Who Decides?

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ABSTRACT

The most unambiguous fact of life is death. Every human on the planet can, in complete confidence, say they will die. What is not so certain is how. Those who are lucky will die of old age. But what about those who sustain severe head trauma and are now "wakefully unconscious?" It is in these cases where the determination of death becomes difficult. The most complicating of cases is when the patient is found to be in a vegetative state (VS). In a VS, the patient can, unconsciously, hear, respond to nonspecific stimuli, and exhibit spastic limb movements. For the first year of being in this state it is logical to think that the patient will recover, but any time following diminishes these chances. Those who are endowed by law to make all decisions when the patient's desires. How can we know this patient's wants if they are unconscious and no explicit record exists? It is in situations like these when better decision-making mechanisms must be implemented. Rather than waiting for tragedies to occur and then sitting in confusion when situations like these arise, we must be prepared to maneuver the unexpected effectively. Refusing to converse about death is the crux of the issue; if the federal government implemented a universal end of life form many ambiguities involved in this process will be circumvented and legal battles regarding this issue will disappear.

KEYWORDS

Death, End of Life Policy, Vegetative State, Patient Considerations

BACKGROUND

Death is no longer a black and white situation; it has turned into a continuum where consciousness is on one end and brain death (BD) is at the other. Between consciousness and BD are two other states, the coma state and vegetative state (VS). The line between vegetativeness and death can only be clearly defined by the surrogate who can choose to leave the patient on life support until BD or cardiovascular death occurs. BD, as defined by legal communities and the American Medical Association (AMA), is a loss of brain function which is equivalent to cardiopulmonary death according to the Uniform Determination of Death Act of 1980 (UDDA). Unfortunately, not all communities agree with the medical and legal communities; some believe death occurs when the heart ceases which does not occur at the same time as brain death and can continue beating while the patient is on life support. A patient is not completely dead until life support has been removed as the body can continue to function without the brain if the patient is assisted (Sade 2011).

The technology which brought the question of death into a more complicated light was the organ support system. This new technology changed patient care drastically when it was introduced in the 1950's (Machado 2010). No longer was the patient dead or alive, they were in a limbo state. The machine allowed physicians to prolong death until a feasible treatment could be found, but it also forced the medical, ethical, and legal communities to redefine what a human is, and to determine the ethics of shutting off a patient's life support. Organ support technologies showed that a patient with a non-functional brain still has functional organs which lead to the question, is this person alive? It is now widely accepted that a patient who is determined to be BD is completely dead when previously the definition of death was the cessation of breathing and heartbeat (cardiovascular death) (UDDA 1980).

A distinction must be made between all forms of consciousness and unconsciousness. A coma is the umbrella term for a complete loss of consciousness. Between a coma and BD lie several other stages, but the state of main concern in this paper is the VS. A VS is defined, paradoxically, as wakeful unawareness; a patient in a VS is awake and can be aroused but is completely unaware of who they are or their environment; there is also evidence that patients in a VS have the ability to hear conversations. In other words, the patient is capable of organic functioning but, in the opinion of this author, lacks all the other characteristics

of humanism. Patients in a VS can spontaneously respond to different stimuli, for example a foul smell might elicit facial grimacing and other physiological responses, spastic movement of limbs, patients in a VS may even frown or smile (and in rarer cases weep or laugh). These responses cannot be confused with a regaining of consciousness as this is the paradoxical nature of the VS. A coma, unlike a VS, is characterized by the inability to force arousal and a complete lack of consciousness; there is no number of stimuli which could cause a patient in a coma to elicit a response.

In all cases, death decisions are put to the patient and the surrogate; the physician's only job is to provide information so the patient and surrogate may make an informed verdict. When the patient is no longer conscious, all information goes to the surrogate who is then to decide what to do next. There are only very specific reasons, according to the AMA, in which the physician can step in and question the surrogate's wishes:

- The patient and the surrogate cannot come to an agreement
- A surrogate cannot be found or the one listed is not willing and the patient is not in a condition to make decisions
- In the physicians best professional judgment, the surrogate is violating the patient's clearly expressed values, goals for care, or treatment preferences or the choice made is not in the best interest of the patient

In these cases, the physician must consult an ethics board before taking further steps in providing care. Additionally, the final point listed is highly susceptible to subjective analysis especially in cases where the patient has not explicitly expressed their values, goals for care, or treatment preferences (AMA Principles of Medical Ethics 2016).

The World Health Organization (WHO) states there is no uniform international consensus on the clinical criteria of brain death. In 2006, several countries, including Canada, published a consensus on the recommended method to determine BD: Computer Tomography Cerebral Angiography (CTA). In 2008, the Academy of Medical Royals College in the United Kingdom published that the preferred method should be a clinical diagnosis of BD and not neuroimaging.

However, the Academy did acknowledge that in certain cases clinical diagnoses cannot be performed and in other cases, neuroimaging increases certainty in BD diagnosis but no recommendations were given in these cases (Dineen et. al. 2012). There are several neuroimaging techniques a physician can choose to determine BD but there is only one clinical method, the apnea test. The apnea test has three subsets:

- 1. The patient must lack all evidence of responsiveness (coma)
- 2. Clear absence of brainstem reflexes (follows eye tracking motions which should not be changing as the head is put into different positions)
- 3. An absence of a breathing drive (Apnea)

The apnea test is usually repeated twice to ensure reliable results or is paired with other testing to improve reliability. If the patient is found to be BD the appropriate documentation is completed and an organ procurement organization is contacted if the patient was an organ donor (as dictated by federal and state laws). In cases where the patient is not found BD, the surrogate has one of two options which will be discussed later (American Academy of Neurology 2010).

A CTA measures blood flow through the blood vessels in the brain. To determine BD there are three different types of evaluation point scales; 10-point, 7-point, and 4-point. These scales refer to different numbers of intercranial (IC) blood vessels; the 7-point and 4-point scales measure vessels in either the posterior or anterior portions and the 10-point scale measures vessels in both the posterior and anterior portions. The common criterion between each of the three scales is a lack of opacification in the middle cerebral arteries and the deep cerebral veins. In other words, if the middle cerebral arteries and deep cerebral veins are not seen in the angiogram this is a sign of BD. Unfortunately, CTA scans are difficult read because it tracks blood through the blood vessels and therefore different forms of blood pools (e.g. hemorrhage) can obscure the reading and consequently confound the assessment of IC filling in BD patients (Dineen et. al. 2012).

Prior to complete cessation of IC blood flow, the IC pressure (ICP) increases dramatically which is the most important mechanism of BD. Given this mechanism

of BD, transcranial doppler ultrasonography (TCD) has been recommended to assess blood flow in suspected BD patients as it is non-invasive. TCD measures blood flow velocity and direction in proximal areas of the brain. Neurologists and internists are given training to perform, read, and interpret TCD scans which, unfortunately, means the results are operator-dependent and can lead to confounding results. BD patients exhibit a reverberating flow and/or systolic spikes which can be seen in a multi-depth TCD scan. A TCD or a CTA can be used in tandem with an apnea test to either determine or confirm BD (Machado 2010).

If the patient is not found to be BD the family can choose to wait, depending how long the patient has been in a VS or they can remove the patient from the ventilator. Patients who have been in a VS from one year or more are considered unlikely to rise from the state (Sade 2012). Because surrogates have the power of decision making, they can pick any of these two options which, if physicians have determined the chances of the patient recovering are not likely, means an untreatable patient is receiving treatment. If surrogates choose to leave the patient on organ support in the hospital, a patient who will probabilistically never recover is now occupying a bed that the hospital could be using for other critical care patients. This also means the family is supporting a patient who will likely never recover from their state and spending thousands of dollars doing so.

The American Academy of Neurology (AAN) guidelines state that organ support is to be discontinued once BD has been declared (AAN 2010). However, because the patient's surrogate is given the power to determine when organ support should be shut off, some people choose to continue to leave their family member on life support following determination of BD. Some states in the United States allow family members accommodations if they object to BD on religious, personal or other basis. The state of New York requires hospitals to have a set of guidelines in place for surrogates who object to the definition of BD. The Reasonable Accommodation clause in the Guidelines for Determining Death (2011), requires hospitals to give surrogates the option for continued artificial respiration for a set period during which surrogates are also given access to other resources such as members of clergy, ethics committees, bereavement counselors, and others to address concerns, objections, to determine next steps, or to come to terms with the situation. New York makes the distinction between those who object to the definition of BD and those who have difficulties understanding what has happened to their loved one and the legislation states that hospitals should

give both groups of people access to the same resources. When physicians start the process of determining BD, the surrogate is only required to be informed or an effort to contact the surrogate must be made; consent to perform BD determination testing is not required in the state of New York.

Each state has separate legislation regarding BD; California, New York, Illinois, and New Jersey all have some form of a reasonable accommodation clause in the legislation in cases where the surrogate disagrees with the definition of BD. New Jersey allows families to keep the patient on organ support until cardiopulmonary death occurs, which means the family would be supporting a patient who is legally and medically deceased. BD means the patient is never "going to wake up" as is the colloquial phrase. Patients who are in a suspected vegetative state (VS) have some potential of recovering some if not all their cognitive functioning. However, those in VS are not guaranteed to recover from their state and have the potential to slip further down the death continuum or stay in a persistent VS for the rest of their life. In these types of situations, the patient is not legally dead and forces many questions:

- 1. Do we have the right to turn off organ support even if the patient is not legally dead?
- 2. If the patient does recover from their VS what will their quality of life be?
- 3. Will their life be diminished complete dependence on their family members?
- 4. At which point does a person cease being a person?
- 5. How can we know if the patient would want to be kept alive if we have no record of their wishes?

DO WE HAVE THE RIGHT TO TURN OFF ORGAN SUPPORT EVEN IF THE PATIENT IS NOT LEGALLY DEAD?

It is medically accepted that once a patient has been in a VS for over one year there is little to no chance the patient will ever regain consciousness. This does not mean, however, that patients never arise from their VS. Researchers in France were able to awaken a patient who had been in a VS for 15 years by stimulating his vagus nerve which is responsible for several conscious functions. The patient is now capable of responding to simple commands, and perceived threats all after one month of vagal stimulation (Begley 2017).

This case brings up the second question: If the patient does recover from their VS, what will their quality of their life be? In the case of the French patient, he will be under constant scrutiny for the rest of his life because now he is a case study for his physicians. Additionally, we are unaware to what extent this stimulation will last. If the stimulation does wear off, will he revert into a VS, will this stimulation cause his condition to worsen and cause BD? Because of these questions, the French patient has lost nearly all his freedoms. His consistent need to be monitored, to relearn all motor movements, he may even need consistent vagal nerve stimulation; this monitoring may force the patient to stay in the hospital for most of his life. Is it ethical for researchers to experiment on humans before having a basic understanding of how this stimulation has an impact on other animals? A literature search found no further research into VS deep brain stimulation in other animals. The FDA requires that drugs are tested on animals before applying the treatment to humans, the same must be applied to this type of testing. This treatment could have a profound impact on this patient's life and the lack of research in this topic on other organisms is disconcerting. For example, deep brain stimulation in Parkinson's disease patients was first tested in monkeys before the treatment was given to humans and the same must be applied to VS deep brain stimulation (The Deep-Brain Stimulation for Parkinson's Disease Study Group 2001).

To further answer the main question in this section, in 1990, Terri Schiavo suffered a cardiac arrest causing severe hypoxia (lack of oxygen) and subsequent brain damage. It was determined that Terri was in a persistent VS and there was little to no chance she would ever recover. Given this information, Terri's husband wished to end her life citing that Terri would not want to be kept alive in such a state. Conversely, Terri's parents were not convinced of the evidence provided to

them by her physicians and wished to maintain her organ support. Both parties had such a severe disagreement regarding her care that this case was argued in front of the United States Supreme Court who ruled in favor of Terri's husband. Her feeding tube was to be removed, thereby removing all support to Terri and killing her. Autopsies later demonstrated Terri's brain had atrophied to the point where no amount of treatment or therapy could have reversed the damage. If Terri's parents had won their legal battle, her feeding tube never removed, and she remained supported by hospital resources, the hospital would be allocating resources to a patient who was never going to recover. Until Terri had been unplugged she was utilizing resources, physician time, and a bed in the Intensive Care Unit all of which could have been given to a patient whose condition would improve. It is not someone's given right to remove organ support, no one has the right to remove what is keeping another alive, but it is important to understand that by allocating resources to someone whose wishes we do not know or whose prognosis is not one of recovery we are costing other patients the right to have access to adequate care (this is an idea we will revisit).

IF THE PATIENT DOES RECOVER AND THEIR LIFE IS DIMINISHED TO COMPLETE DEPENDENCE ON FAMILY MEMBERS, WHAT THEN?

In a hypothetical situation, a woman has been in a VS for almost two years now and spontaneously one day she arises from her VS while her brother is sitting by her bedside. This woman is completely aware of who she is and her environment. She can respond to basic questions, but not verbally, she can only respond by blinking her eyes. Her neurologist informs the family members there is little chance she will be able to recover any other motor function and will require constant care. The family understands and moves the patient to hospice care. From the time at which the patient woke up to the time she will die, the family will not remember her how she was before her traumatic accident but what she is like now; frozen and incapable of basic human qualities like expressing intelligible thought. In every way but the medical diagnosis this patient is a vegetable. If the patient knew she would end up in this state, would she want to have been kept on life support? Every patient has the right to die with dignity; the right to die before severe complications cause other family members to intervene and take care of them. No one wants to die, it is why talking about death is essentially taboo. Humans know what lays at the end, but because humanity refuses to accept that

end, the subject is difficult to approach. This avoidance is understandable, but when patients are left in a state like this hypothetical patient, it is necessary to force conversations before family members choose to spend thousands of dollars and countless hours taking care of a loved one who will no longer be capable of taking care of themselves.

Valentine's day 2010, Sam Goddard suffered two massive strokes during a soccer match. Sam was a healthy, young accountant who was just weeks away from marriage and following these two strokes he was reduced to a man completely dependent on his fiancé and his family. Sam's physicians had determined he would never recover from his VS; Sam's fiancé disagreed and refused to let him go. She eventually found the sleeping medication, Stilnox which rose Sam from his VS. This drug worked miracles for Sam and his family but he can no longer go an hour without this drug. Sam's family has turned into his caretakers; Sam's fiancé can no longer love him as a spouse but as someone she must look after. Yes, Sam is happy to be alive, but his life has gone from a healthy active man to complete debilitation. Is this the life anyone would want their loved one to live? It is inspiring to see a patient with a poor prognosis recover, but everyone deserves to live and die with dignity. But the opinion of this author does not matter, what matters is that Sam is happy to be alive and above all it must always be the decision of the patient who the treatment is being applied to.

IS A PERSON WHO IS NO LONGER CAPABLE OF SELF-CARE, INTELLIGIBLE THOUGHT OR ANYTHING ELSE THAT INTRINSICALLY MAKES THEM A PERSON, A PERSON?

For years philosophers have been attempting to define what a person is and what they have concluded is that a person is capable of what any other person is capable of; intelligible thought, reason, emotions, self-awareness, and the lists go on (Farah and Heberlein 2007). The problem with attempting to define personhood is that what makes us human is not explicit, it is implicit and is verified by the people around us. The issue comes when someone is no longer acting as a person. The people around this human still want to validate his or her personhood because they know this human was a person once. Once a person's recovery stagnates to the point where they require constant care, cannot display the intrinsic properties of personhood, this person is now a human, an empty shell. A person is capable of more than being able to respond to basic necessity

questions; a dog can respond to basic need questions when trained. Once a person can no longer be defined as a person objectively and intuitively, they are a human. This is a difficult concept to grasp and seems wrong, but once a person loses all implicit facets of personhood they are now a human not a person.

HOW CAN WE KNOW IF A PATIENT WANTS TO BE KEPT ALIVE IF WE HAVE NO RECORD OF THEIR WISHES?

In cases where the patient is comatose on arrival to the hospital and then progresses into a VS for more than one year, caretakers likely do not have a record of this patient's wishes. It is the surrogate's decision to keep this patient alive; would this patient have wanted to be kept alive for this long without signs of recovery? This is the main reason why such conversations must be forced. Without knowing, the surrogate could be keeping their loved one alive when they don't want to be kept alive in such a state. These rules can be easily implemented in adult care, unfortunately children are much more complicated especially when cases of unexpected tragedy occur. In the state of Virginia there was a case of a toddler who choked on a popcorn kernel and was subsequently placed onto life support. Mirranda Grace Lawson's physicians wanted to perform an apnea test to determine BD, but the parents refused the testing stating that they thought the test would harm their daughter. Following this, Mirranda's parents gave a handwritten letter to the doctors citing their Christian beliefs do not allow for such testing to occur, as taking their child off life support is considered murder. The ensuing legal battle ruled in the hospital's favor, but the parents were allowed pay a \$30,000 bond to prevent the hospital from performing the test while the parents appealed to the Virginia Supreme Court. This appeal was later retracted when Mirranda died of cardiovascular arrest. What must be considered is that the Virginia Commonwealth University Health System Pediatric Intensive Care Unit has only 14 hospital beds; not only did Mirranda's presence cause other intensive care patients to be turned away, but her care was costing the hospital \$10,000 a day. This brings up two important points. First, if a patient is suspected legally dead, does the hospital have the right to perform the apnea test without the surrogate's consent? Second, does the life of the many other patients outweigh the wishes of one surrogate?

IF A PATIENT IS SUSPECTED LEGALLY DEAD DOES THE HOSPITAL HAVE THE RIGHT TO PERFORM THE APNEA TEST WITHOUT THE SURROGATE'S CONSENT?

In the case of children, if the surrogate is of sound mind, families have the right to refuse BD testing. In July of 2016, Allen Callaway was brought in to St. Vincent's Healthcare (SVH) in Montana. Following his admission he experienced a brain herniation, which lead Allen's physicians to suspect BD and the need to perform clinical testing; SVH sought consent from Allen's mother who subsequently agreed. The evaluation was found to be consistent with BD and to produce reliable results the physicians must perform the apnea test a second time. When Allen's doctors informed his mother, she refused and filed a lawsuit to prevent any further testing. The court found that performing medical procedures on a child requires parental consent citing personal autonomy, privacy, and protection. In this case, because the patient was a minor, Montana ruled in the parent's favor but if every physician sought the permission of the surrogate to perform apnea testing in every case there would be a blockage of death determination. Families do not want to learn that their loved is gone and this has implications not just within the family but would impact other patients who need Intensive Care Unit support (Lewis and Pope 2017).

This statement answers the next question; do the lives of the other patients outweigh the wishes of the one surrogate? Yes. It is difficult for people to comprehend death, but it is not something that must stop other people from receiving the care they need.

POLICY SUGGESTION

Death is never an easy subject to consider objectively. No one wants to consider dying despite knowing we will one day. Given these gray areas, there is a necessity to implement a system and a new law which can, to some effect, circumvent these ambiguous issues. Additionally, more research funding needs to go into studying death, the implications of being in the different stages of unconsciousness, and the most reliable way to diagnose BD. Furthermore, the public needs to become more educated in the different stages of death so when the time comes, all people are capable of making intelligible decisions.

All people have the right to die with dignity, but there are circumstances in which people are not informed of impending death. In cases like this, contingency

plans are best put into place. Like the organ donation card, people should be asked to fill out a form to determine end of life decisions before unfortunate events occur. It would be naïve to think this form would not be met with severe backlash, but the organ donation card implies the same concept. At the time of death, a human's organs would be procured; this form simply goes one step further and defines what the person wants at the end of their life. In cases where the patient is comatose on arrival and the surrogate does not know the patient's wishes, this form can become a rubric of sorts to guide the representative. With this form, people who wish to be left on organ support will be and those who wish to be removed off life support after a given period will be. Asking people to fill out this form would be difficult not only because forcing people to have a conversation they have avoided most of their life is uncomfortable, but also because it is impossible to reach the entirety of the United States population. The best way to circumvent both issues is to ask people to fill out these forms when they are obtaining or renewing a driver's license which is when the question of organ donation arises. Even though there are people who do not procure a driver's license, this is the best method to maximize form fulfillment. Most people procure their first drivers license at age 16, and despite this appearing to be very early to some people to start making such decisions, it appears that at any age a conversation about death is too early. After the form is filled out for the first time it would be updated every time the driver's license is to be renewed, which varies from state to state and is age dependent. This form would detail all the patient's wishes and desires in the event the patient becomes comatose and progresses into a VS; essentially this form would become the person's representative and the surrogate would follow this paper when making decisions regarding their care. Additionally, a federal law needs to be implemented regarding death. Currently, each state has the power to decide what sorts of responsibilities and privileges the surrogates and physicians can have. The federal government needs to create an umbrella law that all states and hospitals must abide by. In doing so, states with differing BD laws will not have people from outside states asking for care that their previous hospital could not provide due to stricter BD laws. This law would need to include clauses regarding reasonable accommodation and children. Death is an emotional process and for this federal law to be effective, people must be given time to process and understand what is occurring and states that allow for reasonable accommodation understand this process. Furthermore, pediatric

care is different than adult care. If the form goes into effect children under the age of 16 will not have forms, it is in these cases where the parents must make the decisions for their children. These two policies must be directed to Congress as they are the ones who can implement new laws and make changes to existing programs. They also direct the budget which would require changes to hire new federal employees to aid people in filling out these forms.

Our complete lack of understanding in what occurs during the limbo stages of death is preventing physicians from treating patients so they may return to normal consciousness. More research needs to be funneled into treatment of brain revival so that cases of VS's are no longer issues. To create more research, more grants need to be directed towards VS studies. The National Institutes of Health creates the grants and Congress creates the budget for the NIH to fund the varying types of research occurring all over the country.

Furthermore, the public needs to be better educated on this issue; most people are unfamiliar with the basic definitions of a coma, VS, and BD. This lack of understanding causes mass confusion when asked to make serious decisions and can be avoided with additional education. One of the jobs of the Department of Health and Human Services (HHS) is to provide education to the American people regarding various health hazards. It is the job of the HHS to create awareness for various medical conditions and determination of death must become one of those issues. The education policy must be directed to the HHS and to Congress. Congress would need to provide more funding to the HHS to allow for widespread education and research.

Additionally, the international medical community must come to an agreement on what the best method to test for BD is and the most reliable interpretation of these scans. In the case of a CTA, which point system is best used to determine the status of the patient's brain. In TCD scanning, uniform training must be given to the internists and neurologists performing the scans so that there is a uniform measure of a VS and BD. This policy can only be directed towards the WHO, who creates the international medical standards for physicians. To determine the best methods for measuring VS and BD more research needs to be conducted, funded by the WHO.

CONCLUSION

With newer life-support technologies emerging humans can no longer starkly define life and death. What used to be a clear line, has turned into a confusing and stepwise process which, in some cases, can revert and lead to recovery but often leave patients in a consistent state of limbo.

The bulk of the decision-making lays in the hands of the patient chosen surrogate; the physician can only provide information to the surrogate to make informed choices. Because the surrogate makes most of the choices for the patient they are representing, the surrogates' biases are inserted into their decisionmaking; religion, morals, personal experiences all come together to allow the surrogate to make a choice about another person's life. These representatives are meant to channel the patients' wishes and coordinate with the physician in accordance with these wishes. Unfortunately, most people do not plan for such events to occur and therefore do not express their wishes in the event of such a situation arising. A new system must be implemented to force people to have these conversations and to avoid situations in which the surrogate projects their wishes onto the patient when the patient cannot make those decisions. Additionally, more research needs to be done so that in the future we may be able to treat people in a VS. Death is never something people choose to discuss, but it is something that requires further education so that humanity becomes less fearful of the topic and so we can move towards less complicated ethical standards.

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