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Consciousness and Futility: A Proposal for a Legal Redefinition of Death

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**Introduction**

Death is a social construct. While objective medical science plays a fundamental role in shaping the social construction and understanding of human death, it is society at large (through its laws, public opinions, religious attitudes, etc.) that actually defines death. The purely clinical criteria of the medical and scientific community, though crucial in the determination of death, play only a part in the greater social exercise of demarcating the boundaries of death in the first place. Formerly understood exclusively in terms of a patient’s heart and lungs, death required redefinition in the latter half of the twentieth century, in part to encompass certain patients who, because of improvements in medical technique, evaded death under the law but were nevertheless dead in both a medical and social sense.\(^1\) The law currently defines death in terms of the “cessation of all functions” of the “entire” brain.\(^2\) Every state in the union now adheres to some form of a “brain-death” statute, where “brain-death” requires the cessation of the functions


\(^2\) *Id.*
of the brain stem. From this process of legislative reform, certain social values and ethical principles can be inferred. As the drafters of the language of the current law said themselves:

The position taken by the Commission is deliberately conservative. On a matter so fundamental to a society's sense of itself—touching deeply held personal and religious beliefs—and so final for the individuals involved, one would desire much greater consensus than now exists before taking the major step of radically revising the concept of death.

Whether the very law that the Commission promulgated was not itself a “radical revision” to the concept of death remains a matter of some debate. The state of New Jersey, for example, revised its “brain-death” statute in 2007 to include a religious exception. Religious exemptions and a priori conservatism aside, however, the question remains: which formulation of legal death ought to be the law’s default?

This essay argues that the “whole-brain” conception of death as currently conceived and enforced suffers from the same kinds of infirmities (under-inclusion and arbitrariness) that necessitated the departure from the purely cardio-pulmonary conception of death. Further, this essay will advance public policy rationales (respect for patient autonomy and proper balance of competing interests) for altering the current definition of death. Finally, this essay suggests that the legal definition of death be reconsidered to emphasize that irreversible loss of consciousness

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4 Wherever the state chooses to define death, properly viewed as a political choice, social attitudes will be implicated.
5 See note 1, *supra*, at 41.
6 N.J.A.C. 13:35-6A.6 (November 4, 2013; 45 N.J. Reg. No. 21)(“Death shall not be declared on the basis of neurological criteria if the examining physician has reason to believe, on the basis of information in the patient's available medical records, or information provided by a member of the patient's family or any other person knowledgeable about the patient's personal religious beliefs, that such a declaration would violate the personal religious beliefs of the patient. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria.”)
such that continued medical treatment would be of no benefit are the crucial principles involved in determining whether someone has died. In achieving this goal, the essay proceeds in three basic parts: part one outlines the history of death definitions in the United States; part two addresses the problems with the current formulation of legal death; and part three proposes new legislation to bring the law into harmony with the social attitudes and greater public interests involved in how our law conceives of death.

I. What is Death and When Does it Occur?

In the 1950’s, death was defined in the United States almost entirely on the basis of total loss of the functions of the heart and lungs. As medical technology advanced to allow for the artificial maintenance of the heart and lungs, this definition faced an existential crisis. Theoretically, for example, a decapitated patient could, despite lacking a brain entirely, retain the functions of her heart and lungs through artificial means. Yet, under the previous, purely cardiopulmonary conception of death, this decapitated individual would not be dead under the law. Following an influential article by the Harvard Ad Hoc Committee on Brain Death in 1968, a nationwide public policy initiative began to redefine death to cure the law of potentially inequitable results, and to bring uniformity to the laws of the states. This effort culminated in the proposal of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research to define death in terms of “whole-brain” death criteria. The legislation proposed by the President’s Commission is known as the Uniform Determination of Death Act, (U.D.D.A.). The statute reads:

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7 See “Proposed Model Legislation,” infra, pp. 22.
8 See note 1, supra, at 3.
9 See note 1, supra, at 36.
10 A Definition of Irreversible Coma, JAMA, Aug. 5, 1968 (Vol. 205, No.6, 85-88)
11 See note 1, supra, at 2.
An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.\(^\text{12}\) (emphasis added).

Before the U.D.D.A. came to carry the legislative day, there was wide divergence among the states in how death was defined.\(^\text{13}\) Barely half of the states had statutory definitions of death at all, relying instead on judicial constructions deriving from the common law.\(^\text{14}\) *Black’s Law Dictionary* was a crucial resource for judges presiding over cases where determinations of death were legally significant.\(^\text{15}\) The definition advanced in *Black’s* was exclusive of brain-related constructions of death, defining death instead as:

> The cessation of life; the ceasing to exist; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereon, such as respiration, pulsation, etc.\(^\text{16}\)

The Court in *Thomas v. Anderson*, in trying to resolve the factual question of which of two men died first, applied this definition with confidence and concluded: “death occurs precisely when life ceases and does not occur until the heart stops beating and respiration ends. Death is not a continuing event and is an event that takes place at a precise time.”\(^\text{17}\) A groundbreaking 1958 work by two French neurologists seriously challenged this purely cardio-pulmonary conception of death.\(^\text{18}\) This study examined patients “incapable of spontaneous breathing. They had not only lost their ability to react to the external world, but they also could

\(^\text{12}\) Id.
\(^\text{13}\) See note 1, supra, at 67.
\(^\text{14}\) Id.
\(^\text{16}\) Id. at 376
\(^\text{17}\) Id.
no longer control their own internal environment.”

These patients were termed *coma dépassé* (beyond coma), “a ‘frontier state’ between life and death.”

The exclusion of such patients from the legal universe of the dead produced some problematic results, as the President’s Commission described the legal landscape in 1981:

> Defendants charged with murder have argued that they could not be guilty of homicide because their victims were alive when physicians—who should bear the responsibility for the deaths—removed them from the respirators. Doctors have also been sued for removing organs for transplantation from a patient declared dead on the basis of brain-oriented criteria. A third category of cases has involved petitioning a court for permission to terminate life-support systems for bodies without functioning brains.

Similarly, the medical community faced difficulties in determining the proper treatment, as well as *when to discontinue* treatment, of such patients. The Harvard *Ad Hoc* Committee on Brain Death, recommending brain-related death criteria, described the difficulties with the cardio-pulmonary definition:

> There are two reasons why there is need for a definition: (1) Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients. (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.

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20 *Id.*

21 *See* note 1, *supra*, at 68.

22 *See* note 1, *supra*, at 85.

23 *Id.*
The Committee’s emphasis on the broader social interests involved (e.g., “those in need of hospital beds”) is noteworthy in that it is an essentially ethical and moral justification for defining death in terms of brain-oriented criteria. The President’s Commission cited the Harvard recommendation with approval when the Commission proposed the U.D.D.A. in 1981.\(^\text{24}\) Further, the Commission explicitly acknowledged that social attitudes and beliefs determine the legal construction of death, stating that the public interest in the definition of death is “part of a process of development in social attitudes and legal rules stimulated by the unfolding of biomedical knowledge.”\(^\text{25}\) The U.D.D.A. reflects the philosophical contemplation that artificially maintained organic processes such as breathing and heartbeat cannot, without more, form the boundary between human life and human death. What emerges, then, from the legislative history surrounding the U.D.D.A., is the basic principle that death is a function of social attitudes formed in reaction to advances to medical technology.\(^\text{26}\) To answer the rhetorical questions posed in the title of this section, death is what we say it is, and it occurs when we say it does. This tautology is meant not to dismiss nihilistically the effort to define death as a hopelessly relativistic exercise, but rather to emphasize that, as we have seen, definitions of death are only as good as the socio-medical ethical principles on which they rest, and the ability of such principles to adapt to unanticipated developments in medical technology.

\textbf{II. Why Change the Law?}

To return briefly to the explicit language of the U.D.D.A., it is worth noting that the law requires the “cessation of all functions of the entire brain, including the brain stem” before an

\(^{24}\text{See note 1, supra, at 24.}\)
\(^{25}\text{Id. at 18.}\)
\(^{26}\text{As a vivid illustration of this basic principle, consider the thesis, advanced in 1740 by the French scholar Jean-Jacques Winslow, that “putrefaction was the only sure sign of death.” Id. at 13.}\)
individual may be declared dead.\textsuperscript{27} (emphasis added). This insistence on “functions” has proven scientifically tenuous over time, however, as it has become clear that “individual, isolated brain cells could be perfused and continue to live even though integrated super-cellular brain function had been destroyed.”\textsuperscript{28} Lingering electrical activity in the brains of putatively “brain-dead” patients posed a similar problem.\textsuperscript{29} As one scholar has observed:

> When the uniform definition of death said all functions of the entire brain must be dead, there was a gentleman's agreement that cellular level function did not count. The President's Commission recognized this, positing that "cellular activity alone is irrelevant" (p. 75). This willingness to write off cellular level functions is more controversial than it may appear. After all, the law does not grant a dispensation to ignore cellular level functions, no matter how plausible that may be.\textsuperscript{30}

The President’s Commission based its conclusion that purely cellular activity is irrelevant on a distinction between function and activity:

> After an organ has lost the ability to function within the organism, electrical and metabolic activity at the level of individual cells or even groups of cells may continue for a period of time. Unless this cellular activity is organized and directed, however, it cannot contribute to the operation of the organism as a whole. Thus, cellular activity alone is irrelevant in judging whether the organism, as opposed to its components, is "dead."\textsuperscript{31}

The President’s Commission presents no analysis for the principle that cellular activity must be “organized and directed” lest it be declared “irrelevant.” Yet one can perhaps understand this conclusion by considering the other explicit reasons presented for the necessity

\textsuperscript{27} See note 11, supra.
\textsuperscript{29} Id.
\textsuperscript{30} Id.
of a brain-oriented conception of death. For example, the President’s Commission considered
the *quality* of a patient’s life in formulating its “brain-death” criteria:

A patient correctly diagnosed as having lost brain functions permanently
and totally will never regain consciousness. He or she will experience no
pleasure or pain, enjoy no social interaction, and be unable to pursue or
complete his or her life’s projects.\(^{32}\)

Forgetting the nuanced distinction between *functions* of the brain versus *activities* of the
brain’s subparts, one can see that the animating philosophical justification underlying the brain-
death conception entails value judgments about human life. Yet, curiously, consciousness,
pleasure and pain, social interaction, and inability to “pursue . . . life’s projects” do not appear
anywhere in the statute meant to separate human life from death. Presumably, then, there is an
assumption that the proposed criteria of the U.D.D.A. sufficiently indicate the absence of some
or all of these values. The flaw in this assumption is that the criterion proposed, while sufficient
to indicate death, are woefully under-inclusive of other extreme physiological states properly
classified as death for the same underlying reasons that patients “beyond coma” are dead. Put
another way, putrefaction is sufficiently indicative of death to form a reliable proxy for the
assessment of death.\(^{33}\) But allowing dying patients to progress to this point would be socially
intolerable, especially in light of existing medical technolo-
gies, combined with the cost of maintaining such patients so unnecessarily.

An example of patients in such an extreme frontier state between life and death is the so-
called permanently vegetative patient, said to be in a “permanent vegetative state”\(^{34}\) (“PVS”).

\(^{32}\) *Id.* at 83.

\(^{33}\) See note 25, *supra.*

\(^{34}\) *Diagnosing the Permanent Vegetative state*, Ronald Cranford, MD., *Virtual Mentor*, Vol. 6,
No. 2 (August 2004). Various criticisms of the terminology “vegetative state” have been
advanced, ranging from lay objections that the term is unfairly derogatory and medical-scientific
This state can be distinguished from the coma dépassé patient in that, in the vegetative patient, “there is extensive damage to the higher centers of the brain, with relative preservation of the brain stem structures.”\textsuperscript{35} In these patients:

Their eyes are open and moving about during the periods of wakefulness that alternate with periods of sleep; there may be spontaneous movements of the arms and legs, and at times these patients appear to smile, grimace, laugh, utter guttural sounds, groan and moan, and manifest other facial expressions and sounds that appear to reflect cognitive functions and emotions, especially in the eyes of the family.\textsuperscript{36}

Essentially, the cognitive functions in these patients are absent, while the reticular activating system, located in the brain stem, continues to function.\textsuperscript{37} Some scholars have argued that such patients should be declared dead on the basis of the lack of neo-cortical activity alone.\textsuperscript{38} These scholars have emphasized the centrality of consciousness to human life, and have argued that the absence of consciousness should form a sufficient indication of death.\textsuperscript{39} Confirmed PVS patients lacking any chance of recovery are estimated to number around 25,000 adults and objections that the term is imprecise. \textit{See Persistent Vegetative state, Adam Zeman, The Lancet, Vol. 351, No. 9096, 144 (Jan. 1998).}

\textsuperscript{35} \textit{Id.}
\textsuperscript{36} \textit{Id.}
\textsuperscript{37} \textit{Id.} Though, revisiting the President’s Commission’s distinction between functions and activities, one could plausibly argue that, because the cortex in PVS patients cannot process the signals received from the ascending reticular activating system (which is why PVS patients have no interaction with their environment), the reticular activating system is only active and not functional. Applying the principle that brain activity must be “organized and directed” or else it is irrelevant, one could reasonably conclude, under this argument, that sleep-wake cycles in PVS cycles are “irrelevant.” This semantic contortion is unnecessary, however. \textit{See pp. ___ in part 3.}


\textsuperscript{39} \textit{See Smith, note 36, supra:} “If the irreversible loss of an organism’s essentially significant attributes characterizes death, and if in humans the significant attributes are the capacity for consciousness and higher cortical functions rather than for autonomic bodily integration, then people who have irreversibly lost these distinguishing features of human life should be treated as dead.”
10,000 children.\textsuperscript{40} It is further estimated that the number of new PVS patients increases annually by 5,000 in the United States alone.\textsuperscript{41} The Multi-Society Task Force on PVS estimates that “total annual costs in the United States for the care of adults and children in a persistent vegetative state is $1 billion to $7 billion.”\textsuperscript{42} Taking the average of these estimates ($4 billion annually), the cost of maintaining PVS patients, in pure accounting terms, will be $40 billion over the next decade.\textsuperscript{43}

As mentioned above, PVS patients are simply one example of patients that occupy an extreme physiological state that tests the boundary between social, value-laden understandings of death and legal constructions of death. Continued advances in medical technology have revealed yet other, different, frontier states. In 2002, for example, a new diagnosis, the “minimally conscious state” (“MCS”) was presented by a group of neurologists.\textsuperscript{44} This state, often misdiagnosed as PVS, “is a condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated. MCS is distinguished from VS by the presence of behaviors associated with conscious awareness.”\textsuperscript{45}

The crucial diagnostic distinction between the MCS patient and PVS patient is that: “clearly

\begin{itemize}
\item \textsuperscript{40} Diagnosing the Permanent Vegetative state, Ronald Cranford, MD., \textit{Virtual Mentor}, Vol. 6, No. 2 (August 2004).
\item \textsuperscript{41} Medical Futility, Treatment Withdrawal and The Persistent Vegetative state, Kenneth R. Mitchell, Ian H. Kerridge, and Terence J. Lovat, Journal of Medical Ethics, (1993, 19: 71-76).
\item \textsuperscript{42} Medical Aspects of the Persistent Vegetative state, The Multi-Society Task Force on PVS, The England Journal of Medicine, (June 1994; 1572-1576, 1576).
\item \textsuperscript{43} This calculation assumes current costs will stay \textit{static} as opposed to increasing. Additionally, accounting costs measure only dollars spent. A more complete economic evaluation (which would calculate opportunity costs) would almost certainly yield a higher number than the modest $40 billion estimate.
\item \textsuperscript{44} The Minimally Conscious state: Definition and Diagnostic Criteria, J.T. Giacino, PhD; S. Ashwal, MD; N. Childs, MD; R. Cranford, MD; B. Jennett, MD; D.I. Katz, MD; J.P. Kelly, MD; J.H. Rosenberg, MD; J. Whyte, MD, PhD; R.D. Zafonte, DO; and N.D. Zasler, MD, \textit{Neurology}, 2002; 58; 349-353.
\item \textsuperscript{45} Id. at 351.
\end{itemize}
discernible evidence of self or environmental awareness must be demonstrated on a reproducible or sustained basis” in order for a patient to be termed MCS. The MCS patient is aware of her surroundings and has the cognitive ability to experience pain, whereas the PVS patient lacks both environmental awareness and cannot experience pain. Further, MCS patients have “significantly more favorable outcomes” than PVS patients. Under whole-brain oriented death theory, neither a PVS nor a MCS patient can ever be classified as dead since both retain functioning brain stems. Whether the law ought to distinguish between MCS patients and at least some PVS patients forms part of the focus of the next section.

III. Consciousness and Futility: The Fundamental Criteria for Death

To return briefly to a concept posited earlier, wherever the political entity of the state chooses to define death, social values will necessarily be implicated. Understood in this context, the legal definition of death is likely to attract the same kind of attention and controversy as the legal conception of life. The two conversations, however, should not be elided: defining death does not entail defining life, nor does it entail defining “personhood.” To illustrate this point, consider a hypothetical personhood statute that was so expansive it included non-human life forms like octopi. The determination of when this life form has died would be an inquiry unto itself. Notably, the current conception of whole-brain death could not apply to an octopus and

46 Id.
48 Id.
49 But see note 35, supra.
50 How society, through its codification of death, chooses to define dead human beings may have a bearing on conversations of personhood and life, but the basic point here is that defining death is a separate exercise from defining a “person.”
would need revision, since octopi anatomy does not include a brain stem in the first place.\textsuperscript{51} Thus, to be sure, there is a relation between personhood on the one hand and death on the other, but the two conversations are not identical. The definition of death does not necessarily determine the definition of a person.\textsuperscript{52} Finally, it is worth observing that the President’s Commission explicitly rejected the word person in the U.D.D.A., reasoning:

\begin{quote}
The word "individual" is employed here to conform to the standard designation of a human being in the language of the uniform acts. The term "person" was not used here because it is sometimes used by the law to include a corporation. Although that particular confusion would be unlikely to arise here, the narrower term "individual" is more precise and thus avoids the possibility of confusion.\textsuperscript{53}
\end{quote}

These observations are offered at the outset to place the proposal for a new definition of death in its proper context and, similarly, to avoid confusion. To suggest, as is the focus of this essay, that the law should recognize that death occurs where a patient has suffered the irreversible loss of consciousness with no meaningful chance of recovery does not necessarily entail a claim about human personhood. To the contrary, as the octopus hypothetical illustrates, to re-define death in these terms would encompass almost any conceivable notion of personhood.\textsuperscript{54}

\begin{footnotes}
\item[51] Interestingly, the cardio-pulmonary definition of death could not apply either, since octopi do not have lungs.
\item[52] If it did, one would expect a louder chorus of opposition to whole-brain death, which specifies the anatomical detail of a brain stem. Presumably, if death works retroactively to determine personhood, only those with fully formed brain-stems are people.
\item[53] Report of the President’s Commission, \textit{supra}, at 74.
\item[54] As a final thought on the octopus, it is worth noting that a group of cognitive neuroscientists recently issued a “Declaration on Consciousness,” stating that: “the weight of evidence indicates that humans are not unique in possessing the neurological substrates that generate consciousness. Non-human animals, including all mammals and birds, and many other creatures, \textit{including octopuses}, also possess these neurological substrates.” \textit{Cambridge Declaration on Consciousness}, Philip Low et. al., July 2012.
\end{footnotes}
1. The Patient or the state: Who has the Greater Interest?

Advances in medical science have required philosophical re-conceptions of traditional social assumptions about human existence. The historical understanding of death as the stoppage of a human heart was challenged by the advent of the artificial heart.\(^{55}\) As already discussed above, the development of respirators and ventilators allowed modern science to maintain, biologically speaking, a human body that, according to traditional understandings of death, was already dead. Of the Harvard Ad Hoc Committee’s many stated reasons for proposing a new meaning of death, respect for the unfortunate patients occupying these unfamiliar frontier states was mentioned first. As the Committee said, “the burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients.”\(^{56}\) (emphasis added). Placing the patient’s interest first reflects the basic value of patient autonomy, which has stood as a pillar of modern American bioethics.\(^{57}\)

Disorders of consciousness, such as PVS and MCS, have played a crucial role in the evolution of autonomy rights.\(^{58}\) It is no coincidence, for example, that the “right-to-die” under United States law arose from a case involving a PVS patient.\(^{59}\) In *Cruzan v. Director*, The United States Supreme Court held that a competent patient could refuse unwanted medical care (termed

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\(^{55}\) See note 1, *supra*. Additionally, the romantic notion of the heart as the physical seat of a the human soul did not survive, so to speak, through the advances of technical science.

\(^{56}\) See note 22, *supra*.


\(^{58}\) *Id.*

by some as a “right-to-die”), but that a state could impose its own judgment in the matter by requiring “clear and convincing evidence” that the patient would have elected to exercise this right of refusal.60 Proceedings in which such evidence is presented are known as “substituted judgment” hearings, and this phraseology emphasizes that, through the Court, the patient’s interest, whatever it may be, transfers to someone else.61 The right of the state so to intervene derives from its “unqualified interest in the preservation of human life.”62

It is not altogether clear, however, how the state may maintain an interest where the patient has none. As Justice Stevens reasoned in his dissent in *Cruzan*:

For patients . . . who have no consciousness and no chance of recovery, there is a serious question as to whether the mere persistence of their bodies is “life” as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence. The state’s unflagging determination to perpetuate . . . physical existence is comprehensible only as an effort to define life’s meaning, not as an attempt to preserve its sanctity.63

The state’s interest in human life, put another way, must logically derive from that life’s existence in the first place. The state “has no legitimate general interest in someone's life, completely abstracted from the interest of the person living that life, that could outweigh the person's choice to avoid medical treatment.”64 Additionally, the state, merely by virtue of acting (imposing an evidentiary standard) asserts an interest potentially adversarial to the patient’s interest. For example, it is entirely possible, even probable65, that the patient would have wanted

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60 *Id.* at 284. (“ . . . a state may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state.”)
61 *Id.* The posture of the law thus reflects the existential precariousness of such a patient.
62 *Id.* at 263.
63 *Id.* at 345.
64 *Id.* at 310.
to discontinue medical treatment. Yet, because the state may assert an “unqualified interest” in the preservation of the patient’s own life, the patient is placed at the disadvantage of having to argue (through her surrogates) and prove by clear and convincing evidence that she, while competent, would have wanted to discontinue treatment. In the words of one commentator, the law’s default position is that “it is morally more acceptable to actively preserve the life of a patient in PVS than to be party to his death.”

But is this default position truly ethically defensible? Without consciousness, what is the PVS patient’s interest in life? As one ethicist phrased this issue:

The most significant ethically relevant characteristic of human beings whose brains have ceased to function is . . . that they have no prospect of regaining consciousness. Without consciousness, continued life cannot benefit them. (emphasis added).

Empirical evidence would tend to support this conclusion, at least to the extent that a majority of poll respondents have concluded they would not want to be kept in a vegetative state:

Asked specifically what they would want for themselves in a 2005 ABC News/Washington Post poll, only 8% reported that they would prefer to be kept alive, while 87% said they would not.

Such empirical evidence does not settle the ethical question, of course, because “in a different society where people believed something different, the evidence might support a

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choose-death-over-vegetative-state.aspx?version=print) (finding agreement among national polls that most Americans, if PVS, would prefer that artificial nutrition and hydration be discontinued).


different policy.” But the disconnect between public attitudes and the law’s posture undermines the state’s a priori moral conclusion that preservation of a permanently unconsciously patient is somehow better than removing unbeficial treatment. Engaging the ethics head-on, then, one is faced with the assertion that the state may protect the PVS patient from the automatic withdrawal of artificial nutrition and hydration (“ANH”) because of the possibility, however unlikely, that the patient may miraculously recover, or that a technological innovation may allow for the patient’s recovery. The question becomes, what cost can be sustained to the public as a whole in the preservation of this remote possibility? Given that, as we have seen, the majority would not wait for Godot, “this personal interest in a near impossibility is not sufficient to trump the public interest in allocating resources to patients more likely to benefit.”

But to maintain the focus on the patient’s interest: the basic principle of patient autonomy requires that we properly locate the provision of artificial nutrition and hydration in the context of active treatment “with all of the ethical ramifications that come with any other [treatment].” Thus, again operating with empirical assumption that the majority of people would not want to receive ANH, the state’s legal intervention in favor of such treatment is, in all likelihood, a violation of the right to avoid unwanted medical treatment. As Justice Brennan reasoned in his dissent in *Cruzan*,

> From the point of view of the patient, an erroneous decision in either direction is irrevocable. An erroneous decision to terminate artificial

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69 Id.
70 See note 57, *supra*, at 283 (relying on “the possibility of subsequent developments such as advancements in medical science” as a justification for preserving PVS patients).
71 Samuel Beckett’s *Waiting for Godot* is a fictional tragicomedy in which two characters wait endlessly for a character named Godot, who never arrives.
72 See note 66, *supra*.
73 Id.
nutrition and hydration, to be sure, will lead to failure of that last remnant of physiological life, the brain stem, and result in complete brain death. An erroneous decision *not to terminate life support*, however, robs a patient of the very qualities protected by the right to avoid unwanted medical treatment. His own degraded existence is perpetuated; his family’s suffering is protracted; the memory he leaves behind becomes more and more distorted.\(^{74}\)

Taking the argument a step further, the state, by asserting an interest in the life of the PVS patient, effectively *appropriates* the patient’s interests entirely. As Justice Stevens, along the same lines as Justice Brennan, wrote in *Cruzan*:

> To argue that the mere possibility of error in *any* case suffices to allow the state’s interests to override the particular interests of incompetent individuals in *every* case, or to argue that the interests of such individuals are unknowable and therefore may be subordinated to the state’s concerns, is once again to deny [a PVS patient’s] personhood.\(^{75}\)

Answering the question posed at the beginning of this section as to who has the better interest, Justice Stevens affirmatively concluded in favor of the patient instead of the state:

> The best interests of the individual, especially when buttressed by the interests of all related third parties, must prevail over any general state policy that simply ignores those interests.\(^{76}\)

The argument from patient autonomy, then, heavily favors a legal default in which the patient’s interests *not to receive* ANH are properly accounted for, as opposed to appropriated by operation of law into substituted judgment proceedings where the state determines the burden of proof.

One potential countervailing response to this line of argument is that the law should allow for those patients who, despite lacking consciousness, would, as competent patients, have wanted every treatment available to prolong physiological existence as long as possible. Though, as we

\(^{74}\) *See* note 57, at 320.  
\(^{75}\) *Id.* at 354.  
\(^{76}\) *Id.*
have seen, it appears this is the minority position of the public generally, it nevertheless must be addressed. One possibility is that advanced directives could accomplish this objective. It is already the current posture of the law that a competent patient could stipulate the withdrawal of ANH should the patient ever become PVS.\(^77\) If, as is proposed in this essay, the legal definition of death were in fact revised, presumably this would increase public awareness in the issue, and those with particularly strong objections to the law’s new presumption against ANH would have some motivation to make their preferences known. The argument here, as has been made elsewhere, is simply that this burden is more appropriately allocated to those who could continue ANH as opposed to those who would refuse it.\(^78\)

2. **Why include Medical Futility?**

Some of the arguments presented thus far have centered on consciousness as the critical criteria for determining whether a patient has an interest in continued physiological existence. It is natural for one to conclude from these arguments that a determination of consciousness should be the deciding factor in assessing whether a patient is alive or dead. In fact, some scholars have proposed such a construction of death:

> The language that seems best is . . . “irreversible cessation of the capacity for consciousness.” That is, after all, what the defenders of the higher brain formulations really have in mind.\(^79\)

The problem with this formulation is that one must be careful not to elide the notion of consciousness with “higher brain” (neocortical) functions exclusively. To collapse the two ideas into one would potentially put advocates of a consciousness-based definition of death on the

\(^77\) *Id.* at 323. Note that simply because advanced directives can accommodate a position is not an argument for elevating that position to the law’s default. (“The probability of becoming irreversibly vegetative is so low that many people may not feel an urgency to marshal formal evidence of their preferences. Some may not wish to dwell on their own physical deterioration and mortality”). *Id.*

\(^78\) See note 64, *supra*.

\(^79\) See Veatch, note 36, *supra*, at 23.
same slippery slope where whole-brain death advocates currently reside. For example, one proposal for a re-definition of death would classify death purely in terms of the neo-cortex, the supposed center of “higher” brain activity such as self-awareness. But a recent neurological study found “brainstem mechanisms are integral to the constitution of the conscious state, and that an adequate account of neural mechanisms of conscious function cannot be confined to the thalamocortical complex alone.” (emphasis added). Complicating matters further, consciousness, at least according to the prevailing view, occurs along a continuum. The so-called “scale of Indian sentience” emphasizes the gradations along this continuum, with each sentence in the scale reaching a different level of cerebral integration and complexity:

“This.”

“This is so.”

“I am affected by this, which is so.”

“So this is I who am affected by this, which is so.”

When it is said that PVS patients “lack consciousness,” what is meant is that the patient is unable to make the first of these statements—“this”—and thus that the patient has no subjective experience. The American Academy of Neurology, for example, defines PVS patients in the very terms of unconsciousness: “The persistent vegetative state is a form of eyes-

80 Id. ("Once [whole-brain death advocates] have made the move of excluding the cellular, electrical, and super-cellular functions they consider “insignificant” they are hardly in a position to complain about the project of sorting functions into important and unimportant ones.")
81 See Smith, note 36, supra.
82 Consciousness without a cerebral cortex: A challenge for neuroscience and medicine, Bjorn Merker, Behavioral and Brain Sciences (2007; 30, 63-134).
83 Id.
84 Id.
open *permanent unconsciousness.*

The difference between a minimally conscious patient and a PVS patient, from a clinical standpoint, is that the former possesses the capability for consciousness while the latter does not. Yet, as already mentioned, MCS patients are routinely misdiagnosed as PVS. Thus, a re-definition of death that considered only the clinical assessment of consciousness would encounter the practical problem of diagnostic accuracy. The significant merits of a consciousness-based criterion would fail as potentially over-inclusive: a misdiagnosis would be a death sentence. It is for that fairly straightforward reason that the proposed criterion includes the requirement that consciousness be irreversibly lost and that continued medical treatment would be of no benefit.

Turning to the concept of futility itself, it is important to stress that, regardless of the economic costs that must be considered, the analysis of futility begins from the patient’s perspective. As one commentator has argued:

> What seems morally important and determines whether any treatment should be employed in particular circumstances with a particular patient is not whether the treatment employs high technology or is simple, but whether the patient judges it to be on balance beneficial.

At some limit, the continued provision of treatment can unconscionably increase suffering while simultaneously providing no hope of recovery. In modern industrialized economies, physicians and the medical scientific community play a significant role in

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86 *Id.*
87 *See* note 42, *supra.*
88 *See* note 45, *supra.*
89 “Futility” carries some unfavorable associations to some observers, and often “medically inappropriate treatment” is substituted, somewhat euphemistically, for “futile care.” The term “futile” is used here in precisely the same sense that “medically inappropriate” is employed, but with an added shade of meaning: the *limits of medical technology.* Thus care is futile not solely because a physician deems care “inappropriate,” but because the care itself cannot restore the patient, regardless of the physician’s opinion.
80 *See* note 64, *supra.*
determining this limit. The right of the medical community not to be compelled to provide “medically inappropriate” treatment thus stands in potential conflict with the patient’s autonomous right to determine the course of her treatment. Consider the English case of Anthony Bland, a (not coincidentally) PVS patient whose physicians sought an injunction relieving them of liability in the event that they discontinued ANH to Mr. Bland. In evaluating the legal duties and obligations attaching to the physicians in this scenario, the court held:

A medical practitioner is under no duty to continue to treat such a patient where a large body of informed and responsible medical opinion is to the effect that no benefit at all would be conferred by continuance. Existence in a vegetative state with no prospect of recovery is by that opinion regarded as not being a benefit, and that, if not unarguably correct, at least forms a proper basis for the decision to discontinue treatment and care.

The current proposal is intended to codify this basic principle: a patient’s right to receive any available medical care is not absolute, and the other interests at stake may fairly weigh against the patient’s interest in this regard.

A potential countervailing objection to this principle might center upon the decision to include this principle at all in a definition of death. Isn’t the determination of death a separate issue from the treatment of the dying? This was the objection of the President’s Commission, which sought to cleave the two:

This Report on "Defining Death" does not address the medical, legal and ethical problems concerning dying patients. Issues in the treatment of dying patients will be the subject of a later study by the Commission. This Report focuses solely on the determination that death has occurred.

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91 See Causey v. St. Francis Medical Center, 719 So. 2d 1072 (La. App. 2 Cir. 1998)(holding that the opinions of physicians as to “medically inappropriate” treatment constituted a defensible standard of care).
92 Id.
94 Id.
95 See note 2, supra, at 4.
The attempted conceptual separation between “the determination that death has occurred” and “issues in the treatment of dying patients” must be viewed skeptically. After all, the President’s Commission and the Harvard Ad Hoc Committee both concluded that death under the law required redefinition because of issues related to the treatment of dying patients, especially patients who could perceive no benefit to continued treatment. Instead of insisting, somewhat disingenuously, that a conceptual separation exists, the current proposal seeks to balance the competing interests at stake in a sensible way that acknowledges that these interests are, in fact, at stake in how death is defined.

3. Acknowledging Consciousness

The effort to place the loss of the capacity for consciousness as the primary indication of death essentially seeks to codify the basic rationale that motivated the President’s Commission to redefine cardio-pulmonary death. As mentioned above, the Commission itself relied on consciousness and the capacity to interact with one’s environment as a crucial reason that cardio-pulmonary death was inadequate: “a patient correctly diagnosed as having lost brain functions permanently and totally will never regain consciousness. He or she will experience no pleasure or pain, enjoy no social interaction, and be unable to pursue or complete his or her life's projects.” 96 Justice Stevens went so far as to suggest that, for patients in such a condition:

There is a serious question as to whether the mere persistence of their bodies is “life” as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence. 97

The effort to define death in terms of purely physiological criteria (e.g., “whole-brain” or “neocortical”) should be understood for what it is: an effort to find the biological correlative of

96 See note 31, supra.
97 See note 61, supra.
the essential qualities that are lost in death. The definition suggested here for consciousness is not overly technical; consciousness is: “the state or activity that is characterized by sensation, emotion, volition, or thought.” A more nuanced definition may of course be possible, but this definition enforces the primacy of subjective experience. Evidence of such subjective experience is thus intended as evidence of the subject, which is to say, the presence of life. It is suggested here that this is what the Harvard Ad Hoc Committee and the President’s Commission actually had in mind when each called for a new understanding of death. The law thus proposed places this claim about essential qualities up front, as opposed to attempting to hide it under imprecise physiological criteria.

4. The “Who Cares?” Objection

A basic counterargument to the proposal to redefine death in terms of consciousness and unavailing treatment that must be addressed is the “anti-intellectual” one, which responds simply: “who cares?” As one commentator has written on efforts to refine a legal notion of death:

Patients' rights, the commercialization of medicine, the Internet, and medical malpractice have diminished public trust in and obeisance to physicians and medical science. An educated, or at least aggressively investigatory press, is quick to highlight controversy . . . It is highly unlikely that the press or the public will have the inclination or stamina to explore thoroughly the controversies about irreversibility and the timing of death, about death as process or event, about the true meaning of “integrative," or about the primacy of some vegetative brain functions over others.

The objection essentially rests on a conclusion about the nation’s political climate: diminishing “public trust” in medical science and a sensationalist media,” quick to highlight

98 See note 81, supra, at 64. Merker refers with approval to a basic dictionary definition of consciousness.
controversy,” are viewed as insurmountable obstacles in the effort even to have this conversation at all. Yet the political climate reflects the larger social and cultural climate, and new social and cultural issues develop and arise with each passing generation. The shifting demographics of the nation are an engine of these social and political changes. One especially significant trend in American demographics will bring issues related to death and the end-of-life to the fore of American public consciousness in the coming decades: the massive increase in the elderly population:

The older population—persons 65 years or older—numbered 39.6 million in 2009 (the latest year for which data is available). They represented 12.9% of the U.S. population, about one in every eight Americans. By 2030, there will be about 72.1 million older persons, more than twice their number in 2000. People 65+ represented 12.4% of the population in the year 2000 but are expected to grow to be 19% of the population by 2030.[100]

The aging of the “baby boomer” generation has ushered in a new era of public concern with issues related to death and dying, as evidenced by a recent trend to legalize assisted suicide:

Four states—Vermont, Oregon, Washington and Montana—have passed laws legalizing aid in dying. Six states have active campaigns to promote aid in dying—Connecticut, Hawaii, Massachusetts, Montana, New Jersey and New Mexico. Another half dozen states are moving that direction.[101]

Some of these “boomers” have organized “death dinners” to discuss the issues they face as they encounter their twilight years over a communal meal:

Over the past month, hundreds of Americans across the country have organized so-called death dinners, designed to lift the taboo around talking

about death in hopes of heading off conflicts over finances and medical care—and avoiding unnecessary suffering at the end of life.\textsuperscript{102}

The assumption that the political climate has no patience for a serious conversation about how we ought to define death fails to anticipate the extent to which issues of death and dying are poised to become more immediate in the American zeitgeist in the coming years. And while it may very well be the case that no legal jurisdiction will change its definition of death anytime soon, this is simply another way of saying that every legal jurisdiction will thus continue to tread along the precipitous fault lines of the whole-brain conception, and will thus routinely face the same legal, moral, and cultural upheavals caused by the law’s poor handling of this subject.\textsuperscript{103} It is at least conceivable that, at some future moment, efforts will be undertaken to reconsider previous assumptions of the law, and that the various contributions on the subject, however obscure, may provide some clarity.

\textbf{CONCLUSION}

The proposal put forth in this essay has presented ethical and philosophical arguments on behalf of a consciousness-based definition of death. Many of the underlying principles for this definition were presented years ago, but were, in essence, deliberately obscured in quasi-scientific terms. The whole-brain oriented criteria for death which now carries the day is essentially a formulation derivative from value judgments about human existence. Specifically, the assumption that an irretrievably unconscious patient is not alive pervades the historical

\textsuperscript{102} Death Dinners at Baby Boomers’ Tables Take on Dying Taboo, Shannon Pettypiece (Sep 24, 2013) \url{http://www.bloomberg.com/news/print/2013-09-24/death-dinners-at-baby-boomers-tables-take-on-dying-taboo.html} (accessed November 19, 2013). These dinners are noteworthy for their general emphasis on dying “with dignity” as opposed to dying in accordance with any prescribed organized religious doctrines. \textit{Id.}

\textsuperscript{103} The tumultuous episode of Terri Schiavo is a salient example of one such upheaval. \textit{See Schiavo ex. rel. Schindler v. Schiavo}, 403 F.3d 1289 (11th Cir. 2005).
record in the most recent redefinition of death, even if this assumption was not prominently on display in the text of the U.D.D.A. In addition to bringing the central aspect of consciousness to the fore of legal concern vis-à-vis death, the proposal includes an assessment of the benefit of continued medical treatment. This step is suggested not to inject social interests unrelated to a clinical definition of death, but merely to acknowledge that these interests (e.g., doctors, hospitals, other patients in need of hospital beds) are, in fact, at stake wherever death is assessed. Finally, the inclusion of a concern for unbefitting treatment in the proposal is meant to reflect a basic reality in every human death: no existing medical technology can restore the patient to a state of wellness. The proposal put forth here thus aims to be adaptive over time and to anticipate medical developments. Thus, no specific clinical diagnostic criteria have been suggested. That task, as is currently the posture of the law, is left to the medical scientific community.

To explore the procedures and legal corollaries involved in “moving the needle” of death would be beyond the scope of this essay, but a brief treatment of such issues is necessary before closing. A patient reliably deemed to be irreversibly unconscious and beyond the reach of medically beneficial treatment, under the current proposal, would be dead. Thus if the patient’s misfortune were the result of negligence in tort, an action for wrongful death would logically follow. So, too, would other “operations of law” such as transfers of property. Inevitably, some revisions in the law would be necessary. Such revisions would seem at this juncture to be entirely manageable, and not so disruptive as to form a serious challenge to a proposal such as this one.

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104 See Smith, note 38, supra, for a more exhaustive treatment of legal consequences involved (e.g., organ transplantation, estate-law issues, wrongful death).

105 Id.
Proposed Model Legislation

An individual who has suffered:

1) The irreversible loss of the capacity for consciousness, such that

2) Continued medical treatment would be of no benefit, is dead.

A determination of death must be made in accordance with accepted medical standards.

Comments:

An “irreversible loss” is one that cannot be restored with present technology and clinical skills.

“Consciousness” is the state or activity that is characterized by sensation, emotion, volition, or thought.

Treatment is “of no benefit” when it cannot make a patient well, even though it may maintain biological existence.