THE COMPLEX PROBLEM OF MEDICALLY INEFFECTIVE TREATMENT AT THE END OF LIFE: EMPOWERING PHYSICIANS AND CHANGING NORMS

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Abstract

Patients at the end of life are often subject to medically ineffective treatments. Despite years of research on medically ineffective treatment, the practice continues in the United States and other healthcare systems throughout the world. In addition to its harmful effects on patients, family members and healthcare practitioners, the provision of medically ineffective treatment contributes to rising healthcare expenditures. Medically ineffective treatment is a complex issue and its causes are multifactorial. Differing opinions and norms at the physician level, lay community level and societal level as well as a longstanding history of mistrust in the medical system complicate this problem. A restructuring of medical education to emphasize an interactive, well designed approach to medical ethics, communication skills and end of life care at all levels of training and career may help to decrease this harmful practice while still respecting the attitudes and beliefs of patients and their family members when faced with medically ineffective treatment options at the end of life.

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Section 1

Introduction

Mr. H is an 84-year-old hospitalized man with a history of widely metastatic head and neck cancer status post unsuccessful surgical resections and multiple rounds of radiation and chemotherapy. His course has been complicated by recurrent episodes of aspiration pneumonia leading to chronic respiratory failure. He has been ventilator dependent for four months and has suffered two cardiac arrests resulting in a severe anoxic brain injury rendering him incapable of interacting with his environment. He remains in a chronic vegetative state with a multidrug resistant pneumonia, stage IV sacral decubitus ulcer and a newly diagnosed subdural empyema. Due to his high risk of intraoperative mortality and extremely poor prognosis, neurosurgery has determined he is not a candidate for surgical drainage. Additionally, infectious disease has documented that any further antibiotic therapy should be considered “futile” and nephrology has noted that despite worsening renal function, he is not a candidate for dialysis.

The patient’s only family is a physician daughter who lives in California. His daughter has consistently stated that she wants “all aggressive measures” taken despite her awareness of her father’s hastening progression to multi-organ system failure. She has said to providers, “I understand where you’re coming from and if I were in your shoes I would be having the same conversation, but my father wanted everything done and I must respect his wishes.” The patient’s code status is full code and his daughter insists that additional rounds of antibiotics be trialed as well as any intervention that may extend his life, including CPR in the event of another cardiac arrest. The primary medical team, which has changed often over the course of his stay, has continued to respect Mr. H’s wishes despite feelings of moral distress. As Mr. H’s condition continues to deteriorate, an increasing number of physicians from multiple specialties express concerns that any escalation of care should be considered medically ineffective. Despite these professional opinions, no physicians feel comfortable withholding further treatment given his daughter’s previously stated expectations. The ethics committee is convened to further evaluate the situation.

Mr. H’s case represents a scenario remarkably familiar to most physicians practicing in the United States healthcare system. He is a terminally ill patient with untreatable metastatic disease, an exhaustive list of related multi-organ complications, and multiple courses of aggressive oncologic, surgical and antimicrobial treatments have not been successful. As a result of his anoxic brain injury, he remains in a chronic vegetative state in which he is unable to respond to his external environment. The chronic vegetative state alone carries a poor neurologic prognosis with studies suggesting only 17% of patients in a vegetative state of non-traumatic etiology regain some level of consciousness at six months and only up to 7.5% thereafter (Lee et al., 2020).

Mr. H’s physiologic function is dependent on artificial life sustaining treatment in the form of mechanical ventilation, artificial nutrition and artificial hydration. He is entirely dependent on others for
around-the-clock care. Without source control for his infection, antibiotics will prove ineffective. As his renal function declines, his body will be incapable of maintaining a volume status, acid base status and electrolyte balance compatible with life and offering hemodialysis to this patient could worsen his already fragile hemodynamic state. While vasopressor therapy may achieve temporary hemodynamic stability and CPR may delay the time of death for as long as it is performed, the reality is, Mr. H is imminently dying. Regardless of how aggressively the medical team intervenes, Mr. H has approached the end of life. His course is irreversible and effectively illustrates the limits of modern medicine. The continued escalation of interventions in this case is an example of medically ineffective treatment.

In this paper, the multifactorial contributors to medically ineffective treatment at the end of life are explored as well as the harms that result at the physician, patient and societal level. Decades of literature on the harms of medically ineffective treatment as well as continuously emerging professional guidelines, policies and laws throughout the world have been aimed at preventing physicians from offering medically ineffective treatment, but the practice continues. Providing medically ineffective treatment at the end of life remains a silent norm in medicine and active intervention is necessary to empower physicians to avoid deliberately offering costly, non-beneficial and often harmful treatments that will not reverse the dying process. To change norms in medicine requires an overarching change in physician behavior. Here I suggest that behavioral change may best be instigated by a reform of medical education at all levels of one’s medical career to underscore the importance of dedicated, high quality, interactive training in medical ethics, communication skills and end of life care.
Section 2

The Scope and History of Medically Ineffective Treatment

The scope of medically ineffective treatment is vast. Critical care physicians worldwide frequently admit patients to the ICU who have “unrealistic perspectives” about the effects of critical care interventions with one study finding that 73% of European ICU physicians and 87% of Canadian ICU physicians admitted to this practice (Kompanje et al., 2013). Estimating the extent of medically ineffective treatments in the United States specifically, a 2014 study looking at over 1,100 patients in five US academic critical care units over a three-month period illustrated that approximately 11% of critically ill patients had received “futile treatment” and an additional 8.6% had received “probably futile treatment” (Huynh et al., 2014). With over five million patients admitted to US intensive care units annually even prior to the onset of the COVID-19 pandemic (Society of Critical Care Medicine), this estimation of up to 20% of critical care patients receiving probable or definite medically ineffective treatment represents an alarming figure.

Cases of medically ineffective treatment generally stem from sophisticated advancements in medicine and biotechnology which have afforded us the capability of maintaining life in a manner that would have been inconceivable less than a century ago (Šarić et al., 2017). With this new technology comes situations in which the advanced treatments only serve to support physiologic function without offering substantial improvements in a patient’s medical condition, overall prognosis or quality of life (Šarić et al., 2017). In some instances, physicians offer medically ineffective treatment due to established uncertainty surrounding a patient’s disease course or a particular response to treatment. In these cases, the treatments are proven to be medically ineffective post mortem, but the situation in which they were offered made such treatments clinically appropriate and of potential benefit. These cases are of less interest to the ethical analysis of medically ineffective treatment and the focus here will be on cases of medically ineffective treatment in which the physician knowingly offers an intervention that will be of no physiologic benefit to the patient.
The deliberate delivery of medically ineffective treatment generally falls into two categories. In the first category, physicians initially offer medically ineffective treatments to patients or their surrogates as a result of clinical practice norms or “personal reasons” (Jox et al, 2012). In the second category, physicians do not initially offer the treatment, but concede to demands for medically ineffective treatments driven by patients or surrogates in an effort to preserve patient autonomy or mitigate uncomfortable conflicts.

Medically ineffective treatment, otherwise referred to as medical futility, has been a topic of longstanding debate in the medical and bioethical communities (Burns & Truog, 2007; Cifrese & Rincon, 2018; Löfmark & Nilstun, 2002; Misak et al., 2014; Neville et al., 2020). The increased recognition of medical futility and simultaneous expansion in published literature on the subject date back to the late twentieth century, but debates over its definition as well as the proper handling of cases of medical futility have never been fully resolved (Burns & Truog, 2007; Löfmark & Nilstun, 2002; Misak et al., 2014).

The emergence of the field of bioethics in conjunction with the evolving role of the physician in medical decision-making sheds light on how the debate over medical futility arose. Up until the mid-twentieth century, physicians assumed a “paternalistic” role in the care of patients and were expected to make medical decisions on their behalf (Carrese & Sugarman, 2006; Cifrese & Rincon, 2018; Roeland et al., 2014). Following the Nuremberg trials and echoing the sentiments of the Civil Rights and Women’s Rights movements as well as the publication of the Belmont Report, which mandated informed consent for research subjects, came a new emphasis on patient autonomy in medical decision making (Carrese & Sugarman, 2006; Cifrese & Rincon, 2018; Roeland et al., 2014). Although the movement towards patient centered decision making likely improved the quality of healthcare for many patients, empowering them to take control of their own health and express individual values relevant to their care, some experts contend that the “pendulum” has shifted too far toward treatment that is entirely driven by the wishes of the patient and surrogate(s) (Roeland et al., 2014). This becomes especially important as it relates to demands for medically ineffective treatments at the end of life.
In response to this increased awareness of medically ineffective treatment, in 2015, a multiorganizational policy statement reflecting the views of the American Thoracic Society (ATS), American Academy of Critical Care Nurses (AACN), American College of Clinical Pharmacy (ACCP), European Society for Intensive Care Medicine (ESICM) and the Society for Critical Care Medicine (SCCM) was released in an effort to help clinicians effectively manage demands for futile and “potentially inappropriate treatments” in the ICU setting (Bosslet et al., 2015; Kon et al., 2016). This policy statement defined futile treatment as an inability to “accomplish the intended physiologic goal” and advised that these treatments NEVER be offered (Bosslet et al., 2015, Kon et al., 2016). For the purposes of this paper, wherever possible, medically ineffective treatment has been chosen as the preferred synonym of the more controversial term “futile treatment” as defined by the 2015 multi organizational position statement.

In addition to recommendations against the provision of medically ineffective treatment, the 2015 multi organizational policy statement also created a stepwise approach to navigating requests for “potentially inappropriate” treatments in which there may be some consideration of a small benefit towards accomplishing a patient’s goal, but medical professionals believe additional ethical concerns offset that benefit (Bosslet et al., 2015). Policy statements like this are important in that they can provide leverage to physicians who are attempting to act in the best interest of patients. Additionally, they contribute to evolving norms and standards across hospital systems. Alone, however, they are not enough to solve the problem of the widespread use of medically ineffective treatments.

**Section 3**

**Exploring the Factors Driving Medically Ineffective Treatment**

**3.1 The Lay Community’s Perspective**

It is widely known that many well-intentioned physicians advise against medically ineffective treatments at the end of life. Despite this, patients and family members often continue to request these
treatments against the advice of physicians. While some of this may be due to denial and the resulting inability to fully appreciate the complexity of one’s medical condition (Winkler et al., 2012), new data suggests that there are a number of other reasons why patients and family members fail to understand the issue of medically ineffective treatment. To better understand this, a 2020 qualitative study by Neville et al. examined the perceptions of the lay community with respect to medically ineffective treatment. The study found that there was a general lack of awareness of the terms “futile” and “inappropriate” treatment and participants found the issue challenging to conceptualize (Neville et al., 2020).

The Neville et al. study further explored the reasons the lay community finds medically ineffective treatment so hard to comprehend. Of these reasons, issues with physician-patient communication were paramount (Neville et al., 2020). Participants drew attention to the physician community’s frequent use of terminology above the layperson’s level of understanding (Neville et al., 2020). Additionally, some raised that the speed at which conversations regarding medically ineffective treatment take place is often beyond the pace of a patient or family’s comprehension (Neville et al., 2020). Other members of the lay community suggested that medically ineffective treatment is a matter of “perspective” and that for someone “fighting” a disease, family members may discount the concept entirely (Neville et al., 2020).

Other reasons families found medically ineffective treatment hard to grasp include the societal lack of discussion regarding death and dying including the deficiency in advanced care planning (Neville et al., 2020). In 2011, Wendler and Rid published a large systematic review examining the effects of decision making on surrogates when patients become incapacitated. The review found that the decision-making process leads to “harmful emotional stress and burden in at least one third of surrogates” (Wendler and Rid, 2011). Additionally, the study found an overall lack of advance care planning and knowledge of patients’ goals of care which was associated with “increased burden on surrogates” (Wendler and Rid, 2011).

Mistrust in the medical community is another possible contributor to patient and or family demands for medically ineffective treatments at the end of life (Neville et al., 2020). Community
members have raised concerns that physicians might be unduly influenced by financial incentives, insurance company mandates and issues of justice (Neville et al., 2020). Complicating this mistrust is America’s complicated racial history and the documented mistreatment of marginalized groups and racial minorities in medical research and healthcare (Sullivan, 2020). Although much of the mistrust in the medical system can have roots in systemic racism, it is not limited to non-white populations: “many patients, no matter their ethnicity or race, will find themselves in situations in which mistrust frustrates their ability to receive adequate care (Sullivan, 2020)”. Acknowledging this mistrust is an important consideration in cases of medically ineffective treatment.

Understanding the community perspective makes it more understandable why patients and families continue to press for aggressive medically ineffective treatments at the end of life. Physicians’ own emotional fears of patient and family reactions as well as difficulty communicating with patients and or decision makers further contribute to the use of medically ineffective treatments (Jox et al., 2012).

### 3.2 Physician Fear of Litigation

Physician fear of litigation remains a major motivation for rendering medically ineffective treatment (Jox et al., 2012). Although it is infrequent for cases of this nature to be argued in the courtroom, it is not surprising that conflicts over medically ineffective treatments become widespread public knowledge via the press, creating damaging publicity for hospitals and physicians regardless of their intentions (Pope, 2011). This fear of litigation and fear of damaging publicity can coerce physicians and healthcare systems into offering medically ineffective treatment at the demands of patients and decision makers (Pope, 2011).

While some cases of medically ineffective treatment do make it to court, and courts in some cases do side with families, it is important to note that several studies have indicated that overall courts typically side with physicians in cases where families retaliate against the cessation or refusal of medically ineffective treatment (Pope, 2011). Landmark court cases may provide physicians with some sense of security when it is determined appropriate that medically ineffective treatment be withheld. The
court cases of Tara Bottom Hawkins, Mel Marin and Wheeler vs Doers are all examples of rulings in favor of physicians (Pope, 2011). Understanding historical legal rulings may provide some sense of ease for physicians struggling with fear of litigation.

3.3 Physician Discomfort with Death and Dying

Physician “inexperience with death and dying” (Willmott et al., 2016) and “fear of death” (Jox et al., 2012) have been implicated as major contributors to medically ineffective treatment. Studies have shown that formal training in end of life care is minimal in both undergraduate and graduate medical education (Schmit et al., 2016). A study by Schmit et al surveyed medical residents from multiple specialties to gain insight into their training in end of life care (Schmit et al., 2016). 54% of residents reported they received little to no end of life education in medical school and 88% reported minimal to no formal education in residency (Schmit et al., 2016). Despite this educational gap, over 50% of residents reported engaging in end of life discussions and approximately 62% revealed that the majority of these interactions were unsupervised (Schmit et al., 2016).

In a qualitative study by Willmott et al., physicians admitted to offering medically ineffective treatment as a result of training in an environment that is highly focused on treatment with ineffective treatments being offered simply because it was something to provide (Willmott et al., 2016). One respondent candidly described providing such treatment as “easier” in contrast to facilitating “high level discussions where you talk about end of life and not treating” (Willmott et al., 2016). An additional comment by an oncologist raised issues of time constraints being an additional barrier to ceasing to provide ineffective treatments, inferring that addressing end of life issues is more challenging and time consuming than maintaining the status quo (Willmott et al., 2016).

3.4 Systemic Barriers to Avoiding Medically Ineffective Treatment

As suggested, physicians also face systemic barriers to addressing the appropriateness of certain treatments with patients and decision makers at the end of life. In addition to discomfort with end of life care, physicians are often overwhelmed by high patient volumes and stressful time constraints. A 2013
survey of over 500 hospitalists revealed that 40% reported assuming care of an unsafe number of patients at least monthly with 36% of these physicians reporting this occurrence at least weekly (Michtalik et al., 2013). As a result of excessive workload, physicians also reported feeling hindered in their ability to appropriately contemplate treatment options with patients (Michtalik et al., 2013). Furthermore, 22% admitted to ordering unneeded diagnostic tests and or procedures as a result of their excessive workload (Michtalik et al., 2013). Understanding the time consuming and intellectually challenging nature of discussing end of life issues with patients, excessive physician workload is no doubt a barrier to thoughtful and comprehensive end of life recommendations.

In addition to a system that relies on maximizing physician productivity, additional systemic factors may also contribute to the continued provision of medically ineffective treatment. Hospital mortality rates are used as a quality metric by a number of government agencies and other organizations such as the Centers for Medicare and Medicaid Services (CMS), US News and World Report, Thompson Reuters and Healthgrades (Cassel et al., 2010). Although some of these agencies and organizations, including CMS, now adjust mortality rates for patients enrolled in hospice or who are discharged to an inpatient hospice unit or hospice bed preceding the time of death, the problem with using mortality as a method of assessing “good” medical care is that it wrongfully suggests that “hospital deaths represent medical failure” (Cassel et al., 2010). The use of hospital mortality rates as a quality measure may be reflective of our larger society’s aversion to and discomfort with death and dying.

Section 4

The Case Against Medically Ineffective Treatment

4.1 The Cost of Medically Ineffective Treatment

According to data from the Society of Critical Care Medicine, the 2010 cost of critical care medicine in the United states was approximately $108 billion—nearly doubling from 2000 (Society of Critical Care Medicine). This number represents “4.1% of national healthcare spending and 0.72% of
gross domestic product” (Society of Critical Care Medicine). For patients receiving medically ineffective treatment in the intensive care unit, the daily average cost was estimated to be $4,004 in 2013 (Huynh, et al., 2013; Huynh et al., 2014). It has been implicated that medically ineffective treatment is a contributor to “waste” of healthcare resources with one study finding that 15% of days spent in a medical intensive care unit and 26% of days spent in a transplant surgical intensive care unit over three months were determined to be “waste” (Almoosa et al., 2016). Delays in end of life decision making were often attributed to this costly continued treatment (Almoosa et al., 2016).

In addition to tremendous financial costs, one must also consider the additional justice issue of “opportunity cost” where patients receive medically ineffective treatment at the expense of other patients with potentially greater chances of survival (Huynh et al., 2014). Even prior to COVID-19, it had been identified that medically ineffective treatment in US critical care units was associated with delays in patients being transferred from outside hospitals as well as prolonged boarding times in the emergency department waiting for ICU beds (Huynh et al, 2014). The consideration of distributive justice in cases of medically ineffective treatment is an uncomfortable one for many physicians as evidenced in one Australian qualitative study published in 2019 (Close et al., 2019). While a number of physicians admitted openly to considerations of resource allocation in cases of medically ineffective treatment, others felt issues of cost and resource allocation were outside of the scope of physician practice and should not play a role in their decision making (Close et al., 2019). Additionally, many physicians felt that formal guidelines should be drafted to assist physicians in navigating the unfamiliar territory of limited resource allocation and medically ineffective treatment (Close et al., 2019).

The issue of scarce resource allocation has been brought to the forefront by COVID-19. Narratives of healthcare workers throughout the world have saturated the media and legitimized fears that healthcare resources are not limitless. The tremendous use of hospital resources for COVID-19 has triggered hospital systems worldwide to establish protocols for allocation of potentially scarce resources. While COVID-19 remains a dynamic situation, it is likely that many physicians will be forced to confront issues of distributive justice at the bedside which could potentially raise awareness of the
harm of medically ineffective treatment in the form of the previously discussed opportunity cost. The effects of such increased consideration on the provision of medically ineffective treatment will be an area of further interest.

4.2 Harms to Healthcare Providers

Moral distress has been formally defined as the experience of “knowing the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (Jameton, 1984). Providing medically ineffective care at the end of life has been shown to contribute to moral distress levels among healthcare providers (Epstein & Hamric, 2009; Epstein et al, 2019). In their comprehensive measurement tool for evaluating moral distress levels in healthcare providers, Epstein et al. uncovered multiple “root causes” contributing to moral distress (Epstein et al, 2019). Among the leading causes included “following the family’s insistence to continue aggressive treatment even though it is not in the best interest of the patient” and “continuing to provide aggressive treatment for a person who is most likely to die regardless of this treatment when no one will make a decision to withdraw it” (Epstein et al, 2019). Both of these scenarios can be associated with cases of medically ineffective treatment.

Moral distress provides valuable insight into the moral values of healthcare professionals. It suggests that something about a certain scenario is ethically impermissible in the eyes of that provider. Responses to prolonged moral distress include “avoidance behaviors...moral disengagement, blunting, denial and the use of gallows humor” (Berger, 2013). Over time, repeated incidents of moral distress lead to the formation of moral residue which leads to an increased intensity of moral distress when one encounters future morally distressing situations (Epstein & Hamric, 2009). This phenomenon of increasing levels of moral distress over time has been described as “the crescendo effect” (Epstein & Hamric, 2009). The effect of high moral distress levels on the personal wellbeing of healthcare professionals is a serious one and can potentially lead to adverse outcomes in patient care. Additionally, studies have shown that higher levels of moral distress are associated with healthcare professionals
resigning or considering resigning from their employment (Epstein et al., 2019). This leads to the loss of essential healthcare workers from crucial fields such as critical care medicine.

4.3 Harms to Patients and Surrogate(s)

Although much concern is focused on the direct harms to patients as a result of invasive, medically ineffective treatment, there is an additional harm that is often overlooked. When physicians offer medically ineffective treatments such as CPR to terminally ill, imminently dying patients (or their surrogates), it forces patients and surrogates to contemplate an overly “burdensome” decision (Cahill, 2019). Sarah Cahill draws attention to a study conducted by Elliott and Oliver in 2008 which revealed the emotional challenges brought to patients and families when resuscitation discussions were held at the end of life (Cahill, 2019). The researchers found that despite an awareness of their terminal prognosis most patients and family members still had minimal appreciation that CPR would not be effective and viewed CPR as a “choice of life or death” (Cahill, 2019).

The ability to make rational decisions in emotionally charged situations or in situations where denial is a factor is difficult for patients and their family members. Winkler argues that it is the duty of physicians to “protect patients from burdensome and potentially harmful decisions that are not based on a realistic understanding of the situation - and which the patients might regret afterwards when they realize that it was based on false hopes” (Winkler et al., 2012). When physicians are mandated to discuss the intricacies of various medically ineffective resuscitation options with their terminally ill patients, this practice may ultimately foster more harm to patients and families than offering more honest anticipatory guidance on imminent death and dying (Cahill, 2019).

4.4 Addressing the Autonomy Issue and Right to Healthcare

Although offering medically ineffective treatment is often tempting in the setting of conflicts with patients and family members over appropriateness of care, physicians should not offer and should not be compelled to offer or continue life sustaining treatments in terminally ill, hospitalized patients who are imminently dying with no available treatment options to reverse disease, restore cognitive function or
improve overall quality of life. While current clinical norms emphasize patient, family and surrogate centered care, limitations on the principle of autonomy must be realized. Sometimes the demands of family members and the prior wishes of patients become extraordinary. The qualitative study conducted by Neville et al. is illustrative of society’s view that the principle of patient autonomy outweighs other ethical principles considered by physicians (Neville et al., 2020). Even in the most extreme cases of medically ineffective treatment, when respondents agreed the treatment should not be offered, the majority of respondents said families and not medical practitioners should always make the final decision (Neville et al., 2020). Despite these current community opinions on who gets to decide which treatments will be offered to patients at the end of life, physicians must uphold their professional duties to patients and society by refusing to initiate medically ineffective treatment.

According to Beauchamp and Childress, “a physician is not morally required to provide a genuinely futile or contraindicated treatment... The physician may not even be required to discuss the treatment” (Beauchamp and Childress, 2013). Respect for autonomy involves an appreciation for a patient or surrogate’s “right to hold views, to make choices, and to take actions based on their values and beliefs” (Beauchamp and Childress, 2013). In respecting patient autonomy, it is important that patients and surrogates be allowed to refuse certain treatments and decide which of the offered treatment options best fit their personal situation, but this does not mean that patients and surrogates can insist upon treatments that are not offered i.e. medically ineffective treatments. If physicians are not compelled to offer medically ineffective treatment, this removes the “choice” from patients and or surrogates. If a treatment option is not being offered on the grounds that it is medically ineffective, there is no choice for the patient or surrogate to make. The physician can still maintain a respect for autonomy by expressing understanding of the patient or surrogate’s perspective, while respectfully declining to offer an intervention that is not a reasonable treatment option.

As Roeland et al. suggest, quests for patient autonomy have become so audacious that physicians frequently give up their own clinical recommendations and allow their “nonexpert patients and surrogates” to make their own clinical decisions (Roeland et al., 2014). Not only does this undermine the
clinical expertise of physicians, but this continued practice could have serious implications as novel technologies continue to emerge. Presently, the decision to offer extracorporeal life support, a costly, resource intensive, life sustaining treatment is only made by physicians and physicians generally agree that this is one therapy choice that should not be made by non-clinicians (Misak et al., 2014). As the lay community becomes increasingly aware of these new technologies, it is possible that eventually patient and surrogate demands for these specialized treatments will also increase (Misak et al., 2014). This could potentially create additional cases of medically ineffective treatments at the end of life.

The concept of rights to various forms of healthcare can sometimes complicate the issue of medically ineffective treatment. Patients, however, do not have a right to unlimited healthcare. To state an example in biomedical research, patients do not have a right to be enrolled in a clinical trial for which they do not qualify. Such trials have strict protocols, and patients who do not qualify for such trials cannot simply be placed in the trial because they or their surrogates want them to be. Similarly, patients who do not qualify for medically ineffective treatment do not have a right to that treatment. Medical providers should not provide treatments which patients do not qualify for by patient or surrogate demands.

Bioethicist Robert Truog claims that there can be some cases where medically ineffective treatment can be beneficial. Truog argues that “the actions surrounding the moment of death are highly symbolic and often of great significance to the surviving family. By sometimes agreeing to provide futile CPR, we send a message to our communities not that clinicians can be bullied into performing procedures that good medical judgement would oppose, but that our hospitals are invested in treating patients and families with respect and concern for their individual needs” (Truog, 2010). Although Truog rightfully addresses the duty of healthcare professionals to treat patients and families with respect, the desire to avoid conflict and assuage the despair of patients and families is not reason enough to provide costly, ineffective and often harmful treatments at the end of life. Furthermore, setting a precedent that this practice will “sometimes” be offered, raises questions of why some patients and their families should receive non-beneficial treatment while others should not. Engaging in this practice of “sometimes”
providing medically ineffective treatment raises issues of justice when future families request the same
treatment in similar scenarios.

Mistrust in the medical community is a contributor to patient and or family demands for
medically ineffective treatments at the end of life (Neville et al., 2020). Concerns over how implicit
physician biases regarding “age, race and disability” might unevenly affect historically marginalized
groups in cases of conflict over medically ineffective treatment prompted an interesting study at
Massachusetts General Hospital (Courtwright et al., 2014). The study specifically looked at the hospital’s
policy on physician initiated do not resuscitate orders, in which physicians can refuse or not offer
resuscitation in cases where such intervention is deemed medically ineffective (Courtwright et al.,
2014). These physicians are then encouraged to consult the hospital’s ethics committee in cases of
unresolved conflicts with family members and the ethics committee decides whether the do not resuscitate
order should be upheld (Courtwright et al., 2014). Looking at data from the ethics committee
determinations, the study found although a greater proportion of cases than usual were on “older, non-
white patients,” “age, race and functional ability” at the time of admission were not associated with any
specific final decisions regarding resuscitation status (Courtwright et al., 2014). Although these fears are
justified given events in US history, this study provides some evidence against any association with
physician or institution driven do not resuscitate orders. Further empirical research is warranted.

Section 5

Changing Physician Behavior

As discussed, medically ineffective treatment is a complex problem with causes stemming from
issues within the broader healthcare system, strong societal views regarding patient rights and autonomy,
a lack of emphasis on communication training and end of life care in medical education and fear of
litigation and poor publicity. Physicians can advocate for change within the larger healthcare system and
position statements and policies can continue to evolve to provide guidance and support to physicians
contemplating cases of medically ineffective treatment. However, without first changing physician
behavior at the bedside, it will be difficult to instigate more widespread change within the larger medical community and the patient communities we serve. If the physician community continues to practice under current norms, medically ineffective treatment will remain entrenched in daily medical care sewing its harmful effects on clinicians, patients, family members and an already overwhelmed healthcare system.

 Changing physician behavior is hard and has proven very difficult in other areas of medicine (Wilensky, 2016). Challenging physician decision making by bypassing it via “hard stops”, prior authorizations and punitive reimbursement strategies can have negative consequences on physicians (Helfrich et al., 2018) and should be avoided. Other exceedingly harsh strategies to change physician behavior have been proposed in some areas of France and Spain where physicians are threatened with fines for providing medically ineffective care (Pope, 2011). Such draconian measures should be avoided and efforts focused on less intrusive tactics.

 Research has suggested that behavioral change can result from meaningful continued medical education (CME) (Cervero & Gaines, 2015). In a synthesis of eight systematic reviews from 2003-2015 investigating the impact of CME, Cevero and Gaines discovered that CME favorably affects both “physician performance” and “health outcomes” (Cervero & Gaines, 2015). The study also found that “CME leads to greater improvement in physician performance and patient outcomes if it is more interactive, uses more methods, involves multiple exposures, is longer, and is focused on outcomes that are considered important by physicians” (Cervero & Gaines, 2015). Mostofian et al. similarly found that medical education facilitating active engagement and multidimensional approaches has been shown to work best (Mostofian, Ruban, Simunovic, & Bhandari, 2015).
Section 6

Where to Focus Continuing Medical Education

Recognizing that continuing medical education is an effective tool for changing physician behavior, we must rely on prior research in deciding where to direct our attention. The three major areas most appropriate to target include communication skills, end of life care and practical medical ethics.

6.1 Communications Skills Training

Numerous authors have proposed that poor communication is a major contributor to medically ineffective treatment at the end of life and related disputes (Burns & Truog, 2007; Cifrese & Rincon, 2018; Hox et al., 2012; Neville et al., 2020; Willmott et al., 2016). Issues with communication which can lead to conflicts between healthcare providers and patients or surrogates include a failure to appreciate previous interactions with the healthcare system, unawareness of specific cultural or religious needs and disagreements between members of the clinical team (Cifrese & Rincon, 2018). Additionally, many physicians neglect to provide prognostication in discussions associated with medically ineffective treatment (Burns & Truog, 2007). Formal training in communications skills using interactive methods such as standardized patients and direct clinical observation and feedback could be highly beneficial. To cite an example, a 2018 study by Schell et al examined the effects of an intensive three day interactive communication training on nephrology fellows who are often faced with patients who are nearing the end of life. The study determined that the training improved overall communication skills with an improvement in delivering bad news and increased efficiency (speed) of patient encounters (Schell et al., 2018). Expanding similar trainings to residency and fellowship programs and CME events throughout the country should be considered.

6.2 Exposure to High Quality Palliative Medicine

The variability of training in palliative medicine in undergraduate and graduate medical education is assuredly a contributor to the practice of offering medically ineffective care. Palliative medicine
physicians specialize in the comprehensive care of patients living with chronic life altering and life-threatening illnesses. In addition to symptom management for complex medical conditions, palliative medicine physicians are uniquely trained to engage in meaningful discussions pertaining to end of life care. In a German study investigating the different communication styles of critical care and palliative care physicians, palliative physicians were noted to be more “swift, direct and personal” during discussions of medically ineffective treatment while critical care physicians were noted to be more “cautious, matter of fact and indirect” in their communication style (Jox et al., 2012). Additionally, palliative physicians were more likely to exhibit empathy and honesty and provide the “treatment alternative of palliative care” (Jox et al., 2012).

A 2019 study by Barkley et al. replicated the results of prior studies in showing that palliative care consultation reduces thirty-day readmission and is associated with decreased in hospital mortality if completed within 6 days of admission (Barkley et al., 2019). Along with the aforementioned effects, it is probable that palliative care consultation has favorable effects on reducing medically ineffective treatments at the end of life. Thus, it is essential that it be included in this interdisciplinary educational approach.

6.3 Exposure to Practical Medical Ethics

Although exposure to medical ethics does occur in medical school, the training is typically limited to the first two non-clinical years which are predominantly focused on the basic sciences (Berger, 2013). When ethical issues arise in the clinical years of medical school and beyond, the training is typically nonexistent (Berger, 2013). Training in medical ethics is important in cases of medically ineffective treatment as knowledge of what is ethically permissible can help ease physician discomfort with these difficult situations. Jeffrey Berger argues that physicians in training are “vulnerable to moral distress” and providing formal medical ethics education with an emphasis on “actual cases” may help to lessen this phenomenon (Berger, 2013).
Section 7

Implementing an Educational Model

Implementing formalized, comprehensive interdisciplinary training in communication skills, palliative medicine and medical ethics into undergraduate and graduate medical education may prove to be an effective means of decreasing the provision of medically ineffective treatments. This education should be required at all levels of training beginning at the medical school level and continued through residency, fellowship and beyond in order to mount the greatest effect. Barriers may include time, disinterest or financial burdens, but all measures should be taken to incentivize employers and educational institutions to employ this specialized training. Notably, a 2012 study by Kogan et al showed an interesting trend among physicians with a 5% increase in referral for end of life services with every one year decrease in age (Kogan et al., 2012). This data suggests that the younger generation of physicians is becoming more comfortable discussing impending death and appropriate end of life care in contrast to their more experienced counterparts whose training may have differed.

The use of “implementation intention” techniques have proven effective in some settings and could be helpful in preparing physicians for situations where medically ineffective treatment is being requested or contemplated (Saddawi-Konefka et al., 2016). Implementation intention techniques acknowledge that behavior change requires more than goals and knowledge (Saddawi-Konefka et al., 2016). In other words, intention does not mean action. Implementation intention tactics prepare the subject to respond to certain situations with specific actions (i.e. if I encounter situation X, then I will respond with action Y) (Saddawi-Konefka et al., 2016). Incorporating these implementation intention techniques into training with a specific focus on end of life and ethical issues across a broad range of scenarios could be helpful. Additionally, incorporating such action plans into patient handoffs could help to decrease the occurrence of confusing information being passed on to patients or families. Miscommunication between physicians can often be detrimental to end of life decision making and lead to diminishing trust in the patient’s care team--a known contributor to demands for medically ineffective treatment (Cifrese & Rincon,
2018). With proper application to a variety of clinical and ethical scenarios, these techniques may prove exceptionally helpful in appropriately preparing physicians for situations where the use of medically ineffective treatment is being deliberated.

Section 8

Conclusion and a Statement on Current Affairs

As medicine has advanced in parallel with an increased societal shift towards autonomous patient choices, medically ineffective treatment has become a topic of heightened concern. COVID-19 has exposed the weakness of our fragile healthcare system and precipitated strong visceral reactions from the public over fears of healthcare rationing. These issues of distributive justice are likely to bring about new scenarios and disputes in cases of medically ineffective treatments. But a global pandemic isn’t the only situation likely to affect our handling of medically ineffective treatments. Nationwide protests renewing attention to centuries-long racial injustices should be a reminder of unconscious biases and a painful American history that has propagated so much of patients’ current mistrust in the advice of medical professionals.

It is important that physicians remain cognizant of the harms associated with medically ineffective treatment and learn effective ways of managing difficult situations when external pressures attempt to dictate care. Continuing to provide medically ineffective treatments contributes to norms in medicine and the lay community and makes it exceedingly difficult to refocus attention on helping patients and families understand, accept and value the end of life. While position statements, policies, legal protections and systems-based changes can help decrease this practice, the moral obligation to change current behavior and avoid providing medically ineffective treatment occurs at the level of the individual physician. Interdisciplinary training in communication, palliative medicine and medical ethics can help physicians and trainees effectively address situations of medically ineffective treatment from a position that is culturally sensitive, historically sensitive and empathetic.
References


Courtwright, Andrew M., MD, PhD, Brackett, Sharon, RN, BS, CCRN, Cadge, W., PhD, Krakauer, Eric L., MD, PhD, & Robinson, Ellen M., RN, PhD. (2014). Experience with a hospital policy on not offering
cardiopulmonary resuscitation when believed more harmful than beneficial. *Journal of Critical Care, 30*(1), 173-177. doi:10.1016/j.jcrc.2014.10.003


https://www.sccm.org/Communications/Critical-Care-Statistics


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