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A Review of End-of-Life care in the US: The conundrum in the absence of a guiding framework

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Abstract: End-of-life care is a topic that many consider to be an uncomfortable one given its emotional, ethical, and legal complexities. The scope of legal death in the US was made clearer by the approval of the 1981 Uniform Determination of Death Act (UDDA). The act is completely adopted word for word by most US states, but there are states like Louisiana that adopted the UDDA with some included criteria for neurological death. It is important to note that the UDDA is a legal guide used to make legal and medical decisions rather than a law that must be followed completely. With the advancement of medical technology, individuals can be kept alive through a variety of medical interventions that sustain necessary physiological functions, such as breathing, in the absence of complete mental status or other basic functions considered to be fundamental to life These modalities at times blur the line between life and death, and disagreement exists on the technical definitions and applications of these terms. The result is an ethical gray area in which medical care can be provided, but the question of whether it should be provided remains. This article is meant to examine the ethical and societal implications of end-of-life care to an individual who- depending upon the definition- may be considered dead.

Keywords: Futile treatment, dignity, Hippocratic Oath, Natural Death, Islam, Legal death

I. INTRODUCTION

End-of-life care today is not what it was decades ago because of evolving interventions and changing perspectives on the ethics of this care. The treatment that a patient receives during the final stage of their life has received more scrutiny with the advancement of medical technology and interventions. Medical treatment may be considered beneficial if it diminishes suffering, restores functioning, or increases an individual's quality of life. Depending on the circumstances, this type of care may be labeled "futile treatment." Futile treatment is typically used when the patient or surrogate desires it, in tandem with the clinical judgement of a physician. In the absence of clear consensus clinical guidelines governing the issues of futile treatment, patient dignity, and determination of legal death; end-of-life treatment gives rise to complex ethical-legal issues, making it critically important for care teams to understand end-of-life care thoroughly.

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II. DEFINITION OF LEGAL DEATH

The scope of legal death in the US is primarily rooted in the 1981 Uniform Determination of Death Act (UDDA). The UDDA defines a dead person as someone who has developed irreversible cardiopulmonary collapse (i.e., they cannot breathe or provide adequate blood flow to vital organs) irreversible loss of brain function (Nikas et al). Despite there being some sort of legal guide for states when approaching legal death, there is still controversy surrounding the guidelines. Of the fifty states that adopted the UDDA, there are twelve states that have a variation on the wording including Virginia, which holds that brain death must be accompanied by loss of spontaneous respiratory function in order to constitute death" (Nikas et al). The lack of a uniformity amongst states- and even within states- in defining legal death has important ramifications upon medical interventions and withdrawal of treatment.

Legal death can be categorized in two different ways, clinical death and brain death. According to the American AED association, clinical death is "when your heart stops pumping blood" (Mike Figuero). The article goes on to define brain death as when "the victim's brain is damaged and cells in the victim's heart, brain and other organs die from a lack of oxygen." The National Health Service of the UK defines brain death as when "a person on an artificial life support machine no longer has any brain functions" (NHS). It is a commonly held belief that brain death is considered legal death and the two are closely associated. A criteria of brain death is that with brain death there is no chance of recovery. However, for clinical death, an individual could be resuscitated with the proper medical technique within a given time interval. According to the AED, without CPR, biological death sets in around 4-6 minutes after the heart stops pumping blood.

Testing for brain death typically includes physical examination, the apnea test, and ancillary rests. Each state has their own guidelines for testing and this section will reference the New York State Department of Health guidelines. A prerequisite for the testing is establishing proximate cause and irreversibility of coma. This requires a physician to assess the extent of damage to loss of brain function and exclude any confounding factors. The facility conducting brain death testing must also inform the patient's surrogate decision-maker that the process of determining brain death has commenced. Once any religious or moral objections are considered, testing can begin.

For the physical examination, there is testing done to find "response to pain and assessment of brain stem reflexes" (Aboubakr et al). In brain death, there is a loss of response to central pain and there is no eye response or motor reflexes. Among the loss of brain stem reflexes the physical examination looks for are loss of eye motion in reaction to head movement and loss of cough reflex. The apnea test is then conducted to assess "the brain's ability to drive pulmonary function in response to the rise of CO2" (Aboubakr et al). Ancillary tests are considered if the apnea test cannot be performed or if there is uncertainty of diagnosis of brain death in general. These tests can test for things like detection of loss of bioelectrical activity of the brain or detection of the cessation of cerebral blood flow. A variety of imaging is used for testing including CT, ultrasound, and angiography.

Consider the case of the "dead-donor" rule, which requires that a patient is declared dead before organ harvesting can occur (Truog and Robinson). Critics have leveled the fact that brain death—which is a basis for legal death—is unreliable and is not rooted in strictly physiologic criteria. Despite this, it can be used to justify harvesting organs from critically-ill patients despite the fact that their circulatory system continues to function and perfuse their vital organs. This could be potentially classified as harvesting organs of living patients and is a complete violation of the principles that govern medical care.

III. DOES NATURAL DEATH EXIST?

Ivan Illich, in his book *Medical Nemesis*, highlights the concept of iatrogenesis, which is the collection of side effects that have resulted from medical care. Iatrogenic harm is typically thought of as physical, such as when a surgeon mistakenly leaves an instrument inside a patient's body. However, Illich also discusses iatrogenesis as an ideological form: the destruction of the traditional ways that existed to deal with and rationalize death, suffering, and sickness. He also uses the term medicalization to describe how the use of such high levels of medicine and reliance on physicians has led to a cultural harm as individuals in society have forgotten how to cope with health on their own. Autonomy is stripped away and what remains is a society that undermines suffering and the ability to deal with suffering, pain, and decline (Illich, 275).

In the section titled *Death Against Death*, Illich talks about how our understanding of the process of death has changed over time. He says, "In its extreme form, "natural death" is now that point at which the human organism refuses any further input of

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treatment" (Illich, 206). Also, he mentions how society decides when and after what "indignities and mutilations" an individual dies. Finally, Illich says that "Mechanical death has conquered and destroyed all other deaths" (Illich, 207). Taking these three notions together, we are in a circumstance where rapidly developing life-prolonging interventions can be sequentially administered to a person who- by their own volition or by opaque definitions of death- can continue being "alive" because they simply do not want to be "dead." This notion is readily apparent in clinical practice today. With the advent of mechanical ventilation and feeding tubes, an individual can overcome obstacles like the inability to breathe and eat on their own. Whereas an individual's inability to breathe, feed themselves, or even produce a heartbeat would have previously been synonymous with death, modern medical interventions have made it so that a patient can be alive without these modalities.

End-of-life care as it exists today appears to threaten, at times, the core medical ethical principles of autonomy, dignity, and non-maleficence. In the absence of clear advance directives from a patient or their surrogate- an ethical quandary that presents itself often in emergent circumstances- the existence of ever-expanding medical interventions may prolong the life of a person who may not have wanted it, particularly in an undignified fashion. If circulatory support can be artificially provided to a person who has irreversible organ failure- to the extent that the removal of external support would result in rapid death, it begs the question of whether the idea of natural death has truly come to an end. Returning to the idea of structural iatrogenesis in society, we see how medical interventional progress drives changes in how a society views and evades death, and those changing perspectives cyclically drive medical interventional progress and demand.

IV. FUTILE TREATMENT

End-of-life care is inextricably linked to the notion of futile treatment. The Nursing 2020 Critical journal defines medical futility as treatment that is "benign nonbeneficial or harmful to a dying patient" and "interventions are unlikely to produce significant benefit to the patient" (Angelucci). Of course, given that numerous medical interventions are unlikely to produce benefit but that this benefit is not impossible, the definition of futile treatment varies tremendously in clinical practice. Angelucci also suggests that "a framework would serve as a conduit to open communication among patients, families, and healthcare providers, to identify procedural steps to assist them in moving forward through the process."

Bioethicist and physician Maurice Bernstein discussed four views of futile treatments in an article discussing therapeutic futility. The first is physiological futility and it implies that "there is no reasonable expectation based on scientific evidence that a physiological outcome from treatment can be achieved" (McCullough et al). Imminent demise futility suggests the treatment may provide physiological good, but it will not reverse the medical condition and the patient will die in the near future. Clinical or overall futility implies that even though a treatment will provide a physiological good and imminent death may be avoided, the results will not cause the patient to be able to recover capacity to function with their environment and continue to be a human being. This is like being in a vegetative state. Quality of life futility is described as one where the treatment has no expected imminent demise, and the patient will still have interactive capacity but the outcome of the intervention will not meet the values and goals outlined by the patient or surrogates who know the patient's wishes.

The elusive concept of futile treatment is one that is widely controversial because of how suggestive the term is. An article from the Palliative Care Network of Wisconsin describes futile treatment as an intervention that "is unlikely to be of any benefit to a particular patient and b) will not achieve the patient's intended goals." The key component of the definition is the focus on the "intended goals." Patients, physicians, and the family of the physician may all be on different pages on what the goal is of the intervention and what is considered beneficial. The article mentions how "medical futility can be easily misunderstood as health care rationing." The main question is to be if the advantages of the therapy outweigh the disadvantages in a given patient. Another common misconception regarding medical futility is the belief that maintaining medical futility is giving "unilateral decision-making authority to physicians at the bedside," however, proponents of the term vehemently disagree and believe that a professional consensus is welcomed in futile treatment.

An example of a bedside conundrum is where a patient has multi-organ failure and extremely low likelihood of regaining mental status and basic functionality. Although this sounds like futile treatment, a family may choose to keep the patient on a ventilator for a prolonged period of time because they are "full code," meaning they want all interventions done to sustain life. The physician has entered a difficult situation because they are subjecting the patient to potential for continued pain and also exhausting valuable resources for a hospital. It also puts the family of the patient in a difficult situation because they are met with weighing the

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life of their loved one against "giving up" on care to alleviate suffering. This tug of war occurs as a result of the lack of a concrete guide for end-of-life care situations and uncertainty around the outcomes of particular interventions.

With the emergence of the term "futile treatment," there has been light shed on the disconnect between the physician and the patient as well as the patient's family. A UCLA study was conducted on "futile treatment" and the results showed that the general public does not understand this term and when they did, most would still pursue "aggressive treatments despite physician's recommendations against them" (Enrique Rivero). This study buttresses the idea that there is a lack of medical literacy in the general population and poor communication on the part of physicians that contribute to misunderstandings around treatment. Efforts to mitigate pain and wastefulness in end-of-life scenarios should focus on excellent patient and family education, even at the expense of uncomfortable conversations, prior to the "end of the road" for patients.

Among the definitions of futile treatment, which is still highly debated amongst scholars, is care that is not only "unable to accomplish the intended physiological goal" but one that causes physician's moral distress (Mullin and Bogetz). However, the term "potentially inappropriate" has been used to describe these interventions that create dissonance within a clinician's decision-making process. This article on moral distress in end-of-life care highlights how moral distress manifests itself due to differences in values or even poor communication between the physician and patient in goals and understanding of care received. Moral distress is described as when "one knows what they feel is the right thing to do, but constraints make it impossible to do so." Based on this article and the UCLA study, it seems that there is a serious gap that exists in end-of-life care that could potentially be futile and there should be heightened diligence in communication between the aforementioned parties.

Given the gray area that exists in futile treatment, medical futility policy plays a major role in resolving potential disputes. Mercy Health developed a policy to provide a conflict resolution mechanism to utilize when a patient or their surrogate decision maker requests rather than refuses an intervention that the attending physician deems to be medically inappropriate. The policy lays out procedures such as having the attending of record inform a patient that they cannot comply with the intervention if it is deemed to be unethical. Along with this, the physician is instructed to explain the nature of the ailment as well as the options available to the patient. Mercy's policy carefully lays out instructions on resolving a disagreement between the patient and attending and includes options such as transfer to another physician. Institutional resources are also made available to the patient and attending during this process. The policy also outlines procedure for appeal with a second physician and is reviewed by the Institutional Ethics Committee. This particular policy is detailed and allows for the dispute over medically appropriate interventions to take place in an organized manner. Guidelines like this however do not exist within every health system and thus makes this process difficult.

V. MAINTAINING A PATIENT'S DIGNITY

Writing on legal death and end-of-life care would be remiss without a proper discussion on the ethical concept of dignity. The Trinity International University Center for Bioethics & Human Dignity defines human dignity as "the recognition that human beings possess a special value intrinsic to their humanity and as such are worthy of respect simply because they are human beings." To further understand this elusive concept, the Samaritan blog on end-of-life palliative care suggests that respect, autonomy, empowerment, and communication are key aspects of maintaining the dignity of a patient (Samaritan). In bioethics, we recognize respect, autonomy, and empowerment as basic rights of patients when receiving care. The question we grapple with in care for those either brain dead or legally dead is, "At what point are we not honoring a patient's dignity?"

The Hippocratic Oath requires physicians to do no harm in caring for a patient in life and death of a patient. A central premise to the oath is beneficence and non-maleficence. A physician must restore health, protect from harm, and to have their disability lessened. According to Doyen Nguyen, "the Hippocratic ethos also requires that physicians recognize when treatment is no longer effective" (Nguyen). Here again we are met with the concept of futile treatment and care that is simply prolonging death when it is imminent. Practically, we see that there is a tension between upholding the Hippocratic Oath and knowingly providing futile treatment. If a physician is providing circulatory support using pressors and respiratory support with a mechanical ventilator with a patient immobilized in a hospital bed while they have sustained irreversible damage to their vital organs that is incompatible with life, it would appear that physicians have an ethical duty to educate surrogate decision-makers on the potential violation of dignity taking place.

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VI. ORGAN DONATION

Organ donation is a practice that is often discussed in the context of end-of-life care. The thought is to give the prospect of life to another as someone is about to lose their own. According to the Organ Donor government under the Health Resources & Services Administration website, 106,367 men, women, and children are on the national transplant waiting list and 17 people die each day waiting for an organ transplant (HRSA). Scholars are critical of the lack of uniform legal death laws in the US because many think this has opened the door for unsavory organ donations. Organ donation is tied heavily to brain death and as a result, states have added specific laws on organ donation out of fear of taking advantage of a patient's death. The ethical norm that has large bearing in this discussion is the dead donor rule (DDR), which states that "vital organs may only be taken from persons who are dead—whether by irreversible loss of all brain or cardiac function" (Nikas et al). This rule further complicates the ethics of declaring a patient dead. How many declarations of death are made prematurely in order to facilitate organ donation?

Those in opposition of the DDR believe that some of the principles that guide this ethical norm can be manipulated for organ procurement. Notably, the DDR is not a piece of legislation or an established rule of medicine either. The concept of brain death was developed, in part, to allow patients with devastating neurologic injury to be declared dead before the occurrence of cardiopulmonary arrest" (Truog). According to the US Department of Health and Human Services, Organ Procurement and Transplantation Network, nearly 80% of organs that were procured for transplants were from deceased donors. This stark contrast of living donors versus deceased donors increases pressure to clearly define legal death in acquiring an organ for transplantation (Nikas et al).

A patient that is incapacitated and has a surrogate to make decisions for them can consent to a living organ donation. In an article on care given in the context of brain death, Nguyen discusses how "even a noble act such as organ donation can be manipulated to serve utilitarian, materialistic, and dehumanizing motives" (Nguyen). This adds another layer to the question of dignity for a dying patient. Bypassing the dying process to harvest a patient's organs is one way to look at this process. Is this not quite literally using someone as a means to an end? Unless the patient has signed an advance directive to have their organs donated, it may be hard to justify prolonging a brain-dead person's process of dying to extract organs from them. A physician must ponder at whether it is dignified for essentially a corpse be kept alive a bit longer to undergo a medical procedure to benefit someone else.

Scenarios of end-of-life care with a potential for organ donation require the family, patient, and physician to weigh the dignity of the patient against the possibility of them recovering full bodily function. Many families recognize that it is not very dignified for a patient to be on a ventilator, urinating into a catheter, etc. but feel it could be worth it because the family may be able to come out of it alive and well. Still, there remains controversy of patient's being influenced to donate an organ given their brain death determination when they may not necessarily be brain dead. The linkage between organ donation and the declaration of death is unsavory for many. The perturbation of those who study this dilemma stems from data from studies like one in 2008 that found that there are significant variances in brain death guidelines among the leading neurologic hospitals in the US. Additionally, not all hospitals adhere to the American Academy of Neurology guidelines (Nikas et al). It remains to be seen if families of patients or even patients are aware of the confounding nature of brain death tests.

The lack of communication surrounding organ donation has made it difficult for a patient to be empowered to make an autonomous decision on their own. Also, consider the concept of respect: It would be respectable for physicians and family to have a plan in place for the patient in the event of a potential organ donation but that likely is not the case. Often, a patient is making organ donation decisions with a clouded mind under the pretense that they have no hope for a prolonged life. Decisions like these require headspace and a process that is consistent in flow as well. A multi-faceted reform is needed for organ donation to be a more dignified process for a patient.

VII. RELIGIOUS CONTEXT

Given that there are not clear consensus guidelines when it comes to the ethics of end-of-life care, it is useful to navigate it using other frameworks, such as religious ones. Within an Islamic framework, theological and jurisprudential considerations are made when considering end-of-life care and the notion of suffering. Miller et al have commented on how in an Islamic framework,

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suffering imposed by God upon humans has redemptive value. Additionally, it is an Islamic axiom to not inflict harm or reciprocate it. The International Organization of Islamic Medicine further states, "It is the process of life that the doctor aims to maintain and not the process of dying" (Miller et al.). Within the clinical context, Alibhai and Gordo, although life is precious in Islam and considered a gift from God and that is why aggressive end-of-life treatment is justified, there are limits to this. The article also mentions that clinicians must be aware that in both faiths, Islam and Judaism, treatment may be withheld when there is a terminal illness from which a patient is dying. An example of this includes metastatic cancer (Alibhai and Gordon). Another point made is that deciding to treat or not to treat is quite difficult and usually involves a religious leader like an Imam.

Islam's view on end-of-life care seems to be in a position where it is encouraged unless care is completely futile. However, the physician should not actively cause or speed up the death of a patient. For example, active euthanasia would absolutely be forbidden in Islam. The question at hand is, if a patient is suffering as a result of some serious pain and there is no cure, is it ethical for a physician to keep the patient on mechanical ventilation as it is preserving the life of the patient? An Islamic framework affirms the intrinsic value of preserving the life of a person but looks to make the dying process a dignified one. Ultimately, the Islamic framework would look to consider both dimensions and encourages the multidisciplinary consultation between a physician, the patient and surrogate, and Islamic jurisconsults and scholars.

VIII. CONCLUSION AND RECOMMENDATIONS

The root cause for the end-of-life ethical dilemmas appears to be inconsistencies in definitions and the uncertainty of outcomes. Ironically, the birth of the controversy at hand is death. States within the US must come together to establish consensus on what is and what is not legal death. Of the two principles of brain death and natural death, brain death is more controversial given the margin for error within testing. Along with shoring up the qualifications for legal death, there must be a more stringent set of qualifications for brain death. There are several things that ride on the concept of brain death including the religious context of end-of-life proceedings, legal proceedings, and organ donation. Futile treatment should be re-examined within the context of tis financial burdens and ethical burdens alike. Futile treatment not only utilizes time and resources, but it could also potentially violate a patient's dignity and put the through unnecessary pain and suffering.

The ethical norm that guides organ donation for patients who are in end-of-life stages must be further established as well. The lack of consensus guidelines contributes to the sentiment of distrust which often exists between care teams and patients and their families. I argue that brain death organ donations should be governed by oversight from neutral third-party ethics committees or eliminated unless there is clear communication in an advance directive. Given the sensitivity of organ donation, we must not approach it with the cavalier attitude that exists with loose and elusive guidance. The link between brain death and organ donation is a dubious one given the opportunity to make a hasty decision if someone is under the impression that they will soon pass. An established and reviewed guide for organ donation processes should cause all involved parties to be much charier and more cognizant before proceeding with decisions.

If the medical system is truly concerned about upholding a patient's dignity, autonomy, and overall well-being, these changes must take place. The nature of end-of-life care is often of great emotion and hardship, and the providers owe it to the patient to be as clear and open with communication as possible. Many of the issues discussed in this paper stem from either an inchoate level of guidance for the parties involved and a dearth of communication. As rudimentary as these things may seem, it will take a concerted effort that will pay off in peace of mind for all parties involved in this care.

Society must think introspectively on whether Illich's description of "Natural Death" holds true today. This book was written in 1974 and many could argue that he predicted the future of medical care today. It would be difficult to argue that Illich was completely correct on his description of natural death today but maybe he was not so far off on the "indignities and mutilations" patients face today. The lack of set definitions, guidelines, and accepted practices has done nothing to parry the attacks of Illich on how patients are treated in end-of-life. It is incumbent on all involved parties to come together and take action to mitigate any more chinks in the armor of the reputation of medical care.

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