility the AMA states that the term “cannot be meaningfully defined” (“AMA’s Code of Medical Ethics”, 1994).

The difficulty encountered defining medical futility has not been for a lack of trying. In their article *Medical futility: Its meaning and ethical implications*, Schneiderman, Jecker, and Jonsen purport that futility in this context has both quantitative and qualitative aspects. The former referring to “an improbability or unlikelihood of an event happening, an expression that is quasi-numeric”, and the latter “the quality of the event that the treatment would produce”; and as such, they futility should be “used to describe any effort to achieve a result that is possible but that reasoning or experience suggests is highly improbable and that cannot be systematically produced” (1990). Of course this definition (as well as others) requires one to define the sum of its parts- that is, what it means to be “improbable”, “unlikely”, “systematic” “benefit”, or “meaningful”. The problem then becomes that of semantics and standardization of terms. There is no absolute reference point; no uniform, working definition of any of these words. They are subject to interpretation, which gives would-be definers a considerable amount of latitude. Our relative inability to define futility makes it impossible to design and implement an algorithm for making these sorts of determinations, and limits the way we are able to move forward with regard to policy.

Impact on Public Health and Ethical Implications

There are several key issues with regard to how the concept of medical futility relates to and impacts public health. The first is the need for the field itself to make end-of-life/palliative care a top national priority- which involves making it a top public health priority. As an institution, public health is a conduit for the protection and promotion of the health of populations, but it seems as though as a nation we are only peripherally aware of the necessity to care well for people at the end of life. Additionally, the extraordinary technological advances that have been made in the field of medicine has placed such an emphasis on conquering illness and extending life that it has become somewhat of the unofficial mantra of our populous. As such, it is possible that this disconnect between understanding what we need to do to assist people that are dying, the desire to prolong life at any cost, and our increasing inability to refrain from blurring the lines between longevity and quality is a function of our culture’s propensity for keeping death and any conversation thereof at arm’s length. Compounding the problem are the public’s misperceptions about what hospice is, and the ill-conceived concerns that as a nation we do not have the financial resources to support large-scale palliative care efforts. A common assumption among politicians and social commentators is that budget woes are keeping us from providing the best possible care for people at the end of life. In reality, few people in medicine, sociology, or health services research who have studied the situation agree with that premise. In fact, our society has had the technical knowledge and professional expertise we need for some time. But knowing and doing are two different things. What is most worrisome today is that caring well for people through the end of life and supporting caregivers are not on the national agenda. The clock is ticking along with 78 million baby boomers’ beating hearts, but the body politic isn’t listening (Byock, 2012, pp. 228).

Here, Dr. Byock refers to our ability – both with regard to the technological feasibility, as well as our knowledge of how to utilize palliative care effectively, but a report published by the National Center for Health Statistics in 2010 showed that while a significant number of patients enrolled in hospice said that they did so in order to have a more comfortable death, nearly 1/3 of those patients had uncontrolled pain at the time of their deaths (NCHS, 2010). This statistic is a glaring reflection of where palliative care stands with regard to prioritization on a national level. We have seen successful public health campaigns, including those aimed at reducing obesity, type 2 diabetes, smoking cessation, heart disease, cancer, and HIV/AIDS, and so we know that these programs, when prioritized, can be extremely effective tools in reducing the incidence and prevalence of diseases and the behaviors that lead to these diseases. That said, the approach to prioritizing palliative care- that is, the way it is publicized and marketed has the presents its own set of different and unique challenges, and has the potential to be extremely problematic for both public health administrators and political figures. Specifically proponents of palliative care must walk a fine line between disseminating information while at the same time mitigating the misconception that they are promoting palliative care for personal gain (in this case personal gain would refer to the collective personal gain of the nation). In other words, their promotion of what is a valuable service cannot appear to be viewed by the public as a way to cull the herd or eliminate the weakest members in order to decrease the cost of sustaining their lives (to be discussed in greater detail in the section on political implications).

But the body politic that is not listening, per Dr. Byock, is only one part of the problem we have in with the promotion and wide-spread use of palliative care and hospice in the United States. A major hurdle that we have yet to overcome is the public’s misperception of what palliative care and hospice actually means. Some of the more common

beliefs regarding palliative care and hospice are that a patient entering hospice is giving up, or that it is something a person enters into when they believe that there are no other medical options for them (i.e. all medical interventions would be futile). There is also the belief that not everyone is eligible for hospice care, that it is limited to patients with specific diseases (i.e. cancer or AIDS) or specific populations (i.e. the elderly), or that death has to be imminent to be accepted into hospice care. Another misperception is that persons entering hospice will be forced to leave their homes and enter a facility where they will go to die ("National Hospice and Palliative Care Organization - Common Misconceptions Regarding Hospice", n.d.).

It is easy to understand how these have become such common misconceptions, and that is because the lack of prioritization of palliative care and hospice options on the national agenda for whatever reason. Whether it be the difficulty in broaching the subject and starting a national conversation, or even just a relative unwillingness to cede that even in the face of incredible medical technologies, palliative care is a necessary service with incalculable benefits, the onus is on those that work in the field of public health to make it a priority, and part of that process is to educate the public, and set the record straight and dispel any misconceptions it might have.

Dispelling those misconceptions is perhaps one of the biggest challenges public health officials face in educating the public about palliative care and encouraging them to take advantage of those services. There are a great number of people who mistakenly believe that being offered these services and the encouragement to use them is really a ploy; a code, of sorts, for a you are sick and as a result are costing us money, and so it is your duty to die. This belief can make such an attempt at education contentious and unproductive, ending the conversation just as soon as it has begun. Therefore the concept of informed consent must come up early, and be emphasized throughout.

Informed consent is "an autonomous action by a subject or a patient that authorizes a professional either to involve the subject in research or to initiate a medical plan for the patient (or both)" such that the patient has a "substantial understanding" of their situation "in substantial absence of control by others" and who, given that information, "intentionally authorizes an professional" to either initiate an intervention, or to refuse such intervention/treatment (Faden & Beauchamp, 2003, pp. 145-148). The substantial understanding on the part of the patient means that he or she is fully aware of their situation, as well as what the consequences of their decision (in this case, to either proceed with or abstain altogether from treatment). In a situation where the patient or their family must make a decision regarding treatment relatively quickly, part of being "fully aware" requires full disclosure of all of the information known to the physician so that the patient is able to take that into consideration. This disclosure may be best described in the record of the 1957 court case of *Salgo v. Leland Stanford Jr. University Board of Trustees*, which stated:

A physician is required to provide his patient with all the information necessary to make an informed decision: A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment. Likewise the physician may not minimize the known dangers of a procedure or operation in order to induce his patient's consent... The basic requirements for informed consent include disclosure of the patient's disease process, the risks and benefits of the proposed treatment, and any viable alternative therapies, including doing nothing (Halevy, 2008).

It is impossible to overestimate the benefit of using this concept of informed consent as a tool to educate the public, assuage their fears, and underscore the valid and useful place palliative care and hospice services have in our society.

The discussion of informed consent in this context also provides an opportunity to assure those who remain wary and skeptical about palliative care services, that they are rooted in the basic ethical principles of benevolence, non-maleficence, justice, and autonomy. That their physician or medical team practice medicine in the Hippocratic tradition, where their foremost concern is doing right by the patient, not doing harm, distributive equity in terms of providing the same standard of care for all patients, and their understanding that ultimately, a patient is primary decider of how to proceed with their treatment, even if that means that they elect to forgo treatment (providing they are competent to make that decision). The important thing to convey is that autonomy will not be taken away. However, until public perception changes such that there is an understanding that their medical fate is in their own hands, and will not be decided by a panel of government-appointed strangers determining medical futility, we will continue to have trouble initiating a productive national discussion on palliative care, and which will subsequently continue to prevent us from taking full advantage its benefits.

Historical Perspective

Decisions regarding futility occur most often when there is a question as to whether to maintain life support for patients are in a persistent vegetative state (PVS), or to resuscitate a terminally ill patient, or whether to aggressively treat, through the use of chemotherapy or radiation, advanced stage cancers in late-stage patients (CEJA, 1999).

Historically there have been a number of landmark cases dealing with the issue of medical futility and refusal of treatment, with such claims levied either on the part of the medical staff (i.e. *The Baby K Case*, *the conservatorship of Helga M. Wanglie*, and *Gilgunn v Massachusetts General Hospital*), or on the part of the patient's family (i.e. *Cruzan v Director, Missouri Department of Public Health*, and *Quinlan v. NJ*), and there are obstacles specific to each instance which need to be overcome before any decisions are made or actions taken.

Physicians citing medical futility must make a careful case to avoid accusation of trampling over a patient's right to autonomy. Oftentimes the arguments made on behalf of physicians seeking to withdraw or withhold life-sustaining care "emphasize the limits of physician obligations" (Schneiderman, 1994). They may believe that administering such treatments are in direct conflict with their oath of benevolence and nonmaleficence: "A professional has the obligation to allow a person to choose from among medically acceptable treatment options... or to reject all options. No one, however, has an obligation to provide interventions that would, in his or her judgment, be countertherapeutic) Paris, Cassem, Dec, & Reardon, 1999).

Families of patients citing medical futility must show that they are acting according to their loved ones' wishes, and not because they have grown weary of caregiving. Ideally, an advance directive will have been in place prior to the catastrophic event that has placed their family member in this situation, and that this paperwork will be able to be produced at such time to minimize confusion and mitigate conflict among family member. If there is no advance directive in place or physically available, the medical staff must rely on the testimony of family members with regard to how the patient would proceed if they were able to make the decision for themselves at that time. The patients' wishes, whether written or verbal, are binding, and should be communicated to the medical staff with the expectation that they will honor those wishes. Discrepancies or conflicts of opinions between family members as to how the patient would proceed should be shared with the medical staff, hospital ethics committee, or, if necessary, the court system, and taken into consideration along with the patient's current medical condition, and impact and efficacy of treatment on prognosis and probable outcome. However, even with that information, when a case involving a family who wants to continue treatment and physicians who do not reaches the court level, the outcome almost always favors the family: "the history of legal cases involving futility has been that the courts have almost uniformly ordered continued treatment when asked to resolve disputes between families who favor treatment and physicians who oppose it" (Luce, & Alpers, 2000). This, it would seem, is the desire on the part of the court system to avoid causing a death, especially in those circumstances where there is some question as to what the patient would choose, but no question that withdrawing life-sustaining treatment will result in that patient's death.

Legislative and Political Impact



In his article *Medical Futility*, Robert Truog references his favorite definition the term- a cartoon written and illustrated by Gahan Wilson and published in the New Yorker Magazine. His description of the cartoon is as follows: A browbeaten physician kneeling before a tombstone in a cemetery, anxiously fiddling with his stethoscope over the grave. Standing behind and over him with an intimidating expression is someone we take to be the wife of the deceased, seemingly demanding that the physician perform a miracle. All the physician can do is look back over his shoulder and apologetically explain "I'm afraid there is really very little I can do..." (Gahan, 1999, as referenced in Truog, 2008). This cartoon illustrates the predicament many physicians find themselves in when faced with these situations, but it also gets at the crux of the position we find ourselves in our attempt to define and legislate it. It begs the question, which side should take precedence, how that should be decided, and can there be standardized policy that may be applied across the board. That is, is it possible to come up with an objective definition that lends itself to the creation of such policy? It seems, at least up until now, that the answer is not really. There have been no legal precedents which unequivocally support a unilateral standard or algorithm that may be used to determine when a treatment may be considered futile; however efforts to define and implement policy continue to be made.

The Council on Ethical and Judicial Affairs outlines several approaches that have been explored to solidify and move forward with these efforts. These include definitions based on quantitative and/or qualitative approaches, physiological outcomes, community and/or institutional standards, or a due-process approach (CEJA, 1999). With regard to quantitative approaches, Schneiderman, and Jecker proposed which "asserts that if the intervention does not work in more than one percent of attempts, it should be considered futile" (CEJA, 1999). Qualitative approaches, usually used in conjunction with quantitative approaches, attempt to determine an "acceptable" outcome would be and then, select which person/persons have the right to decide what acceptable means (e.g., the patient and/or their proxy, the physicians, or both). Definitions of futility based on physiological outcomes may be the most problematic, because it can never be a holistic approach. For example, if one's respiratory system fails and they are placed on a ventilator, then the intervention itself may be successful- that is, they continue to breathe, but that breath, while an integral part of the life process, does not return them to any semblance of normalcy: "Individuals do not judge the worth of an intervention by the physiological outcomes alone; for instance, successful preservation of renal function should rank differently in the absence of presence of possible quality personal interaction" (CEJA, 1999). Community and/or institutional approaches involve allowing those entities to decide for themselves which interventions would be appropriate to administer. This approach presents a number of challenges, the first that it would be extremely labor/time intensive to design and maintain. Members of each community/institution would have to consider an inordinate number of potential medical circumstances and pre-determine what interventions should be administered for each. They would also have to consider exceptions to any of the standards they impart, and finally there would have to be a sustainable way to monitor the changes in medical technology that impact policy, and update policy accordingly. Finally, the due process approach would emphasize "process between parties rather than on definition of the parties" with the benefit being that "professional standards, patient rights, intent standards, and family or community involvement can all be accommodated" (CEJA, 1999).

CEJA concluded their report by stating that it found "great difficulty in assigning an absolute definition" because it is "inherently a value-laden" determination (CEJA, 1999). Therefore their final recommendations were that all health care institutions adopt medical futility policy; that the aforementioned policy should follow a due-process approach such that it would accommodate all parties with a stake in the outcome; that "earnest attempts" should be made (between patients/proxies and physicians) to clarify expectations regarding interventions in advance; that conflicts should be negotiated if possible, and if a resolution cannot be reached independently, that an ethics committee should be consulted; if a resolution still cannot be reached, measures should be taken to transfer the patient to a different facility; and finally, if the patient is not able to be transferred, that the intervention "need not be offered" (CEJA, 1999).

III. Recommendations

With regard to policy and legislation, in the absence of an absolute definition of medical futility, the due process approach as outlined by CEJA is the closest we may be able to get to a policy which respects the four main ethical tenants for all involved parties. The creation of a medical futility policy on the part of a health care institution, however, is only as good as it is enforceable; and implementation will be a two-step process which must occur simultaneously. The first part will require a large-scale effort on the part of the institution to make sure that the policy is well publicized, understood, and believed in by its stakeholders (i.e. the people utilizing that institution's services, and its staff). Additionally, there must be a recognition on the part of the institution that adopting a medical futility policy may leave the institution vulnerable to litigation. Therefore, maximum efficacy and ultimate success is dependent upon how well the

institution is able to integrate the policy, and a big part of the integration process is how the policy is perceived. This is where prioritizing the discussion of advance care planning, palliative and hospice care services on a national level becomes critical; and it must be done carefully as to avoid the type of panic that set in during the 2008 presidential election campaign where the discussion of advance care planning devolved into talk of death panels and weeding out the weakest members of society for the sake of financial solvency during difficult economic times: “commentators have noted repeatedly that there is a danger that judgments about futility mas a covert motive to allocate resources” (CEJA, 1999). As we witnessed, it was not hard for some to make the leap from one to the other; that encouraging us to talk to our physicians about advance care planning was part of a larger plan devised by the government to put us down when the cost-benefit of keeping us alive was deemed not to be worth it. In their article *Futility and Rationing*, Jecker and Schneiderman pose the questions

It seems more than coincidental that at a time of great concern over rising health care costs and fears of rampant technology, debates are suddenly taking place about medical futility and health care rationing... Are futility and rationing two different words to describe the same impulse, the desire to cut costs? Is the idea of futility nothing more than a subterfuge for rationing? Is rationing inappropriately invoked when making judgments about medical futility? Are they both ominous signs that society is seeking covert ways to dispose of unwanted persons? (Jecker, & Schneiderman, 1992) They conclude that as a society, by not coming to a consensus on either medical futility or rationing, we actually have made a choice about them; and that these are, in fact, covert tactics in which we have already engaged.

Whether one chooses to accept their premise or not becomes secondary to the justification they give for their conclusion. Specifically, our silence as a nation on these subjects speaks volumes. Not acknowledging that we already ration health care does not make it an untruth; and our inability to define futility absolutely may enable it to be used as an accessory to employ rationing. What they make clear is that we cannot continue to falter on this slippery slope. An open and honest discussion about advance care planning, palliative care, hospice services, medical futility, and rationing needs to be initiated, first by public health officials who are not politically polarizing, and then once the message is out, supported (or not) by elected political officials. Intention and action under these (and most other) circumstances is trumped by perception, and if the perception is that we are employing covert tactics to dispose of vulnerable populations, no amount of logic or reasoning will overcome it.

IV. Future Implications

As the discussion of medical futility continues to unfold in the wake of the implementation of laws such as the Affordable Care Act which promote transition to a universal health care paradigm, our approach will determine the direction of health care in the United States. If we let public health officials initiate and drive a discussion of futility as it applies to the big picture (i.e. health care in general); and that discussion is transparent with regard to motives and intent, and aimed at confronting the issues that make us the most uncomfortable (i.e. death, end-of-life decision processes, and rationing), the potential for our current system to evolve into something better is high. If, however, we continue to politicize these issues and use them to prey on people’s fears as an election strategy, we will be doing ourselves tremendous disservice because it moves us further away from attaining a “more consistent and ethical system of health care” (Jecker, & Schneiderman, 1992) which would be a difficult thing to argue for.

V. Conclusion

What makes the concept of medical futility so complex is that there are too many moving parts to define it objectively. There are ethical issues to confront- specifically with regard to respect for patient autonomy, which needs to be reconciled with a physician’s duty of benevolence and nonmaleficence, and professional standards and integrity. There are also legal implications. Hospitals and other health care institutions are encouraged to adopt a medical futility policy, but also in doing so accept that the application of such a policy may open them up to the threat of litigation should family members disagree with physicians’ and/or ethics committees’ decisions. There are political ramifications to medical futility decisions as well. Candidates running for government office on a platform which promotes and encourages the use of advance directives and other issues aimed at end-of-life decisions may be subject to having that position used against them by their opponents. Finally, there is the financial aspect to consider- especially in a country like the United States whose economic policy is based on capitalism, which makes the question about who will incur the cost of administering life-sustaining treatment long-term a major point of contention. Currently there is no definitive answer, and so futility remains a “poorly-defined concept that does not adequately illuminate legal and ethical decision-making at the end of life. Even among experts in this area, there is no consensus on the definition, meaning, scope, and implications of

this term” (Cranford, & Gostin, 1992). Under these circumstances, the best approach seems to be the one recommended by the Council on Ethical and Judicial Affairs - a fair or due process approach which makes decisions on a case by case basis which takes into account the information provided by all parties invested in the outcome of that case.

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