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Brain Death, Paternalism, and the Language of "Death"

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Brain Death, Paternalism, and the Language of “Death”

ABSTRACT. The controversy surrounding the dead donor rule and the adequacy of neurological criteria for death continues unabated. However, despite disagreement on fundamental theoretical questions, I argue that there is significant (but not complete) agreement on the permissibility of organ retrieval from heart-beating donors. Many disagreements are rooted in disputes surrounding language meaning and use, rather than the practices of transplant medicine. Thus I suggest that the debate can be fruitfully recast in terms of a dispute about language. Given this recasting, I argue that the language used to describe organ donation is misleading and paternalistic. Finally, I suggest that the near-agreement on the permissibility of heart-beating organ retrieval ought to be reconsidered. If the paternalism is not justified, then either the language used to describe organ transplantation must change radically, or it would seem to follow that much of the transplant enterprise lacks ethical justification.

INTRODUCTION

The controversy over brain death and the dead donor rule continues unabated, with some of the same key points and positions starting to see repetition in the literature. One might wonder whether some of the participants are talking past each other, not all debating the same issue, even though they are using the same words (e.g., “death”). One reason for this is the complexity of the debate: It’s not merely about the nature of human life and death. Interwoven into this debate are deep philosophical issues on realism, the normative/descriptive distinction, the relation of thought and language to the world, the mind–body problem, personhood, moral status, and the ethics of killing. There are also social and legal factors, biological disputes about organismic functioning, and, of course, organ transplantation is a key feature in the dialectic. The persistence of controversy is therefore unsurprising.

My aims in this paper are three. First, I’ll argue that, despite persistent disagreement regarding the nature and criteria for human death, there

is general, but not complete, agreement on the permissibility of organ retrieval from heart-beating (brain-dead) donors. Oftentimes, the disagreements are rooted in disputes surrounding language meaning and use, rather than the actual practices of transplant medicine. Thus the debate can be fruitfully recast in terms of a dispute about language. Second, given this recasting, I suggest that the remaining semantic dispute is not trivial, because the language used to describe organ donation to the general public is misleading and paternalistic. Third and finally, I suggest that the near-agreement on the permissibility of heart-beating organ retrieval ought to be reconsidered in light of the paternalism. More specifically, if the paternalism cannot be justified, then neither can organ retrieval from heart-beating donors (at least, given our current means of describing the practices of transplant medicine); and I submit that, *prima facie* at least, the paternalism is not justified.

OVERVIEW OF THE LITERATURE

The literature on brain death and organ transplantation is vast and complex, incorporating contributions from philosophy, the health sciences, law, history, anthropology, and others. Any attempt to organize the ideas in this literature under a coherent conceptual rubric is bound to underemphasize certain important views; nonetheless, I'll attempt to provide a reasonable overview of the major positions in the literature and to organize them along what I take to be their conceptually important dimensions. In particular, I am interested in organizing positions according to a view on death, as well as a view on the dead donor rule, which states that donors must be dead prior to organ retrieval (i.e., the process of organ removal must not kill the donor).

One conceptual framework that has had a great deal of influence on the debate is the definitions-criteria-tests framework, widely attributed to Bernat, Culver, and Gert (1981). This model proposes that we start with the definition of "death" (a philosophical task), then identify the physiological criteria that would satisfy that definition (a philosophical/medical task), and then finally devise tests that would identify when those physiological criteria have occurred (a medical task).¹ Although this framework is not universally accepted, it nonetheless has structured much of the debate over the last 30 years.

The theoretical conception of death that has clearly had the most impact, at least from a biological/medical perspective, is that death is the cessation of the integrated functioning of the organism as a whole (Bernat, Culver,

and Gert 1981; President’s Commission 1981a). Some related, likely equivalent formulations of this idea are that death is the irreversible cessation of the integrated unity of the organism as a whole; or, death is the irreversible cessation of the functioning of the organism as a whole in its maintenance of internal homeostasis and resistance of entropy (cf. Korein 1978; Korein and Machado 2004). One proposed physiological criterion for this definition is the irreversible cessation of all functions of the entire brain, including the brain stem (known as *brain death*); the diagnostic tests purported to be satisfactory in determining such cessation include unresponsiveness, brain-stem areflexia, and apnea. Alternative diagnostic tests would involve showing that the heart and lungs have irreversibly ceased functioning (since the permanent lack of oxygenated blood to the brain guarantees the irreversible cessation of its functioning). Adjoined to an endorsement of the dead donor rule, this combined position is the best candidate for what might be called the “mainstream” view, and is most visibly championed by James Bernat (Bernat, Culver, and Gert 1981; Bernat 1998, 2006).²

Alternatives to the Bernat view come in several varieties. One such variety accepts the definitions-criteria-tests framework, and accepts the conceptual theory of death in terms of the cessation of integrated functioning of the organism as a whole, but rejects the assertion that the cessation of all brain function is a criterion for that definition. Instead, the claim is that a body with no brain function but maintained on a ventilator can nonetheless continue to function as an integrated whole, and is therefore still alive. D. Alan Shewmon’s work in particular on this question has had a large impact on the literature (Shewmon 1997, 1998a, 1998b, 1999, 2001). Instead of appealing to irreversible cessation of brain functioning as a criterion for death, Shewmon argues that the integrative unity of a living organism is an emergent and holistic, nonlocalizable phenomenon deriving from mutual interaction between the parts, and mediated by circulating oxygenated blood. Therefore he proposes that the irreversible cessation of all circulo-respiratory function—that is, the cessation of the circulation of oxygenated blood as well as the cessation of gas exchange at the cellular level throughout the entire organism—is an adequate physiological criterion for the integrative unity concept of death (Shewmon 2001). When the Shewmon view on brain death (viz., that brain death is not biological death) is adjoined to a view on the dead donor rule, two different positions emerge, depending on whether one accepts or rejects the dead donor rule.

Theorists such as Franklin Miller and Robert Truog argue that brain-dead organ donors are biologically alive and the process of organ removal kills the donor (thus violating the dead donor rule); however, they argue, the dead donor rule ought to be abandoned. In place of the dead donor rule, Miller and Truog argue that the moral principles of respect for persons and nonmaleficence are most relevant here. Since the brain-dead body is irreversibly unconscious, it is beyond harm and thus nonmaleficence is satisfied. Assuming consent and hence respect for persons, organ removal from a brain-dead donor is acceptable, they argue, even though it kills the donor (Truog and Robinson 2003; Miller and Truog 2012). By contrast, theorists such as Paul Byrne, Michael Potts, and several others are in agreement with Miller and Truog that brain death is not death and organ removal kills the donor. However, these authors (whom I shall consider to be represented by Paul Byrne) accept the dead donor rule, and thus object to the removal of nonpaired vital organs from brain death patients, since such patients are, on this view, alive (Byrne et al. 1982–1983; Potts, Byrne, and Nilges 2000).

A newer challenge to the Bernat view comes from a white paper released by the President's Council on Bioethics (President's Council on Bioethics 2008). Like Bernat, the President's Council accepts the claim that brain death is biological death, but they reject the claim that brain-dead bodies lack integrative unity, accepting the physiological arguments made by Shewmon and others on this point. Rather than conceding that brain-dead bodies are biologically living, however, they replace the integrative unity conception of death represented by Bernat with a teleological theory: What distinguishes dead from living organisms is their fundamental drive to exist coupled with commerce between the organism and its environment, which is manifested particularly through breathing. The President's Council also endorses the dead donor rule.³

Each of the above views, to a greater or lesser extent, is broadly consistent with the basic framework of the definitions-criteria-tests model, and attempts to understand death solely in terms of biological or physiological properties. However, there are a number of additional views that reject one or the other of these assumptions, or supplement them with additional considerations.

Rather than attempting to understand human death in exclusively biological terms, many theorists argue that the capacity for psychological states, or considerations involving personhood or personal identity, are critical to understanding human death. Robert Veatch has argued,

for example, that the integration of mind and body are necessary for life; thus, once all psychological states have ceased to exist, the individual has died (Veatch 1975, 2004). Presumably, this can occur before brain death, as in the vegetative state or anencephaly. Further, he argues that the dead donor rule ought to be followed. Therefore organ removal from brain-dead donors is acceptable because they are already dead, but organ removal would also be acceptable from infants with anencephaly and vegetative patients as well, as they are also dead on this view. In a sense, Veatch’s view is similar to Bernat’s integrative unity view; the difference is that Veatch contends that the capacity for psychological states is a necessary “integrating factor,” such that when that capacity has ceased, the integrated functioning of the whole person (which includes both mind and body) has ceased, even though integrated bodily functioning and hence biologic life can continue. One of the more distinctive aspects of Veatch’s work (to my mind at least) is his claim, to be discussed more fully below, that in the context of the organ donation debates the word “dead” has taken on a new meaning, and now means something like, “lacking membership in the moral community” (Veatch 2003, 2004). Thus Veatch explicitly connects moral considerations to the definition of the word “dead.”

On the other hand, Michael Green and Daniel Wikler argue that considerations of personal identity across time, specifically rooted in John Perry’s theory of personal identity (Perry 1975), demonstrate that in brain death, the person has died; however, they reject the claim that brain-dead bodies are biologically dead (Green and Wikler 1980). In essence, the argument is that the persistence conditions on personal identity across time involve psychological continuity as a necessary condition. Since brain death strips the body of the capacity for psychological properties, then the body is not identical to the person that existed before brain injury, and nothing else is identical to that person, therefore the person doesn’t exist, therefore the person has died, and brain death is death.

Another important view in this family is John Lizza’s. While Veatch explicitly brings normative considerations into the definition of “death,” and Green and Wikler explicitly reject conflating moral questions with what they take to be a purely ontological question about the persistence conditions on personal identity, Lizza argues that ontological, moral, biological, and cultural factors are all relevant to understanding death (Lizza 2006). Lizza accepts the physiological arguments made by Shewmon and others that the brain-dead body is a biologically living body. However, he rejects the “biological paradigm” of death, which treats the question as a

strictly biological matter, and instead argues that to understand death we must supplement the biological paradigm with an ontologically, ethically, and culturally informed analysis of what dies (i.e., the human being, or the person). For Lizza, to accept the biological paradigm is to ignore the psychological, cultural, and moral aspects of ourselves, and distorts our nature. He proposes a nonreductionist, substantive view of persons as substances that have both psychological and biological characteristics (which is distinct from what he calls the functionalist or qualitative accounts of personhood that he argues are assumed by Veatch, and Green and Wikler), thus arriving at a distinct account of a consciousness-based formulation of death that treats the capacity for consciousness or mental activity as a necessary condition on personhood. Hence, Lizza would argue that brain-dead bodies are dead persons (in a substantive, nonmetaphorical sense), as are anencephalic infants and patients in a permanent vegetative state.

Winston Chiong has also challenged the definitions-criteria-tests framework, but in a different way, arguing that it relies on the assumption that there are necessary and sufficient conditions for class membership and that these conditions can be discovered through an analysis of language (Chiong 2005). Chiong challenges these assumptions, arguing that Saul Kripke (1980) and Hilary Putnam (1973) have convincingly shown that the reference of our terms is partially based on external causal factors rather than only internal descriptions; thus, simply analyzing the meaning of the word “death” and then articulating necessary and sufficient conditions for membership in the extension (i.e., reference class) of “death” as previously defined will not lead to knowledge of the world. Instead, Chiong argues that the concept of death, like other concepts, has more of a prototype structure than a quasi-linguistic definitional structure. Thus we need not look for one universal, privileged definition of “death,” accompanied by necessary and sufficient conditions for class membership, nor should we assume that there is one objective and essential property that distinguishes all living from all dead things. Rather, the property of being alive involves a cluster of characteristics, typically co-instantiated but they need not be, none of which are necessary and sufficient for life.

On this view, brain-dead bodies are dead, but not because they satisfy a privileged definition. Rather, they are dead because they have lost some critical number of this cluster of characteristics. Importantly, what constitutes a critical number or which characteristics should be treated as more important than others—that is, the distinction between life and death—is indeterminate, and social considerations have a legitimate role to play by

introducing a somewhat though not entirely arbitrary dichotomy between life and death, in the same way that the age of 18 marks the somewhat though not entirely arbitrary cutoff line for adulthood.

Similarly, George Khushf (2010) rejects the reductionist approach of the definitions-criteria-tests model, which presupposes that the levels must be hierarchically arranged. Although he appeals to the similar framework of the four levels of generality proposed by Capron and Kass (1972), Khushf argues that the levels of generality work together, revising and constraining concepts both up and down the levels, in an iterative fashion similar to Rawlsian reflective equilibrium. Furthermore, facts (what death is) and values (what social interests are relevant to the debate) cannot be entirely separated. Neurological criteria for death represent a policy compromise between legitimate social interests, and thus the brain death policy is a satisfactory means of clarifying, for social purposes, what is inherently vague. Further, the dead donor rule is important and should guide organ donation policy, thus organ removal from brain-dead donors is justified because the donor is dead; however, organ removal from vegetative and anencephalic individuals is not justified because they are not dead.

Finally, in his some of his latest work, Shewmon has also begun to reconsider the semantic and metaphysical assumptions that appear to underlie the definitions-criteria-tests framework (Shewmon and Shewmon 2004; Shewmon 2004). Specifically, he argues that we have traditionally been assuming a univocal concept of death—that there is and can be only one “true” death—as a result of two mutually reinforcing factors. First, until very recently in human history, there simply was no need to distinguish different events that might plausibly be labeled with the word “death,” such as final expiration, final asystole, loss of potential for consciousness, loss of all brain function, etc., since all of these events traditionally had happened around the same time. Language therefore developed in such a way that a single word, “death,” was used to refer to that constellation of equally real events. Since language shapes thought, this single word now tends to restrict our thinking when applied to new situations arising as a result of modern medicine in which these different yet equally real events can be separated. He advocates expanding our vocabulary regarding these events, and furthermore, that the dead donor rule has been addressing the wrong question all along. The right question is not “Is the patient dead?” but rather “Can specific organs be removed without causing or hastening death or harming the patient?” (Shewmon 2004, p. 277).

In a later publication, Shewmon (2010) builds on these ideas by advocating a “paradigm shift,” wherein we recognize dual death-related events: That of *passing away* (or becoming *deceased*), which is the sociolegal ceasing-to-be (which criterion is the *permanent* cessation of functioning of the organism as a whole) and *deanimation*, which is the ontological/theological ceasing-to-be of the bodily organism (which criterion is the *irreversible* cessation of functioning of the organism as a whole). Shewmon accepts what he calls the *deceased donor rule*, arguing that at least in some cases it would be theoretically possible to remove certain organs in a non–heart-beating protocol (i.e., after final asystole) while respecting the deceased donor rule, but this would not be respected by removing organs in the case of brain death, since these bodies have neither irreversibly nor permanently ceased to function as an organism as a whole.

To impose some organizing structure on the variety of views presented here, it is helpful to consider several sources of disagreement. The first is in the background metaphysics: Is the nature of death purely biological, independent of social or legal factors, or do social considerations have some role to play in determining the very nature of death? According to Bernat, the President’s Council, Byrne, and Miller and Truog, death is a biological phenomenon, to be studied just like other biological phenomena, and there can be only one death for each individual. We do not socially construct what death is; although social practices play a role in the grief process and the manner in which we react to death, it is not open to revise or stipulate *what death is* as a result of social policy decisions. By contrast, while Chiong and Khushf both begin from a similar biological realist perspective, they also argue that biological reality underdetermines the truth of statements about death. That is, there may not be one, unique property that separates all living from all dead things. Rather, the boundaries of the class of dead things may be fuzzy and indeterminate, in which case social policy considerations play a legitimate role in choosing what death is. Shewmon appears to share a thoroughly realist metaphysics with Bernat and others, but also argues that we have been mistaken in supposing that there is only one “true” death. Instead, there is more than one real event, each of which had traditionally been referred to as “death.” As a result of changes in medical practices we have been forced to acknowledge these different yet equally real events, and to acknowledge them as distinct.

Veatch also accepts that biological reality constrains biological death, but he does not think that the brain death debate is about biology; instead it is about ethics. And this leads to another disagreement: What does the

word “death” mean? Note the difference: the dispute about metaphysics has to do with *what death is* (the event, not the word), and whether social considerations play a role in determining that. Here, the dispute is about *the word* “death.” Bernat, Miller, and Truog, agree that “death” is a commonsense word that we all use reasonably correctly and refers to a biological event. Lizza also agrees that “death” is a commonsense word that we all use reasonably correctly, yet he argues that to accept that “death” refers solely to a biological event is to violate ordinary language and to distort our nature (Lizza 2009). By contrast, Veatch argues that “death” has evolved to take on a new meaning, and now means something like “lacking membership in the moral community” (Veatch 2003, 2004). Thus, although Veatch agrees with Miller and Truog that brain-dead and vegetative patients are biologically alive, he also argues that in the context of the brain death and organ donation debate, the word “dead” now means something different, and on this new meaning, anencephalic, vegetative, and brain-dead individuals are all dead. Chiong, on the other hand, argues that “death” refers to a constellation of characteristics, some of which are social and relational, some of which are psychological, and some of which are biological. And Shewmon argues that the single word “death” has constrained our thinking and needs to be expanded with additional language to capture the complexity of the underlying concepts.

A further quarrel concerns the roles of personhood and personal identity. Lizza, Green, and Wikler, and argue that the death debate is about the death of the person; therefore understanding death requires a theory of personhood (for Lizza) or personal identity (for Green and Wikler). By contrast, Veatch claims that a theory of personhood *per se* is irrelevant to the debate; rather, what gives one full moral standing (and thus renders one *alive*, on Veatch’s use of the term) is the embodied capacity for consciousness, with the capacity for mental function being a necessary but not sufficient condition on embodied consciousness and mind–body integration, and thus on being alive (Veatch 2005, p. 370). Nonetheless Veatch, Lizza, and Green and Wikler would all agree that brain-dead and vegetative patients are dead, albeit for different reasons (partially because they are using the word “dead” in different ways).

Another disputed question is normative: Is it ever acceptable to intentionally kill an innocent human (i.e., one who is not attacking another), even with consent or an autonomous request, and even if death is imminent? Miller and Truog, in rejecting the dead donor rule, argue that it is permissible to kill the brain-dead (but, according to them, living)

individual, assuming that consent was obtained. All other parties adhere to the dead donor rule: It is not acceptable to kill an individual for the purpose of removing organs.

Biological questions are disputed as well, namely, whether the brain-dead individual in fact satisfies the largely accepted definition of (biological) “death” in terms of the permanent cessation of functioning of the organism as a whole, or, of the processes of internal homeostatic maintenance and entropy-resistance. According to Shewmon, Miller and Truog, Veatch, Byrne, and many others, the brain-dead individual (maintained on a ventilator) can nonetheless continue to perform a variety of homeostasis-maintaining, entropy-resisting processes of the organism as a whole, including circulation, nutrition, cellular respiration, gas exchange at the alveoli, generation of waste, salt and water balance, and others (Truog and Fackler 1992; Halevy and Brody 1993; Veatch 1993; Shewmon 2001). As a result, they argue that brain death does not correlate with the permanent cessation of the functioning of the organism as a whole, and therefore brain death is not biological death. Lizza, Green, and Wikler argue that the body is still alive for similar reasons, although they maintain that the person (as distinct from the biological organism) has died. By contrast, Bernat challenges this biological claim, arguing that such processes are not significant or that they are not critical or vital functions, and thus are irrelevant in the determination of biological death (Bernat 1998, 2006).

The President’s Council also acknowledges that the mechanically ventilated brain-dead individual can indeed maintain a variety of homeostatic, organism-as-a-whole functions, and that the empirical claim that brain death perfectly correlates with the loss of integrative unity of the organism as a whole⁴ has been shown to be false. However, they do not accept that the definition of “death” ought to be given in those terms. Instead, they argue that “death” should be defined in teleological terms; that is, a living organism engages in commerce with its environment guided by a fundamental drive. This gets operationalized in terms of the drive to ventilate (along with other functions, particularly consciousness). On this view, the variety of remaining biological functions that are often found in clinically diagnosed brain-dead individuals are not signs of life, but are instead masks that hide the death that has already occurred.

Khushf, Chiong, and the later Shewmon, on the other hand, argue that these are not the right questions to ask in the first place because they are based on background metaphysical and linguistic assumptions that should be rejected, namely, the definition-criteria-tests model. This standard model

for thinking about death and brain death is often used by the opponents of Bernat’s view, by arguing that the tests do not match up with the criteria, and the criteria do not match up with the definition, therefore, Bernat’s view ought to be rejected. Similarly, while the President’s Council rejects the integrative unity conception of death, they have instead proposed a new definition of the word “death.” But in so doing they have also implicitly adopted the definitions-criteria-tests model; they have simply proposed a new definition that is consistent with the preservation of a variety of physiological functions and organismic unity, thus seemingly avoiding the older criticisms of Bernat’s view.⁵

By contrast, Khushf argues that this is the wrong way to go about it from the start (Khushf 2010). Brain death forms the core of a policy that is intended to bracket the deeper philosophical questions about personhood, the nature of life, etc., and thus need not “match up” with some privileged definition. This allows disagreement at that deeper level while forging consensus at the policy level. Further, the different levels of generality work with each other, allowing for iterative changes both up and down the levels. Thus, showing an imperfect match between any two levels does not present a *reductio*, rather, it shows the legitimate iterative refinement of our policy and its conceptual basis.

Similarly, Chiong (2005) argues that this background structure makes assumptions about language and concepts that are unfounded, and instead recommends that brain death marks an acceptable (albeit somewhat arbitrary) demarcation between life and death, and need not correspond exactly to one particular concept defined by necessary and sufficient conditions. As a result, many of the questions asked above regarding whether tests, criteria, and the definition match up with each other are confused to begin with. And this brings us right back to the start, to some of the most fundamental philosophical questions: How are our words or concepts related to the world? Is death “out there” to be discovered, or do we somehow stipulate what it is? Is death biological, socially constructed, or does it mark a change in the moral regard owed an individual? Is it all of these things, or some combination?

As can be seen from just this brief (and surely incomplete) overview of the literature, there is a great deal of dispute. There is dispute about metaphysics and whether facts can be separated from values; about semantics and the meaning of the term “death”; about ethics and whether the prohibition against killing is an absolute, exception-less rule; about biology and whether the mechanically ventilated brain-dead individual

maintains homeostasis and resists entropy; about whether death is a biological, social, or moral phenomenon; about personhood and its relation to the death debates; and more. With this much fundamental dispute on intersecting philosophical and scientific questions, it may seem that finding major points of agreement is impossible, and that the death debates truly are interminable.

However, there is also a key locus of agreement, among most but not all views discussed above, but describing it requires neutral language. I'll use the term "state X" to refer to the state in which the individual has suffered the irreversible cessation of all *clinical* functions of the brain.⁶ I intend this language to be neutral with respect to both death and the dead donor rule. With the exception of the families of views represented by Byrne and by Shewmon, the remaining authors discussed above agree that, at least under certain conditions (e.g., with a valid consent), removal of vital organs from an individual in state X is morally permitted. The justifying reasons why this is acceptable are quite different, and are indeed incompatible: Veatch would say that the individual is dead and the dead donor rule is followed, but he would also say that the individual is biologically alive; biology just isn't what's at issue. Lizza, Green, and Wikler, would say that the person has died even though the body is alive, but personhood is what matters. Bernat and the President's Council would say that the individual is biologically dead but for different and incompatible reasons; yet the dead donor rule is followed either way. Chiong and Khushf would say that the individual is dead because the social policy that we've agreed upon says that she is, and also accept the dead donor rule. Miller and Truog would say that the individual is biologically alive, but the harm of biological death is minimal or absent, autonomy is respected by obtaining a legitimate consent, and the dead donor rule need not be followed. If we simply bracket these reasons and their underlying theoretical disputes, many agree that the practice itself is morally acceptable. I think that is a significant point. Despite fundamental disagreement on a number of theoretical questions that underlie the practice, most (but not all) of the major views in this literature consider organ retrieval from individuals in state X to be morally permitted, at least given certain conditions such as informed consent.

In light of this near-agreement, I suggest (temporarily) bracketing the deeper philosophical questions about life, death, personhood, and so forth. However, this does not settle all disputes. While there seems to be near-agreement that the practice should continue, how should we *describe* it?

This is not the same as the dispute on whether death is a moral, social, or biological phenomenon. Rather, it is a question of communication—with clinicians, legislators, the general public, and family members of state X patients. Thus, I suggest explicitly recasting the debate in linguistic terms, as a question of what is the appropriate means of describing state X, and considering the practical and moral implications of both retaining and abandoning the word “death” as a description of state X. While some verbal disputes are trivial, as we shall see, this one isn’t.

AN ARGUMENT FOR USING “DEATH” TO REFER TO STATE X

I will first consider an argument for continuing to use the word “dead” to describe those in state X on the basis of the social entrenchment of the practice and the international acceptance of brain death as death, adapting some of Veatch’s arguments (Veatch 2004) (although he was arguing for broadening the legal definition of “death,” not simply maintaining it).

The position in question is represented by Miller and Truog: Assume that state X is not biological death; although it may very well involve a change in the moral regard owed an individual, and it may coincide with the ceasing to exist of the person, nonetheless let us assume that the body is biologically alive. Should we reject using the term “dead” to describe this state, but at the same time allow exceptions to the dead donor rule so that organs may be procured?

Veatch considers this position, and describes it as “more logical” than what he argues actually occurred, where “death” was redefined to mean something involving the moral community. He notes, regarding the Harvard Ad Hoc Committee’s seminal report (Beecher 1968), “the striking thing about the committee’s report is that in no place does it bother to defend the claim that people with dead brains should be classified as dead people.” Further, “none of the members [of the committee] was so naïve as to believe that people with dead brains were dead in the traditional biological sense of the irreversible loss of bodily integration” (Veatch 2004, p. 267). Instead, the committee implicitly held that these individuals had lost their membership in the moral community; the moral regard owed a human person is not owed individuals with lack of brain function, and in particular, no special moral justification was needed for biologically killing them in order to remove organs. Hence:

[T]he group from whom life-prolonging organs can be taken without special justification of homicide are thus “dead” by definition [since now “dead” means something like, “morally permitted to kill without special justifica-

tion”]. We first identify the group and then label them with the name. The name, unfortunately, is the same name we used to apply to those who have experienced biological death. (Veatch 2004, p. 268)

Thus, the more logical approach would have been to make the moral judgment explicit and open to careful consideration, rather than implicit through the creation of misleading technical jargon by using the word “dead”—the same word that applies to those who are biologically dead in the more usual sense—to mean something involving the moral community. However, that is not what happened, so we must consider the practical consequences of trying to go back and take the more logical approach.

As Veatch notes, there would have to be a change in all homicide laws so that transplant surgeons would not be considered guilty of murder by removing organs from living individuals in state X (assuming, that is, that there is broad social agreement that removal of their organs is morally licit). All of the brain death statutes that have been enacted in every state in the United States and in almost every nation in the world would need to be repealed. Everyone would need to unlearn the definition of “death” in terms of the lack of brain function. All of the other “death behaviors” associated with death would need to be sorted out: Do wives and husbands become widows and widowers when state X occurs, even though individuals in state X are alive? Do life insurance policies pay out? Do health insurance policies continue to provide coverage?

Perhaps the most important question is this: Would organ transplantation—for which the majority of retrieved organs come from individuals in state X—continue in its current form or would it be severely curtailed? Veatch notes:

In an environment in which a large part of the population has a strong interest in not changing any of the rights of the living to avoid being killed, all of these battles would be hard fought and contentious. (Veatch 2004, p. 273)

I think that he understates his important point. These battles may not be just hard fought, but impossible to win. In an era in which providing federal coverage for primary care physicians to speak with their patients regarding living wills gets met with cries of “death panels” and “killing Grandma” (see, for example, Rutenberg 2009), what would realistically happen were the medico-legal community to use the word “alive,” not “dead” to describe those in state X, yet nonetheless request social approval for removing their organs?

I believe that this is the strongest argument against the Miller and Truog position, and it is an argument from utility.⁷ Quite realistically, changing the language from “dead” to “alive” while attempting to delineate exceptions to the dead donor rule may very well result in a serious backlash against organ transplantation, and thereby result in many preventable deaths as the organ supply dramatically decreases. Thus, in the face of widespread (though not universal) agreement on the practical question of whether organ removal is permissible from those in state X, along with the potentially significant consequences of attempting to change the words used to describe the practice, a strong practical argument is made for keeping the language as is.

THE LANGUAGE OF “DEATH”

Although there are strong reasons to continue using the word “death” to describe state X, there are also strong reasons to discontinue doing so. In particular, *all* can agree that self-determination, the promotion of autonomous decision-making, and an open democratic society are each important (not necessarily overriding) moral values. Therefore we ought to look at the linguistic question again from this perspective: Does the language of “death” generate unnecessary confusion? Does it interfere with liberty or autonomy? Does it hinder an open democratic process of negotiation and policy construction on, literally, a matter of life and death? In this and the following two sections I argue that the language is misleading, and that the use of this language to describe state X should be construed as paternalism.

Consider what we might call the “ordinary” use of the term “dead.” In general, the (same) term applies to the insect in the backyard, the mouse that the cat brought in, the family pet, and one’s human family members. A well-known insecticide company advertises, for example, that it “kills bugs dead,”⁸ and this sense of the term “dead” shares an overlapping similarity with the use of the term as it applies to a family pet or a human family member. “Dead” is an ordinary word that has commonsense purchase, and there is an overlapping consensus (but not perfect agreement) on the entities in the world to which that term refers, even in the absence of an explicit definition appealing to necessary and sufficient conditions. For example, when one comes upon a cold, stiff body, there is no question that that individual has died, whether it be one’s beloved grandfather, one’s beloved canine, or an unwelcome rodent or insect in the house.

Surely, the word “dead” is also used in other ways, to refer to languages, civilizations, etc. Plausibly, one might also argue that the “ordinary” concept of death includes, *in addition to* biological functioning, some reference to the psychological, in that, for one who has died, there will never again be anything it is like to be that person (Holland 2010). However, first, I suspect that the use of the term “dead” to refer to languages and civilizations is metaphorical and derivative on the concept of death as it applies to humans, animals, or biological organisms more generally. Moreover, all I want to establish here is that the word “death” and its cognates are not (or not solely) technical jargon or neologisms. Furthermore, some (imprecise and revisable) notion of biological functioning is surely embedded in the connotation of the ordinary word “death,” at least when applied to humans (rather than civilizations). This simple point has some important ramifications for the use of the word “dead” to refer to state X.

Given this standard use of the term, consider the mechanically ventilated individual in state X. She will typically be warm to the touch and not bearing the grayish hue normally seen in the dead, due to continuing circulation. She may become feverish in response to infection, and some bodies in state X can gestate fetuses, grow, and sexually mature (Shewmon 2001; Powner and Bernstein 2003). Such bodies also maintain a variety of spinal cord reflexes, and thus may exhibit limb movements in response to stimuli and sometimes spontaneously. They may show movement during the apnea test or upon removal of the ventilator in what is known as the “Lazarus sign,” in which the arms reach out and then cross over the chest along with what appear to be short exhalations (Jain and DeGeorgia 2005). They metabolize nutrients and produce waste products; hence, they wear diapers and urinary catheters that need to be changed. Such bodies can be supported in this state for extended periods of time of several weeks or more (Yoshioka et al. 1986; Sugimoto et al. 1992), and there are cases of bodies in state X remaining in this state for up to 14 years (Shewmon 1998b). Leave aside, for the moment, whether this constitutes biological death or not; instead consider whether a person who has not studied the literature on state X, and is told that state X is death, is capable of understanding that statement given the connotation associated with the ordinary word “death” when applied to a human. At least for the most part, many people do not associate the gestation of fetuses, growth and sexual maturation, having a fever, moving limbs, and the need for regularly changed diapers, with being dead.

Now this is not to say that ordinary language determines reality or that state X cannot be death because “that’s not what ordinary people mean by the term.” It is however to say that, if state X is biological death, then scientists have discovered something interestingly different about biological death than what we had previously believed, and now the word “death” would take on a different, more technical meaning. It has become technical jargon whose meaning is importantly different (but also derived) from the older term, since the older term would not have been considered to apply to bodies that grow healthy, living babies (etc.).

However, consider some quotes from websites where people might go to learn about organ donation. The first is from OrganDonor.gov, a website of the United States Department of Health and Human Services (DHHS), and the second is from the United Network for Organ Sharing (UNOS), the agency responsible for allocating organs in the United States. “Patients who are brain dead have no brain activity and cannot breathe on their own. Brain death is not coma. Brain death is death” (United States Department of Health and Human Services, “Organ Donation: The Process”). Similarly, UNOS writes:

Your knowledge and action may help alleviate the suffering of the thousands of people who die annually for lack of available donor organs and tissue while a multitude of healthy organs are being buried every day. This dilemma itself is an ethical issue. (United Network for Organ Sharing, “Theological Perspectives”)

It is important to consider the context and veracity of these claims. The statement “brain death is death” does not make clear that, in this context, the term “death” is now associated with a different connotation *even if state X is biological death*. Even when read as using “death” to mean *legally dead*, the statement is still misleading. Although it might signal something about biological functioning or about the law, the connotation of the term “dead,” in this context, is now importantly different from that of the word “dead” as it applies in most other contexts. This new sense of the term does not apply to pets, rodents, or insects. Nor does it apply in the usual manner by which we might use the term with respect to humans: Finding a beloved family member in her bed, cold and unmoving, with no breath or pulse, engenders the appropriate use of the commonsense term “dead,” which is very different from the warm, heart-beating, waste-producing, possibly moving, feverish, or fetus-gestating “corpse” in state X. These different connotations would seem to generate confusion.

The quote from UNOS is also misleading. A “multitude of healthy organs” are *not* being buried every day. Once the individual in state X loses her capacity to circulate oxygenated blood, those organs suffer from ischemic damage very quickly and become unusable for transplant purposes. But in stating it this way, it sounds as if organ retrieval occurs after the “deceased” individual has become what most people would consider the kind of body that gets buried; namely, a cold and rigid cadaver. But this is not the case.

Thus, in general communications with the public, it is made to sound as if the word “death” means what it always has, and that when you sign up to be a donor, doctors will recover your organs after you become a corpse in the ordinary sense of the word, when that is not what happens.⁹ Using the word “death” and its cognates in the absence of explicit clarification of the differences between state X and what is more usually considered death, is importantly misleading, and this is so *even if state X is one and the same as biological death*.

BIOLOGICAL DEATH AND STATE X

But is state X one and the same as biological death? If not, then the paternalism issue becomes far more pressing. In this circumstance, the statement “brain death is death” is not just misleading, but false, at least when read from a biological perspective. And what other perspective should we expect our Department of Health and Human Services to speak from? Is it a moral authority, a philosophical authority, or a biomedical authority? Furthermore, Bernat (who represents the view with the most claim to being the “mainstream” view) has consistently and explicitly argued that brain death is death in the biological sense, not in a metaphorical, social, or moral sense, nor in the sense involving personal identity or personhood with which many philosophers have been concerned (Bernat, Culver, and Gert 1981; Bernat 1998, 2006). Similarly, the President’s Council has also made it explicit that they take the relevant question to be whether brain death (in their terminology, *total brain failure*) is biological death (President’s Council on Bioethics 2008). So I shall address them both.¹⁰

Bernat’s view on death has been decisively shown false time and again. He makes an empirical claim: Entropy increases when the “critical system,” i.e., the brain, stops working, and that is the justification for identifying state X with biological death. For example, he writes, “With the loss of the critical system [i.e., the brain], the organism loses its life-characterizing processes, especially its anti-entropic capacity, and entropy (disorder) in-

evitably increases” (Bernat 2002, p. 334). *All* other parties to this debate, including the recent President’s Council’s report, acknowledge that this is not the case. A variety of homeostasis-maintaining, entropy-resisting functions of the organism as a whole can continue in a ventilated patient with lack of brain function, therefore, entropy does not inevitably increase after brain function ceases, and lack of brain function does not equal the cessation of the integrated functioning of the organism as a whole.

The President’s Council, for example, writes:

Nonetheless, *something like health* is still present in the body of a patient [in state X]. This can be seen clearly in the “donor management” procedures . . . [that] aim to maintain the body in a relatively stable state of homeostasis so that the patient’s heart does not stop beating prior to surgery and the organs remain as healthy as possible. Thus, there is some degree of somatically integrated activity that persists in the bodies of patients who have been declared dead according to the neurological standard. The bodies of these patients do not “come apart” immediately upon succumbing to total brain failure. (President’s Council on Bioethics 2008, p. 39; emphasis in the original)

This argument, that the category of “brain death” does not correspond to the biological sense of the word “dead” in terms of homeostasis and organic integration, has been around for decades, and indeed since the concept of brain death was first introduced.¹¹ Yet despite obvious and irrefutable evidence to the contrary, Bernat’s view remains the orthodoxy, and is taught to new doctors and communicated to the public: Brain death is death, in the traditional sense of the word “dead.” Period.¹²

The President’s Council correctly acknowledges that if biological death is the cessation of homeostatic, somatically integrating functions, then state X is not biological death. However, the Council proposes a new definition of “death” that, they claim, total brain failure satisfies. Their new concept is a teleological one: a living organism is what it is in virtue of what it does, guided by a fundamental drive. All organisms, they write, “have a *needy* mode of being” (President’s Council on Bioethics 2008, p. 60). Organisms (unlike inanimate objects) continue to exist only through their own exertions; they must engage in commerce with the surrounding world:

This is the definitive work of the organism *as an organism*. It is what an organism “does” and what distinguishes every organism from nonliving things. And it is what distinguishes a *living* organism from the dead body that it becomes when it dies. (President’s Council on Bioethics 2008, pp. 60–61)

This fundamental work, they write, depends on three capacities:

1. Openness to the world, that is, receptivity to stimuli and signals from the surrounding environment.
2. The ability to act upon the world to obtain selectively what it needs.
3. The basic felt need that drives the organism to act as it must, to obtain what it needs and what its openness reveals to be available (President's Council on Bioethics 2008, p. 61).

Two objections are worth considering. First, no reason has been given for adopting their new analysis of biological death; they have simply asserted it without independent justification, therefore we need not accept it. Since all parties accept some version of the concept of *biological* life in terms of homeostasis, the functioning of the organism as a whole in its resistance of entropy, or something broadly along those lines, then showing that the brain-dead body is not in that category, as Shewmon, the President's Council, and countless others have shown, is sufficient for showing that biological life continues. If we are to adopt a new concept of biological life then it must be independently motivated and justified, consistent with a wider body of physical and biological theory, and have explanatory value through enabling predictive and manipulative utility or by providing a unified framework for explaining disparate phenomena. In other words, it must be a well-motivated theory, not just an *ad hoc* construction generated for the purpose of concluding that bodies in state X are biologically dead. But that is all this view amounts to, so we should not accept it.¹³

Furthermore, even given this new conception of biological death, the body in state X nonetheless fails to satisfy their own definition, partially as a result of the way that they explain their concepts of "openness to the environment," "act upon the world," and "felt need" (for similar arguments, see Joffe 2009; Joffe et al. 2012). Because they (correctly) believe that vegetative patients are biologically living, they are careful to explain these crucial concepts in such a way that an unconscious individual will satisfy them. Thus, "act upon the world" needn't imply organized and coordinated overt bodily movements, and "felt need" does not refer to consciousness, experience, or perception in the usual sense, but rather is manifested through such activities as the spontaneous (and unconscious) drive to contract the diaphragm, mediated by automatic and unconscious cellular activity in the medulla.

As a result of their interpretation of these concepts, an individual in state X thereby satisfies their definition. Such an individual is still "open

to the world” in many ways. Spinal reflexes continue, as do hemodynamic responses to incision and immune system responses to infection. Unconscious sensory processing can be present, as evidenced by intact evoked potentials (Halevy and Brody 1993). Temperature can be sub-optimally regulated. As a result of surgical stress from incisions and sternotomy for organ retrieval, heartbeat and blood pressure can increase (Pennefather, Dark, and Bullock 1993; Hill, Munglani, and Sapsford 1994), and stress hormones can be released in a coordinated fashion (Fitzgerald et al. 1996). The exchange of gases at the alveoli enables the organism to pursue its “vital work,” allowing it to continue maintaining its “openness.” It selectively obtains oxygen molecules and releases carbon dioxide. Furthermore, since unconscious ventilation mediated by the medulla evinces a “felt need,” then the pacemaker cells in the cardiac sinus node also manifest the organism’s “felt need,” driving the organism to act as it must by contracting the myocardium, to obtain the oxygen it needs by circulating the blood, and which the organism’s openness and receptivity to that oxygen at the alveoli reveal to be available. Furthermore, the contraction of smooth muscles in the gut to achieve peristalsis and move food and waste products through the gastrointestinal system would also constitute a “felt need” or basic drive for the organism to act as it must in its exchanges with the world. In the heart-beating donors who become tachycardic, hypertensive, and generate endocrine stress reactions in response to midline incision and sternotomy for organ retrieval, their receptivity to external stimuli allows the organism to attempt to obtain what it needs: more circulation mediated by faster contraction of the myocardium and a change in vascular diameter, bringing those vital molecules of oxygen along with the cells and cellular building blocks needed for repairing the “felt” damage to its tissue.

The President’s Council has taken a very important step forward by acknowledging that the mainstream view on biological death represented by Bernat is false (and obviously so), nonetheless they have replaced it with an unmotivated conception of biological death, which does not even do the *ad hoc* work for which it was intended: Even if this were the correct theory of biological death, the body in state X maintains its receptivity to the environment, and acts upon that environment as a result of its “basic felt need.” It is therefore an unsuccessful justification for considering state X to be biological death.

This has important implications for two other views. Khushf and Chiong each have relatively subtle metaphysical views informing their positions. Both argue that the biological reality of death, in an important

way, underdetermines the truth of our statements about death. As a result, sociolegal precisification is in order, in which case extrabiological considerations play a role in determining what death is. However, biological reality nonetheless must play an important constraining role: Those extrabiological considerations are brought in only to adjudicate where—along the spectrum of vagueness—we ought to draw the line for social purposes. But social purposes will not allow us to draw that line at someone walking and talking, for example, any more than it will allow us to draw the line for adulthood at the age of 3. Rather, social considerations come into play when we have reached a point at which biological considerations no longer provide determinate criteria of the nature of the underlying state. In other words, the mere possibility of vagueness, or of biologically underdetermined cases, does not get us to the conclusion that the individual in state X is in that vague category.

The biological considerations discussed above, however, help clarify this: Those mechanically ventilated individuals who engage in a variety of physiological functions aren't in some vague ontological category. They are clearly biologically alive, on the standard homeostasis/organic integration theory of death as well as on the President's Council's teleological theory. This is not to say that social considerations shouldn't play a role in determining policy or legal statutes or anything else, and it's not to say that those individuals are owed moral regard or are persons in any robust sense. Nonetheless, it has been clearly established at this point that the *biological* term "dead" does not apply to those in state X. And this is so whether we begin with the more straightforward realism adopted by the President's Council and Bernat (death involves an immutable, objective, biological fact), or the more subtle realism of Chiong and Khushf, which allows for the possibility of vague cases or the sometime conflation of facts with values. Either way, state X isn't *biological* death, in any sense, whatever else it may be.

Thus, if state X is biological death, then the language is misleading because the connotation of the ordinary word "dead" is very different from that associated with state X. If state X is not biological death (as I have argued), then the language is both misleading *and false*. Clearly, there are many aspects of state X that are relevant to morality, as Veatch argues, and to personhood, as Lizza has argued. But using the language of "death" to describe these individuals, or as a means to describe their moral or ontological personhood status when they are biologically living, is misleading. Being misleading, however, is not the same as being pater-

nalistic. In the following section I show that the use of the term “dead” to describe state X constitutes paternalism.

PATERNALISM AND THE DEAD DONOR RULE

Paternalism involves limiting the liberty or autonomy of another by acting contrary to or without regard for her wishes, based on the justification that doing so is in the best interest of that person, or that doing so will promote that person’s welfare or prevent harm. For example, Dworkin writes,

P acts paternalistically towards Q if and only if (a) P acts with the intent of averting some harm or promoting some benefit for Q; (b) P acts contrary to (or is indifferent to) the current preferences, desires, or values of Q; and (c) P’s act is a limitation on Q’s autonomy or liberty. (Dworkin 1999, p. 649)

Crucially, paternalism involves not simply acting without regard for the wishes of another, but based on a justification that doing so is for the good of the other; some classic examples of paternalism are seat-belt laws and withholding medical information to prevent emotional distress.

At this point in the dialectic I take the following as given: The language of “death” as applied to state X is misleading. And this is so even if state X is biological death, but is even more misleading if state X isn’t biological death. From this premise, I’ll argue that the use of such misleading language constitutes a limitation on someone’s autonomy, that doing so is indifferent to that individual’s preferences, desires, or values, *and* that this limitation can promote the good of the one whose autonomy is diminished.

The first step is to establish the relevant parties, and it is clear that this issue involves essentially everyone. No one knows if at some point she or a loved one will need an organ transplant, or if she or a loved one will be in state X. Furthermore, from a political perspective, most people want to have a say in the laws and policies of the land, including those that govern medical practices surrounding death and dying. Therefore I will consider “Smith” to be any arbitrarily selected, adult member of society; Smith’s autonomy is paternalistically limited. The second party is the medical profession construed very broadly (but particularly those involved with transplantation), including bodies such as the DHHS and UNOS; it also includes the legal statutes defining “death” in terms of neurological function.

In the case at issue, by using “dead” to describe state X, particularly in the context of organ donation, the medical profession is providing

misleading or false information to Smith. Should Smith use that misinformation to make decisions regarding herself or a family member, then Smith's ability to direct her life based on informed reason, and hence her ability to exercise her autonomy, is diminished.

Furthermore, Smith participates in the political process, and wants to have a say in the laws and policies that govern her land, including those directives that apply to medical practices. Smith believes that state X is death in the usual sense with which she is familiar, and so supports or at least does not oppose organ transplantation on that basis. But state X isn't biological death or, if it is, is a state that is very different from the "death" with which Smith is familiar. Thus, Smith's political support is based on misinformation, and her autonomy is further limited because her ability to participate meaningfully in the democratic process has been diminished. Her vote doesn't really count, because it isn't *her* vote; that is, it's the vote that she cast, but it does not necessarily reflect her values. Therefore, the use of misleading language impedes Smith's ability to direct her life and to pursue what she values, particularly in terms of her political participation; therefore, it limits her autonomy.

Second, the misleading language reflects a disregard or indifference for her preferences and values. Assuming Smith had a clear understanding of state X, she might agree with Veatch that the individual in state X is not owed moral regard in the same sense that she was prior to her injury or illness. She might agree with Miller and Truog that organ retrieval from those in state X is licit because those in state X are beyond harm. But Smith might agree with Byrne, Shewmon, and the many other authors who recognize that brain death is not biological death, but who also support the dead donor rule and thus oppose organ retrieval from brain-dead patients. Smith might have religious commitments that imply that biologically living humans have souls, or inherent dignity demanding they not be killed, irrespective of their capacity for psychological states or self-ventilation. Or she might not consider those in state X to have inherent moral value, but nonetheless might oppose a policy that permits killing biologically living though irreversibly unconscious humans on slippery slope grounds. Or, at the very least, Smith might oppose a policy that permits organ retrieval from those in state X simply on the grounds that it is still very much under debate among the relevant professional communities whether state X is biological death or not. Whatever her values, the use of misleading language that prevents Smith from informed deliberation and informed political participation shows an indifference to those values.

To show that this is paternalism, it must also be shown that this limitation on Smith’s autonomy along with indifference to her values is for her own good. I submit that, at least partially, it is. No one knows if she may ever suffer organ failure, or whether a loved one will be in need of a transplant. Organ transplants save lives, without a doubt, and this is a substantial good. Having the political and legal possibility of an organ transplant, should Smith (or her loved ones) ever need it, is clearly for her benefit.

However, just because it appears to be in the interest of all to have the possibility of a transplant, it doesn’t follow that there is any need for a limitation on Smith’s autonomy or an indifference to her values in order to achieve that goal. Since everyone agrees that saving lives is a good thing, then why the misleading language? Here it is very clear, and this is a critical point that bears emphasis: *The misleading language is necessary precisely because so many people support the dead donor rule, which is a manifestation of a much older injunction to refrain from intentionally taking life.* Many if not most people believe that killing someone for her organs is not acceptable. Just a brief glance at the major positions above shows this: Only Miller and Truog explicitly advocate abandoning the dead donor rule. Consider, for example, the view of the President’s Council:

As for the second reform option—that is, abandoning the “dead donor rule” as a guide for practice—the Council believes this is not ethically justifiable. *If* indeed it is the case that there is no solid scientific or philosophical rationale for the current “whole brain standard,” then the only ethical course is to stop procuring organs from heart-beating individuals. (President’s Council on Bioethics 2008, p. 12; emphasis in the original)

Of course, it is an open empirical question what the public in different states and nations would want, assuming an adequate understanding of state X (which, currently, we may not assume). Nonetheless, it is reasonable to assume that, had the medical community not redefined “death” in such a way that those in an irreversible coma might be reclassified as dead, the field of transplant medicine would not have flourished as it did. Intentionally, directly causing the biological death of a human is nowhere legal in the United States (except, of course, in state-sanctioned killings as in the death penalty), and is practiced in only a handful of nations. Since organ retrieval from the biologically living individual in state X is the direct cause of the biological death of that individual, it only stands to reason that similar policies would have been enacted with respect to it. However, by reclassifying those who are in an irreversible coma as *dead*,

the politically fraught and extremely controversial debate surrounding end-of-life issues is avoided, thus making the benefit of transplant medicine available to all (including, of course, Smith). Therefore the misleading language of “death” interferes with Smith’s autonomy, particularly her active participation in the political process. It does so with disregard for her preferences or values, and, furthermore, it creates the political and legal possibility of transplant medicine, which is a benefit to Smith. Therefore we ought to construe it as paternalism.

REASONS, INTENTIONS, AND THE ACTIVE SUPPRESSION OF CONTROVERSY

In this penultimate section I’ll address one important objection to my claim that the language of “death” is paternalistic, discussion of which will enable clarification of my claim, and will also enable me to strengthen the argument. I’ll close the section with some comments on why, at least *prima facie*, the paternalism does not seem justified.

As I see it, the most important objection is this: A crucial element of paternalism seems to be that the paternalist *intends* to promote some good for her beneficiary. Have I shown that “the medical profession, very broadly construed” has *intentionally* misled the public, rather than, say, was (and remains) simply confused?¹⁴ Indeed, with such an amorphous entity comprised of government agency websites, language at Motor Vehicle Departments, state statutes, etc., is it even coherent to attribute any kind of unified intention?

To address this concern, I’ll begin by clarifying a number of key distinctions. Next, although my chief concern is with contemporary practice and discourse, I’ll briefly mention the kinds of concerns that motivated the initial shift to neurologic criteria in the 1960s, as this provides important context. Finally, I’ll provide a number of examples that clearly demonstrate that contemporary practice and discourse should be construed in terms of paternalism.

First, the very same action can have more than one motivation or justification. For example, seat-belt laws protect the person wearing the seat-belt, and leave no choice to that person as to whether she will wear it; therefore they are paternalistic. However, such laws also have the effect of decreasing the strain on the healthcare system by decreasing the number of serious traumatic injuries. For a different example, speed limits protect the driver of the car by decreasing the likelihood of a crash, but at the same time, they protect the public safety and hence protect others from harm. Shall we call speed limit laws and seat-belt laws nonpaternalistic because

they can have an additional justification that does not refer to the good of the one whose autonomy is restricted, but instead refer to the protection or benefit of others? Grill recognized this key point, and proposed to define “paternalism” in terms of “action-reason compounds”:

In order to distinguish the invocation of one particular reason for some action with a mixed rationale, we need a way to talk about the compound of a certain reason for a certain action. I propose that we simply adopt the term “action-reason” to refer to such compounds. As a definition of paternalism, I propose that only action-reasons can be paternalistic and that an action-reason is paternalistic if and only if the reason is one referring to the good of a person and the action is an interference with the same person. (Grill 2007, p. 442)

Thus, insofar as the motivation or justification for using the word “dead” to describe state X adverts to the good or the benefit of others, and insofar as that language interferes with those very same others (for example through preventing legitimate political discourse), then that action-reason compound should be construed as paternalistic.

However, in appealing to “reasons,” it’s important to be clear on distinct kinds of reasons. In particular, there are explicitly stated motivations for action, which might be distinct from deep yet psychologically real motivations that an actor harbors, but which might not be explicitly stated. These two kinds of “reasons” are causal concepts: What is the causally relevant psychological state that played a key role in the agent’s allegedly paternalistic action, which the agent might point to as her “reason”? By contrast, there are *justifications* for actions, which are logical concepts, and need not be explicitly stated or held by anyone; these can be further broken down into *prima facie* justifications and *ultima facie* justifications. The former involve those justifications which upon first glance appear to be relevant considerations for justifying an action but are defeasible, and the latter are those justifications which, once all the evidence is in, an ideal moral cognizer would recognize as ultimately morally justifying the act in question. Thus there is a major distinction—motivation (which is causal) versus justification (which is logical)—and each component has its own further distinction. These are not mutually exclusive, as an agent’s stated reason may be that agent’s deep motivation, and that reason may be both *prima* and *ultima facie* justifying of the action in question.

I don’t think that there is any need to settle which of these (at least) four possible senses of “reason” are necessary for defining “paternalism.” Instead, there are probably different types of paternalism that correspond

to these different kinds of reasons, and perhaps the language of “death” falls under some but not all the kinds of paternalism.

Insofar as the relevant type of reason in the action-reason compound involves the causal concept of motivation, the paternalist need not intend to mislead *per se*, only to benefit. It is possible for language to mislead the hearer without the speaker intending that the hearer be misled. So long as the paternalist’s action interferes with her beneficiary, and the reason in the action-reason compound adverts to some form of benefit for the person with whom the action interfered, the action-reason compound is paternalistic, regardless of whether the paternalist intended to interfere or mislead *per se*.

In light of these clarifications, let’s have a look at the practices and discourse surrounding transplant medicine. Without question, one of the most historically important events is the 1968 publication of the Harvard Ad Hoc Committee’s “A Definition of Irreversible Coma.” Here are the first words of the Report (Beecher 1968, p. 337):

Our primary purpose is to define irreversible coma as a new criterion for death. 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.

As stated, the Committee’s motivations for reclassifying comatose patients as dead patients involve protecting a variety of people from the burden of maintaining the irreversibly comatose. This includes the families of comatose patients, other patients in need of those beds, and society more generally, by relieving hospitals of a financial burden. Second, the Committee explicitly states that part of the motivation is to dispel or avoid controversy in retrieving organs from these comatose patients. By that point doctors were well aware that ischemia quickly damages organs and makes them unusable for transplant purposes. The most effective means of obtaining healthy, viable transplant organs is to remove them from a heart-beating donor.

Thus, there are a variety of benefits that can be provided to many people, *if* we agreed to treat irreversibly comatose patients in ways that

were previously reserved only for the dead. Namely, if we agree that no consent is required for ending their occupation of a hospital bed and use of medical resources, then a more just use of those resources can presumably be achieved. Furthermore, families can be relieved of confusion and suffering, to a certain extent, because the grieving process can begin in earnest, rather than kept in limbo while the comatose patient is biologically maintained with no psychological states or hope of recovery. Second, everyone agrees that autopsy, burial, or cremation is acceptable on at least some dead bodies. If we can agree to treat the irreversibly comatose in a similar way—that is, that it would be permissible to cut them open and take out their parts—then a major benefit can be provided to thousands of ill people, people who previously had no hope without an organ transplant. These are significant benefits to individuals and to society, allowing for more efficacious medical treatments, hope where once there was none, and a more just distribution of scarce medical resources. But these benefits could not be achieved unless we *first* agreed that it would be acceptable to treat irreversibly comatose patients in ways that, previously, only dead bodies had been treated. To address these concerns, the Harvard Committee (and others) recommended reclassifying irreversibly comatose patients as dead patients; achieving these benefits was their *explicitly stated* motivation.

Surely, human motivation is complex, and social changes are even more complex. Perhaps some of the key players did truly believe that state X is biological death, and that the benefits provided by a statutory redefinition, which included transplant medicine as well as unilateral authority to cease treatment of irreversibly comatose patients, were simply by-products of what they believed to be the independent truth that state X is biological death. Perhaps others were simply confused, and did not realize that they were conflating moral questions about the permissibility of organ retrieval with factual biological questions about the nature of biological death. It may also be the case that many (or all) involved were simply passive players, unable to withstand the inexorable advances of the “technological imperative” (cf. Hofmann 2002): Once organ transplantation became technically possible, perhaps it was believed to be morally obligatory, and a variety of *post hoc* justifications were advanced to enable the technology to proceed.

I’m not here taking a stand on the best historical explanation for the shift, because it is complex and well beyond the scope of this article (for different historical explanations, see Stevens 1995; Belkin 2003). Instead,

it is important to appreciate that a number of factors and motivations were involved in the initial shift, but they were mostly with respect to *ethical*, not scientific questions: Can treatment be withdrawn, allowing ventilator-dependent comatose patients to die? Can this be done in the absence of family agreement, or even unilaterally and over objection? Can organs be removed from such patients? These are all ethical questions, not scientific questions, and therefore they are not subject to assertions of medical authority. Yet many contemporary discussions seem to presume that the identification of state X with death is a question of medical, scientific fact, rather than a response to ethical or philosophical problems (for more on this see Nair-Collins 2010). This is important because by treating the issue as a technical medical question rather than one of ethics, the authority of medicine can be brought to bear in dismissing doubt and controversy as a result of lack of understanding of the “science” that supposedly undergirds such claims, or by dismissing such objections as unscientific.¹⁵

This crucial shift in discourse, which treats the question as one of medical fact, along with the concept of the organ “shortage,”¹⁶ are both critical differences between earlier discourse and contemporary discourse. In particular, the idea that there is an organ “shortage,” and that ever more organs *must* be procured, is presumably a major driver of the misleading language and, as I’ll detail below, the active suppression of doubt and controversy.

Whatever relations it may hold to personhood or moral status, state X is not biological death, either on the homeostasis/organic integration theory or the teleological theory of biological death. Medical knowledge of coma *has* advanced since the days of the Harvard Committee report; it was previously believed that bodies in state X would inevitably suffer cardiovascular collapse within a few hours or days (Pallis 1983), but this isn’t true (Yoshioka et al. 1986; Sugimoto et al. 1992; Shewmon 1998b). It was believed that the cessation of all brain function perfectly correlates with the cessation of the functioning of the organism as a whole in its ability to maintain homeostasis and resist entropy (Bernat, Culver, and Gert 1981), but this isn’t true (Shewmon 1998b, 1999, 2001). It was believed that the state identified by unresponsiveness, brain-stem areflexia, and apnea correctly identifies the irreversible cessation of all brain function (President’s Commission 1981b), but this isn’t true (Halevy and Brody 1993). It simply isn’t a reasonably open scientific question as to whether the body in state X satisfies the traditional theory of biological death in terms of homeostasis and entropy. Surely a number of the more subtle

philosophical questions, such as the relationship between facts and values, the nature of linguistic reference, the revisability of scientific or social categories, the moral status of unconscious yet biologically living humans, and the relationship of consciousness, personhood and personal identity to this debate, are still reasonably open. But the clinical, biological status of irreversible coma is quite clear: Such patients are critically ill but are no more biologically dead than other, often less homeostatically stable patients found in our ICUs (Shewmon 2010, p. 259). I'll even temper my strong assertions: At the very least, it is clearly the case that there are serious contemporary *scientific* objections to the biological claims made by Bernat and others who continue to assert the mainstream view that state X is biological death. Are these facts—at the very least the existence of significant *scientific* doubt and debate—made clear in contemporary discourse?

Anthropologist Margaret Lock writes, “[shortly after the shift to neurologic criteria took place,] disputes by experts about the status of brain death were erased from both general medical and public attention by a judicious use of the metaphor of the ‘gift of life’” (Lock 2004, p. 137). This differential emphasis on the “gift of life” for the transplant recipient, along with a suppression or dismissal of controversies regarding the practices of transplant medicine, characterize the majority of the discourse that is intended to reach either the general public or a general medical audience today. And this differential emphasis on the benefits to transplant recipients, coupled with active suppression of doubt and controversy, strengthens my claim of paternalism over and above the issues regarding use of the language of “death”: It illustrates an ethos in which autonomy is subverted by attempting to restrict access to or dismiss the legitimacy of information that might result in decreased organ donation rates or political opposition to the practices of transplant medicine.

Woien et al. (2006) undertook a quantitative study of all 60 UNOS websites where the public can go to learn about organ donation and sign up to be donors, and documented that not even one satisfied the requirements set forth by the DHHS for informed consent for organ donation. In a later study, the same group (Rady, McGregor, and Verheijde 2011) documented the provision of biased information regarding organ donation that has not been verified for scientific accuracy, along with the suppression of medical, ethical, and religious controversies involved in determining death for organ donation, in mass media campaigns targeted at increasing donor enrollment at departments of motor vehicles. Instead of providing

unbiased information on state X and organ retrieval, including the fact that there are very real scientific, ethical, and religious controversies surrounding organ donation, organizations such as UNOS attempt to replace those controversies with positive reinforcement and encouragement to donate organs, especially through noble-sounding slogans such as “donate life.” For example, UNOS has the following on its “Common Myths” webpage:

Myth: Your religion prohibits organ donation.

Fact: All major organized religions approve of organ and tissue donation and consider it an act of charity. (United Network for Organ Sharing, “Common Myths”)

This is highly misleading. Most (if not all) major world religions forbid killing one person in order to harvest organs to save the life of another. Therefore insofar as it exists, religious support for organ donation is dependent on the accuracy of the assertion that individuals in state X are dead. But such individuals are biologically alive, and the numerous philosophical arguments regarding personhood, the nature of facts and values and their sometime legitimate conflation, or that “death” now means “lacking membership in the moral community,” are unlikely to be appealing to many religious persons concerned with a nonphysical soul, inherent human dignity, or some other religious concept.

Furthermore, although it is correct that some interpretation of most major organized religions can be found in support of organ donation, to claim that “all major organized religions approve of organ and tissue donation” is to misrepresent the ongoing controversy among religious scholars and faith leaders regarding the legitimacy of neurological criteria for death, and thereby the legitimacy of organ harvesting from heart-beating donors. These controversies have existed from the inception of transplant medicine, and as the scientific controversy has grown, so has the religious controversy. Doubts regarding the adequacy of death determination for transplant purposes are found from the perspectives of Buddhism (Keown 2010; Mizuno and Slingsby 2007), Shinto (Mizuno and Slingsby 2007), Confucianism (Cheng-tek Tai 2009), Taoism (Cheng-tek Tai 2009), Judaism (Kunin 2004), Catholicism (Shea and Magazine 2007; Verheijde and Potts 2010), and Islam (Bedir and Aksoy 2011; Rady and Verheijde 2012). Yet the transplant community continues to assert uniform religious support in the absence of controversy, while even advocating that faith leaders should reinterpret religious scriptures in order to gain more support for transplant medicine (Sharif et al. 2011).

For another example, it has been well known for decades that the standard clinical tests, even when augmented with ancillary tests including four-vessel angiography, are not sufficiently sensitive to detect the irreversible cessation of all brain function, particularly the neurohormonal functions of the hypothalamus. Yet the American Academy of Neurology, in its “Guideline for Caregivers and Families of Patients” writes, “When a loved one suffers a severe brain injury, all brain function may be lost. This is known as brain death. Doctors can accurately determine brain death” (American Academy of Neurology). In this statement, the word “this” clearly refers to the state when *all brain function is lost*, and the assertion that doctors accurately determine the presence of that state is false. Again, this is irrespective of any controversies as to whether such neurohormonal function should count as a “critical” function of the organism as a whole (Bernat 1998) or whether it is “sufficiently integrative” (Capron 2001). By *all* accounts, hypothalamic control of plasma and urine osmolarity is a brain function, and by *all* accounts, doctors do not rule this function out when they diagnose “brain death” (i.e., state X), and then unilaterally withdraw treatment or remove organs on the basis of this diagnosis. Everyone who has ever written on this topic knows this. So why does the American Academy of Neurology assert something that is simply factually incorrect, if not to avoid confusing the public (by acknowledging that some brain function indeed remains in state X) and thereby to prevent distress for families, or to prevent a decrease in organ donation rates?

At the bedside, procurement coordinators use communication strategies to dismantle cultural, religious, and ethnic barriers to organ donation, in order to seek compliance of families to donation requests, rather than to maximize understanding and thus the moral legitimacy of consent (Rady, McGregor, and Verheijde 2011). This includes “team-huddle” programs in which transplant coordinators have access to medical charts of potential donors prior to family consent to such access, and use this information to learn about potential donors’ ethnic and cultural background and religious affiliation before approach (Rodrigue, Cornell, and Howard 2008). Others communicate about the family with hospital staff, and observe the family from a distance, prior to approach, in order to target their request (Rady, McGregor, and Verheijde 2011). Procurement coordinators also use what is known as the “presumptive approach” to gaining consent, entering the conversation on the assumption that the family will consent, and conveying the benefits of donation to those on the list, presuming that donation is a good thing and that families will consent (Shafer 2009).

In one study (Franz, DeJong, and Wolfe 1997), researchers followed up with the next of kin of 164 consecutive candidates for organ donation in Delaware, New York, and New Jersey, and documented that only 61% of consenting families and only 53% of nonconsenting families answered affirmatively to the question: “Thinking back to the time when all of this happened, was the meaning of brain death ever explained to you?” (Franz, DeJong, and Wolfe 1997, p. 16). This finding is hardly surprising given the ethos of transplant medicine, with its overemphasis on the benefits to the recipient and the use of such tactics as team-huddle, presumptive consent, and suppression of doubt and controversy regarding the adequacy of determinations of death for purposes of organ removal.

Portrayals of organ donation by the transplant community focus almost exclusively on the good that can be achieved for the recipients of transplanted organs, but rarely if ever mention the potential psychological trauma for those families who consent to heart-beating donation. Quoting from a subject of their study involving traumatic memories of relatives of state X patients, Kesselring et al. write:

[After consenting to donate a relative’s organs,] I was totally shaken: we just cannot cut him and take these things out—I barely survived it . . . and since then, I have asked myself a 100 [sic] times if he was really dead or if we killed him by consenting. (Kesselring, Kainz, and Kiss 2007, p. 5)

Part of the trauma for this person lies in the ambiguity of what was consented to: Was it to remove organs from a loved one who had already died, or was it to remove organs from, and thereby kill, a loved one who was irreversibly comatose, but not yet dead? The ambiguity, and hence part of the psychological trauma, is rooted in the misleading language of “death” in this context. This person’s loved one was biologically alive before organs were removed and biologically dead afterwards (issues of personhood, moral status, and legal status aside), therefore, her/his confusion and concern as to whether she or he had consented to killing a loved one is quite justified. For another example, after consenting to donate on behalf of her 16-year-old daughter in state X, Joanne van Os describes how the operating team came to explain that they would be taking her daughter to the operating room while still attached to life support, a fact not adequately understood before she had consented:

Our immediate response was one of horror and disbelief, and we told her that no one would be taking our child while she still had a heartbeat, that they would have to wait until she was *dead*. . . . We spent the rest of the

night in turmoil. Logically, we knew that our daughter was gone. . . . We also knew that Ali would want her organs donated. . . . But the sudden reality of what her donation asked of *us* was unbearable. (van Os 2009, p. 612; original emphases)

Ms. van Os goes on to explain that she and her family did eventually give surrogate consent on behalf of her daughter, and she still supports organ donation. However, she also makes a plea for greater public understanding and discussion of the actual practices of organ donation, which are not made clear by organizations like UNOS and the DHHS when they state that organs are taken “after death,” given the usual connotation of the word “death.” Unfortunately, this grieving mother had to learn firsthand what organ donation actually entails, at a particularly painful moment in her life.¹⁷ Using the language of “death” to describe state X when discussing organ donation is misleading, confusing, and potentially traumatizing to family members left with an ambiguous uncertainty regarding what they had consented to, and this is exacerbated by the active suppression of open public conversation and debate regarding the ethics of organ removal from biologically living bodies in state X.

In her ethnographic study of 32 American and Canadian intensive care physicians who treat state X patients and have conversations with their families, Lock (2004) reports that “*Not one believes that a diagnosis of brain death signifies the end of biological life*, despite the presence of irreversible damage and knowledge that this condition will lead, usually sooner rather than later, to complete biological death” (Lock 2004, p. 140; emphasis added). Rather than explain to families that the diagnosis of brain death does *not* signify the end of biological life, such physicians instead emphasize that “the things that make her her” are no longer present, or emphasize the impossibility of recovery (Lock 2004, p. 141), without making clear that the patient is not yet biologically dead, despite the fact that *this is what the physician believes to be true*. This point is so crucial that it bears repeating: *The 32 physicians in Lock’s study do not themselves believe that the diagnosis of brain death signifies the end of biological life, yet they do not explain this fact to families*. If genuinely informed consent for organ retrieval (and hence respect for autonomy and for individual preferences and values) is truly considered to be important, doesn’t this fact seem relevant to explain to families before they consent? And furthermore, is it surprising that next of kin, such as the person quoted from the Kesselring study above, are left with an ambiguous uncertainty regarding whether they had consented to killing their loved one?

Attempts to suppress controversy so as not to decrease organ retrieval rates seem to be epitomized in two recent articles by James DuBois (2010, 2011). DuBois argues that, since expressing doubts about death criteria can lead to lower organ donation rates and distress for both families and healthcare professionals, public expression of such doubts through the publication of scholarly articles “should be viewed through an ethical lens, and subjected to ordinary risk-benefit analyses . . . publishing such articles is proportionate when, and only when, they substantially engage and advance the debate” (DuBois 2011, p. 47). Furthermore, academic journals should establish editorial policies so that, when articles that doubt death criteria yet manage to substantially advance the debate¹⁸ are published, they are to be accompanied by editorial comment, especially by physicians, responding to those doubts (Dubois 2010). Of course, as has been decisively shown countless times, state X patients are biologically alive (which the intensivists in Locke’s study all acknowledged), irrespective of their personhood, moral status, or legal status. Yet DuBois seems to believe that pointing out such facts to the public so that they may make an informed decision about their own or their loved one’s healthcare, and may legitimately participate in the democratic process, is something that should be accompanied by a physician’s (presumably authoritative) statement to the contrary, so as not to decrease organ donation rates, and so as not to upset families. Is this not paternalism?

To summarize, paternalism involves action-reason compounds, thus, insofar as at least one reason adverts to benefiting those with whom the action interferes, that action-reason compound is paternalistic. However, plausibly, the reasons appealed to may be either causal concepts of motivation or logical concepts of justification. Insofar as they are justifications, such reasons need not be actually asserted by anyone in order for such an action-reason compound to be paternalistic, so long as the action ignores preferences and interferes with autonomy and the reason adverts to the benefits of the action for the person with whom the action interfered. Clearly the language of “death” ignores preferences and subverts autonomy, particularly in terms of political participation. That organ donation is a benefit and the language of “death” makes organ donation politically possible, is a *prima facie* justification, and this is thereby sufficient to classify that action-reason compound as paternalistic.

Insofar as action-reason compounds involve the causal concepts of motivation, one need not intend to mislead, one need only intend to benefit, and the outcome of the action that was intended to benefit must result in

an interference with the intended beneficiary. As I’ve mentioned, motivations are complex, and social change is even more complex. At the outset of the shift to neurologic criteria, motivations such as benefiting society by decreasing a financial strain on hospitals, benefiting families by relieving them of psychological burdens, and benefiting transplant recipients by making transplant medicine legally possible were certainly floating around in the literature, and surely played an important role in the shift. I will leave it to historians to decide how much of a role such motivations played. In contemporary discourse, however, the case for paternalism is clear: The assertion that state X is death is treated as a medical claim subject to assertions of medical authority, a claim on which only medical professionals have the expertise to comment, rather than a response to certain ethical questions, on which all have a legitimate voice. Furthermore, there are active attempts to suppress serious medical, ethical, and religious controversies surrounding transplant medicine using mass media campaigns, misleading websites, less-than-candid bedside conversations with families of state X patients, communication techniques by procurement coordinators that are designed to maximize compliance with the request, rather than to maximize understanding and thus the legitimacy of consent; and finally, there are scholarly articles asserting that “doubts about death criteria” should be published only accompanied by a physician’s rejoinder, explaining why those doubts are not justified. Therefore, it is quite clear that the overarching ethos of contemporary practice and discourse from the transplant community and its various supporters is one that interferes with autonomy and informed deliberation through the misleading language of “death” as well as through active suppression and dismissal of doubt and controversy; it thereby ignores preferences and values; and the misleading language is necessary in order to achieve the benefits of transplant medicine since, quite plausibly, *without the language of “death,” transplant medicine would not exist*. The overarching ethos of our contemporary discourse, therefore, should be construed in terms of paternalism.

While not all paternalism is unjustified, it is far from clear that this instance of paternalism is justified. How to appropriately weight the value of free, democratic deliberation and autonomous decision-making against the value of lives saved from transplant medicine is an important question that should be carefully and explicitly addressed. But there are some considerations I will briefly mention that strongly suggest that this paternalism is not justified.

Insofar as this involves soft paternalism, in which the decisional capacity of the intended beneficiary is diminished or questionable, to justify such paternalism one must show that some crucial ability to understand the issues is lacking in the general public. I seriously doubt that this case can be made. The issues are complicated, but they are made so unnecessarily by the use of the misleading language of “death,” not by the issues themselves. It is quite simple to state that patients in state X are biologically alive (or even more modestly, that there is serious debate and doubt among the medical and philosophical communities as to whether state X is biological death). However, they are irreversibly comatose and will not wake up again. Is it acceptable to remove their organs and thereby cause biological death? Those are not complicated ideas; they are only made so by the misuse of the language of “death.”

Insofar as this is hard paternalism, in which the decisional capacity of the intended beneficiary is not in question, to justify such paternalism one would need to show, for example, that this meets something like the requirements that Beauchamp and Childress (2009, pp. 215–216) proposed.¹⁹ This would involve showing that a particular patient is at risk of a significant, preventable harm, that the paternalistic action will probably prevent the harm, that the benefits to the patient outweigh the risk, that there is no reasonable alternative to the limitation of autonomy, and finally that the least autonomy-restrictive alternative is utilized. The case under consideration does not seem to meet these requirements, since the autonomy restriction applies to basically everyone, whereas the clear intent of Beauchamp and Childress’ analysis is that the beneficiary of the paternalistic action is the very same individual whose autonomy is restricted.²⁰ In addition to the aforementioned considerations, one would also need to address each of the following concerns.

First, as mentioned above, the use of misleading language obstructs informed personal medical decisions. Informed consent for organ retrieval is very difficult, if not practically impossible, as argued above (for more on this, see Collins 2009). In addition to those who donate organs, the misleading language can also obstruct informed medical decisions by the recipients of transplanted organs. Some people place tremendous, possibly infinite value on biological human life, considering it a gift from God, or perhaps God’s property of which we must be good stewards. Just as Jehovah’s witnesses find it morally objectionable to accept blood products because of their religious views, so much so that many would prefer death to accepting a transfusion, some people might take a similar

stance on accepting an organ from a heart-beating donor in state X if they understood that it was taken from a biologically living body in such a way that removal of the organ killed the donor. I imagine that this might be a minority of people, but nonetheless, the misleading use of the term “death” in this context prevents autonomous moral agents from directing the course of their own lives. If the paternalism is justified, it would have to follow that informed consent is not ethically necessary for *either* organ donation or transplantation.

Second, as discussed above, the misleading language of “death” in the context of organ donation is potentially traumatizing to families who consent to organ donation. If the paternalism is justified, this harmful outcome would need to be justified as well.

Third, the misleading language violates substantial autonomy interests of religious individuals with fundamental, deeply held beliefs regarding the absolute prohibition of killing innocent persons. For example, the Abrahamic religions of Judaism, Christianity, and Islam share an objection to active killing that forms a core aspect of their moral system. By not making clear to such persons that individuals in state X are biologically alive, or at the very least, that there is serious scientific doubt regarding whether individuals in state X are dead, such individuals may end up consenting to or supporting a practice that violates their own fundamental moral beliefs. To be clear, I am not suggesting that religious beliefs should dictate any public policy. But I am suggesting that religious persons can plausibly be misled into violating their own deeply held moral beliefs by the lack of clarity on what organ donation actually entails. If the paternalism is justified, one would also need to justify the violation of these religious persons’ substantial autonomy interests.

Fourth, the misleading language generates illegitimate political support for a practice that, if described in clearer terms, would surely be at least as controversial as other life-and-death issues such as physician-assisted suicide and euthanasia. If the paternalism is justified, it must also follow that on this issue, the general public *does not have the right* to reasonably accurate information (expressed in unambiguous and understandable language) in order to make decisions on which policies and laws to support or oppose.

Fifth and finally, it is well understood that medical professionals have a broad obligation to tell the truth and, more generally, to be trustworthy. Justifying the paternalism here will require showing why that general obligation ought to be overridden, or, that the false or misleading language

is somehow consistent with the general obligation to be trustworthy. This seems quite difficult to do. Using the word “dead” to describe biologically living bodies in state X seems neither truthful nor demonstrating a worthiness of public trust. Taken together, these considerations generate a strong case for the claim that the paternalism is not justified.

CONCLUSION: A WAY FORWARD

I’ve argued that, despite a great deal of controversy on a variety of theoretical questions, there appears to be a near (but not complete) agreement on the moral permissibility of organ retrieval from those in state X, at least under certain conditions. Furthermore, a fruitful strategy for moving forward with this debate is to recast it as a debate about language. From that perspective, I’ve argued that the language of “death” in this context is paternalistic and, at least *prima facie*, unjustifiably so. Hence, the near-consensus on the permissibility of organ retrieval deserves reconsideration.

Those who agree that organ retrieval from patients in state X is permissible do so under certain assumptions. But the most important of these assumptions doesn’t actually hold. All agree that informed consent for organ retrieval or, at the very least, respect for persons is ethically required. However, as we have seen, consents are not informed, and persons are not respected in virtue of the paternalism inherent in the language and practices surrounding organ transplantation.

It is rarely if ever noticed that respect for persons applies far more broadly than just with respect to potential organ donors. Respect and moral regard are also owed to the people who choose to sign up for organ donor registries on misleading UNOS websites, to potential recipients of transplant organs, to families who must make surrogate decisions, and to the general public in its deliberation on how to structure a democratic society and, in particular, on which medical practices surrounding death and dying should be accepted and which should not. Respect and moral regard for such persons demands *honest, forthright communication*, not the use of misleading language or the suppression of legitimate scientific, ethical, and religious controversy.

I have argued elsewhere that, although state X is not biological death, nonetheless organ retrieval from patients in state X is morally licit, *assuming* informed consent (Collins 2010). I still hold to that, but I also wonder whether it is appropriate to continue this conversation based on the assumption of informed consent, or on the assumption that persons are respected by current practices in transplant medicine. Instead, perhaps

it is time that this debate moves closer to actual clinical practice and actual political discourse. That is, let us have this conversation on *these* assumptions: Using the language of “death” to describe state X is false or misleading. Consents to sign up for donor registries are not informed. Surrogate consents to donate organs are not informed. Consents to receive transplanted organs are not informed. There is potential for psychological trauma on families that consent to donate based on the ambiguous language of “death.” There is potential for violation of substantial autonomy interests of religious persons who consent to or support organ transplantation based on the ambiguous language of “death.” There is widespread failure to respect the right of autonomous moral agents to decide how to direct the course of their own lives, both in terms of personal medical decisions as well as political participation.

Unlike the assumptions of informed consent or respect for persons, these are the assumptions that actually hold, and so the conversation should be had in these terms, and we must ask: Is the paternalism inherent in the language surrounding organ transplantation justified? If not, I believe it would follow that much of the transplant enterprise lacks ethical justification.

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NOTES

1. Although Bernat, Culver, and Gert (1981) are widely cited in association with the aforementioned framework, the ideas go back somewhat earlier, at least to Capron and Kass (1972). They introduce a four-part framework, including the *basic concept* of death, the *general physiological standards* for recognizing the instantiation of the concept of death, *operational criteria* for those general physiological standards, and finally *specific tests and procedures* to determine if the operational criteria have been realized. For example, one way of cashing out this framework might be to claim that the concept of death involves the irreversible cessation of the integrated functioning of the organ-

ism as a whole; the physiologic standard for this to occur is the irreversible cessation of all circulo-respiratory function; the operational criteria for this standard are the absence of blood flow and the absence of gas exchange at the alveoli and in cellular metabolism; and the tests for determining whether this has occurred involve feeling for a pulse, looking for blood flow in the retinal vessels, watching for the chest to rise, and feeling for the expiration of air from the mouth.

2. For each view I describe, there are several theorists who espouse similar positions, though with subtle distinctions separating them. I'll refer to each position with specific authors' names (e.g., "Bernat's view"), though it should be understood that I intend to refer to the family of views of which I consider the named author's to be an exemplar. I've elected to use specific author names rather than attempt to construct informative labels (e.g., "mainstream view") since, given the number of dimensions along which these views vary, informative labels would quickly become unwieldy and more confusing than helpful.
3. In a personal statement appended to the President's Council's report, Alfonso Gómez-Lobo expressed disagreement with the majority view, essentially agreeing with Shewmon's view on biological death, and accepting the dead donor rule. Thus Gómez-Lobo's views would more correctly be categorized as amenable to what I'm calling the Byrne view above. Throughout, when I refer to the President's Council, I mean to refer to the majority view expressed in the body of the report.
4. This important claim is made at page 391 of (Bernat, Culver, and Gert 1981).
5. It is also interesting to compare the President's Council's stance with the standard position in the United Kingdom (cf. Royal College of Physicians 1995), which holds that brain-stem death (requiring loss of brain-stem, but not whole-brain functions) is death. The justification for this claim is essentially the same as the new justification proposed by the President's Council: Death involves the loss of the capacity for consciousness and breathing. Thus we may see the President's Council and the UK positions as in agreement on the definition of "death" but disagreeing on the physiological criteria that satisfy that definition; the US President's Council requires "total brain failure" and the Royal College of Physicians requires lack of brain-stem function.
6. Note that I have appealed to all *clinical* functions of the brain rather than *all* functions of the brain. Earlier expositions of brain death (e.g., Beecher 1968; Bernat, Culver, and Gert 1981), along with the legislative statutes based on the Uniform Determination of Death Act (cf. President's Commission 1981a), define brain death in terms of the lack of *all* functions of the brain, and this is how I've described it above. However, some tweaking is required: Once

it was discovered that individuals might satisfy the clinical tests of unresponsiveness, apnea, and lack of cranial nerve reflexes yet maintain certain neurological function, particularly neurohormonal function, proponents of Bernat’s view (the mainstream view) recommended changing the definition of “brain death” to the irreversible cessation of all *clinical* functions of the brain, which (arbitrarily) rules out endocrine functions of the hypothalamus (Bernat 1998). Thus, the individuals who satisfy the standard clinical tests of unresponsiveness, apnea, and brain-stem areflexia, are, by definition, in state X.

7. And it would appear that Miller and Truog have accepted this argument, at least partially. In a recent article Shah, Truog, and Miller (2011) argued that we ought to maintain the language of “death” to describe these individuals, but acknowledge that it is a “legal fiction,” akin to considering a corporation a person. Their argument is spelled out more fully in chapter 7 of Miller and Truog (2012). Although I appreciate the attempt to work out a reasonable compromise view, this strikes me as further gerrymandering that will not result in better understanding by medical professionals and the public alike.
8. The phrase “kills bugs dead” is copyrighted by Raid, a subsidiary of S. C. Johnson and Son, Inc.
9. Lest it seem that I have selectively sampled websites to make my points, readers are suggested to consult Woien et al. (2006), a quantitative study of all of the 60 UNOS websites, where we may go to sign up to be organ donors. Using the recommended data elements for informed consent regarding organ donation recommended by the DHHS, the authors found that 0% of them—not even one—mentioned the factors that the DHHS considers important for informed consent, such as criteria for brain death and cardiac death, changes to end-of-life care that are incompatible with organ donation, etc. I provide additional support for this claim in the penultimate section, “Reasons, intentions, and the active suppression of controversy.”
10. Khushf and Chiong also maintain that state X is biological death, in a sense, but they also argue that biological reality underdetermines the truth of our statements about death. I will briefly address their views at the end of this section.
11. According to Veatch (2004), even at the outset of the shift to neurologic criteria for death, no one was so naïve as to think that this constituted biological death in the traditional biological sense of organic integration. Yet apparently that naiveté has become the orthodoxy; Franklin Miller and Robert Truog (2008) write on page 3, “Most physicians have been taught to regard the equivalence of ‘brain death’ and ‘death’ as a medical ‘fact’ on a par with the Krebs cycle.”

12. For example, in a well-regarded medical textbook on intensive care (*Principles of Critical Care*, 3rd edition), Rosengart et al. write, “The medical and legal definitions of death are clear: brain death and cardiac death are the same. Dissenting opinions from the strict religious orthodoxy of Roman Catholicism and Orthodox Judaism persist, however, due to individual interpretations and applications of religious beliefs” (Rosengart, Novakovic, and Frank 2005). This textbook would seem to teach medical students and residents not only that brain death is death, in the traditional sense of the word “death,” but also that any “dissenting opinions” on the issue must be a result of idiosyncratic interpretations of religious beliefs.
13. In fairness, perhaps this view on the nature of biological life ought not be dismissed quite so abruptly. It does connect to an older tradition, the view known as *cybernetics* (and certainly before that to the Aristotelian concept of *telos*), which attempted to describe both biological and mechanical systems in terms of purposes or goals (see, for example, Rosenblueth, Wiener, and Bigelow 1943). Nonetheless, as mentioned in the text, essentially all current views on biological life appeal to *something like* homeostasis, organic integration, integrated unity of functioning, or resistance of entropy—a related family of concepts—to explain what biological death is. For the President’s Council’s view to succeed, they must first explain what is wrong with this currently well-accepted family of views, and second why the teleofunctionalist/cyberneticist view is superior. But no attempt is made on either of those points. Finally, as I detail in the text below, even if this were the correct theory of biological death, the body in state X nonetheless fails to satisfy it anyway.
14. I thank a reviewer for pressing me on this important objection.
15. For example, see the quote cited in endnote 12 above. For another example, consider the wording of the State of New York’s “reasonable accommodation” clause: “Hospitals must establish written procedures for the reasonable accommodation of the individual’s religious or moral objections to use of the brain death standard to determine death *Since objections to the brain death standard based solely upon psychological denial that death has occurred or on an alleged inadequacy of the brain death determination are not based upon the individual’s moral or religious beliefs, ‘reasonable accommodation’ is not required in such circumstances.* However, hospital staff should demonstrate sensitivity to these concerns and consider using similar resources to *help family members accept the determination and fact of death* [emphases added]” (New York State Department of Health 2005, pp. 2–3). In both of these quotes, the identification of state X with death is treated as medical, scientific fact, and objections to it are treated as being either rooted in

(unscientific) religious beliefs, “psychological denial,” or are simply dismissed (“the alleged inadequacy”). Thus, the authority of medicine is brought to bear in dismissing objections as rooted in a lack of understanding of issues that only experts have the authority to address. This is deeply problematic, given that the actual biological science so obviously demonstrates that patients in state X are biologically alive, and furthermore, the shift to neurologic criteria was a response to ethical questions, not the result of accumulated scientific understanding of biological death.

16. I use scare quotes around the word “shortage” to signal my growing suspicion of the legitimacy of the concept of an organ shortage. Obviously the demand for organs outpaces supply and I’m not denying that. However, it seems to me that to assert that there is a shortage for some item implies that the demand for that item is morally legitimate; e.g., there may be a shortage of clean water after a devastating hurricane, but there is no “shortage” of exploitable labor even if demand for it exceeds supply. If it turns out that I am correct that current communication surrounding organ donation is paternalistic, and further that the paternalism is not justified, it would seem to follow that much of the transplant enterprise, and with it the retrieval of human organs, lacks ethical justification. If that is the case, perhaps it would follow that the demand for human organs is not morally legitimate since such organs are largely obtained under false or misleading pretences, and therefore, perhaps there is no organ shortage. This idea is tentative at best however and requires further exploration; I’m not firmly endorsing it here.
17. One reviewer commented that this seems to be an unfair reference, since the family clearly did not initially give an adequate consent to organ donation; therefore the fault does not lie with the language of “death.” I disagree. As mentioned in the text, it is part of the ethos of transplant medicine to use communication strategies that maximize the probability of compliance with the request, not that maximize adequacy of understanding and thereby the legitimacy of consent. As Franz, DeJong, and Wolfe (1997) have documented in their sample, only about 50–60% of families recall having the meaning of brain death ever explained to them. Therefore it is unsurprising that the family in this case did not understand brain death either, and this is consistent with my argument: They were presumably told that their daughter’s organs would be removed after death, and they consented to this, not realizing that “death” in that context meant “state X.” Furthermore, the media campaigns that promote organ donation and say only “after death,” or that “healthy organs are being buried,” create the mistaken belief among the general public—including Ms. van Os—that organs are removed only from what most people consider dead bodies, when this is not the case.

18. It is hard to make sense of this claim; what scholar, peer reviewer, or academic editor submits, recommends, or accepts an article for publication that she or he does *not* believe to substantially advance the debate?
19. I'm not suggesting that Beauchamp and Childress' criteria are the only reasonable criteria that might need to be satisfied for a hard paternalistic act to be justified. Rather, this seems like a reasonable starting point to me, though I of course leave it open that cogent arguments might be presented in favor of a different set of criteria.
20. One might think that this consideration undermines my claims of paternalism, since the good Smith accrues does not come directly from Smith's being misled; rather it comes from *everyone else* being misled, which is what makes transplant medicine a political and legal possibility. Unlike the seat-belt law, where Smith's benefit comes directly from Smith's loss of liberty, this is a case where Smith's benefit is derived from a collective loss of autonomy, and Smith would not lose the benefit if Smith were not misled (so long as the majority remained misled). However, this objection requires that the benefit to Smith must be a direct result of Smith's loss of autonomy, but I don't think that this should be required for an act to be paternalistic. Such a requirement on paternalism implies that, were it not for the loss of choice, there wouldn't be a benefit. Hence, if the benefit would be accrued without the loss of choice, then the act is not paternalistic. But this implies that the seat-belt law isn't paternalistic to those who would choose to wear the belt even if it were not for the coercion, because those individuals would get the same benefit of lowered risk of death even without the law. But this doesn't remove the paternalism. It is precisely *because* the law is indifferent to each individual's preferences that it is paternalistic; some would wear the belt (and get the benefit anyway), some wouldn't, but because no choice is given, and because it is in our interests to wear a seat belt, the law is paternalistic. Thus, it isn't the lack of choice that results in the benefit; it's wearing a seat belt. In a similar fashion, it isn't Smith's lack of choice that results in the benefit accrued to her; rather, it is the possibility of an organ transplant should she need it. Thanks to David McNaughton for this objection and for helpful comments throughout.

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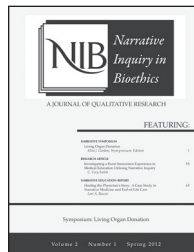
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