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Justice, Profound Neurological Injury, and Brain Death

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The impairments associated with what's known as the "vegetative state" (henceforth VS) are devastating. A VS patient, such as the well-known Terri Schiavo, lacks all higher-order cognitive functions; presumably she is completely unaware of herself or her surroundings and cannot engage with her environment in any meaningful way. She has no thoughts, no memories, no purposeful behavior, and will likely never recover, although she maintains the ability to breathe on her own. A brain-dead patient shares these characteristics, except the brain-dead patient also lacks the ability to perform "vegetative" functions such as autonomic regulation of hormones, blood pressure, and ventilation. The brain-dead patient is legally dead, whereas the VS patient is not. Issues of legality aside, these patients have much in common. They both lack (or can be presumed to lack) psychological states, and many would say that the *person* that once was no longer exists, in both cases. This unusual situation of the presence of some biological function coupled with the absence of psychological function—what presumably makes us persons in any meaningful sense—creates difficult questions regarding the allocation of scarce medical resources.

Given the severe impairments and presumed lack of psychological function in such patients, it is natural to wonder: Does social justice demand that resources *not* be allocated to them? If those resources currently spent on maintaining the profoundly neurologically impaired in what may be termed a "minimal existence" were used elsewhere, they might have a much greater effect in curing or preventing illness, alleviating suffering, and so forth. Is it a fair allocation to spend an inordinate amount (or even any amount) of resources on patients who many would say aren't even persons?

Several authors have expressed this concern. For example, Brody (1988) writes:

> Other patients [without VS], who can benefit in substantial ways from access to health care, can be provided the time and resources freed if [the VS] patient dies. Even without a comprehensive theory of justice in the allocation of health care resources, it seems plausible to say that other patients have a greater entitlement to those resources.[1]

Similarly, in a paper on the aspects of consciousness that should be considered morally relevant in the context of vegetative patients, Kahane and Savulescu mention, in passing, that "considerations of distributive justice may tell against continuing to sustain the life of such a [vegetative] patient at great cost" (Kahane & Savulescu 2009, 13). Dworkin too discounts the value one might attach to a being in VS. In considering what insurance would be prudent to purchase, Dworkin writes, "[i]t would be irrational for almost any twenty-five-year-old to insure himself as to provide for life-sustaining treatment if he falls into a persistent vegetative state" (Dworkin 2000, 313). Perhaps more strikingly, Veatch (1975, 2004) argues that vegetative patients should be considered legally dead, presumably implying that any use of resources on their behalf is unjust.

Similar questions arise in the context of the brain dead. Although a brain-dead individual is legally dead, nonetheless certain biological functions do remain, and some states make provisions for "reasonable accommodation" of the views of

the patient or her caregivers in determining death (and hence, using medical resources on a brain-dead individual). The New York State Department of Health's *Guidelines for Determining Brain Death* (2005, 2–3), for example, includes the following 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 when such an objection has been expressed by the patient prior to the loss of decision-making capacity, or by the next of kin or other person closest to the individual. Policies may include specific accommodations, such as the continuation of artificial respiration under certain circumstances, as well as guidance on limits to accommodation.

The State of New Jersey has provisions that are stronger in this regard, in the 1991 New Jersey Declaration of Death Act:

> The death of an individual shall not be declared upon the basis of neurological criteria pursuant to sections 3 and 4 of this act when the licensed physician authorized to declare death, has reason to believe, on the basis of information in the individual's available medical records, or information provided by a member of the individual's family or any other person knowledgeable about the individual's personal religious beliefs that such a declaration would violate the personal religious beliefs of the individual. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria pursuant to section 2 of this act. (*New Jersey Declaration of Death Act* 1991, c. 90, s. 5)

Given the large amount of resources necessary to maintain a brain-dead individual—an ICU bed, a ventilator, and a large time commitment from ICU nursing staff—it is plausible to wonder whether social justice demands that scarce resources not be used in such a way. In this chapter we shall explore the issue of distributive justice as it arises in these contexts of profound neurological impairment and brain death. We begin with a brief review of the medical/clinical background on VS, brain death, and related states, and then move to the ethics of health care resource distribution. Ultimately, we argue that a position of tolerance is the optimal one in these circumstances.

MEDICAL BACKGROUND: COMA, BRAIN DEATH, VEGETATIVE STATE, MINIMALLY CONSCIOUS STATE, AND THE LOCKED-IN STATE

We begin by distinguishing wakefulness from awareness. Wakefulness is linked to arousal, alertness, or the absence of sleep, but its presence does not imply cognition, mental content, or awareness of self or environment. While extremely rough, we trust that the intuitive distinction between being awake but not aware, and being aware of one's self and environment, is relatively clear. This distinction is the basis for much of what follows.

Coma is a pathological state of eyes-closed unresponsiveness; comatose patients have a sleep-like appearance and do not respond to sensory or noxious stimuli. Wakefulness is absent and, presumably, awareness is absent as well. True sleep-like coma almost never lasts for more than 2 to 4 weeks (Bernat 2006, 1181–1182; Plum & Posner 1980, 3), before progressing to the vegetative or minimally conscious state, to recovery, or to death.

Brain death is, in essence, a form of coma. In brain death, all functions of the brain have ceased irreversibly. The patient is in a state of eyes-closed unresponsiveness, is apneic, and lacks all cranial nerve reflexes. A brain-dead patient, if mechanically ventilated, can maintain spontaneous circulation, cellular respiration, and spinal reflexes, but cannot carry out brain stem-mediated autonomic functions such as thermal regulation and blood pressure control. It is widely maintained that a brain dead-individual is dead,[2] although it is also well understood that some biological functions, such as those mentioned above, do remain. Brain death is not typically described as a form of coma, of course, because comatose patients are alive whereas brain-dead patients are thought to be dead.

The non-brain-dead comatose patient who does not recover awareness typically progresses to *VS*, which is a state of wakefulness in the absence of awareness. The vegetative patient exhibits irregular sleep–wake cycles, lies with her eyes open while awake, and breathes spontaneously. She has preserved autonomic and hypothalamic function and cranial nerve reflexes, but does not exhibit any evidence of awareness of self or environment

through sustained, reproducible, apparently purposeful or voluntary behavior in response to stimuli. Importantly, even though a VS patient may lie with her eyes open, responses to visual cues are absent. Consistent, sustained, reproducible visual tracking is considered evidence inconsistent with VS (Jennett & Plum 1972; Multi-Society Task Force on PVS 1994a, 1994b).

Some patients progress, either from VS or directly from coma, to a state of severely impaired responsiveness resembling VS, except that they show some limited evidence of awareness. This is known as the *minimally conscious state* (MCS). The patient in an MCS, like that in VS, exhibits sleep–wake cycles, spontaneous breathing, preserved autonomic and hypothalamic functions, and cranial nerve reflexes. Additionally, she is able to gesture yes/no answers, show reproducible visual tracking, or reach for or grasp objects in a way demonstrating a cognitive association between the object's size, shape, or location, relative to the patient (Giacino 2004; Giacino et al. 2002). Thus, the MCS patient does exhibit limited evidence of awareness of self and environment, in addition to wakefulness.

Finally, a distinct neurological disorder that is sometimes confused with coma, VS, or MCS is known as the *locked-in state*. This is not a disorder of consciousness at all; it is instead a movement disorder characterized by nearly complete paralysis. However, the patient does retain the capacity for vertical eye movements and eye opening when asked, and maintains normal cognitive function (Bernat 2006, 1184).

DESCRIPTIVE DISTINCTIONS AND NORMATIVE CONCLUSIONS

In theory, there is a great difference between the vegetative and minimally conscious patient. While the vegetative patient maintains sleep–wake cycles and some primitive neurological functions, presumably she is also entirely unaware of herself and her surroundings. She lacks all thought and all mental content; she has no goals or desires, no fears, no pain, and no interests whatsoever. The *person*, the subject of experience or the experiencing self, no longer exists.[3] There is, as one might say, "no one there."

By contrast, the minimally conscious patient does show some limited evidence of awareness. She is able to follow some simple commands and respond to her environment in some meaningful ways. Therefore we may presume a limited amount of thought or other psychological states, and hence, at least in the psychological sense of the term, we should conclude that the *person*, that locus of experience or psychological states, exists.

The presumed difference between the VS and MCS patient lies in the absence or presence of psychological states, which is a descriptive, non-normative distinction. However, supposing this distinction to be accurate, the normative concerns about social justice and the distribution of resources mentioned at the outset of this chapter become pressing. Namely, if the VS patient lacks all psychological states, then she feels no pain, has no capacity for awareness of self or others, and has no memory, desires, or thoughts. Therefore presumably she has no interests and is no longer a locus of moral value, at least not in the same way that a non-VS individual is a locus of moral value. As a result, there is *prima facie* reason to suggest that justice demands that resources not be allocated to the VS patient. On the other hand, there is less reason to suggest this with respect to the MCS patient, since she does enjoy some psychological states, and so presumably has interests, at the very least in not feeling bodily pain, and perhaps she has further interests in fulfilling her goals.[4]

We need not adjudicate here whether the normative conclusion—that VS patients have no interests and are *prima facie* entitled to fewer or no resources on these grounds—follows from the descriptive distinction between the presence and absence of psychological states. Instead, we suggest that for this basic argument to direct practical decision-making on resource allocation, there should be at least a reasonable (but not absolute) level of confidence in the claim that patients diagnosed as VS do in fact lack all psychological states. If we cannot make that claim with reasonable confidence, then the normative conclusions suggested above have no practical import in actual decision-making.

There are two reasons why we should currently lack such confidence. First, we don't yet know enough about the many forms of consciousness and their neurological substrates in general, nor the specific pathology of VS in particular, to ground practical allocation decisions.[5] Second, the misdiagnosis rate for VS is unacceptably high. We shall begin with the former concern.

There are many different aspects of consciousness, and the medical term "awareness" seems to capture a conglomeration of several. Specifically, it

seems to involve *phenomenal consciousness*, which involves the qualitative "raw feel," or the "what it is like to be" a conscious subject having a conscious experience (Block 1995, Nagel 1974). It also seems to capture *access consciousness*, or the ability to integrate sensory and mnemonic information in the guidance of goal-oriented behavior (Block 1995). Additionally, the medical term "awareness" may involve both *transitive consciousness*, or consciousness *of* something, as well as *state consciousness*, which is a property of conscious mental states, not persons (Rosenthal 1997). By possibly conflating these, it isn't clear to what the claim "VS patients lack awareness" actually amounts. Thus, more conceptual clarity is needed.

Further, the diagnosis of VS is made based on third-person behavioral criteria, not anatomic or neurophysiologic criteria. At its core, the diagnosis is essentially a clinician's determination of whether a particular patient's behavioral repertoire is "meaningful" or not. But this is necessarily speculative. A VS patient can grimace, blink, grunt, cry, smile, and move her limbs and eyes. The clinician's responsibility is to determine whether these behaviors are purposeful or not. But when the patient is unable to communicate, if there is some purpose to any of these behaviors, or if they are in response to some internal stimuli (sadness, an itch, a pain, etc.), it will be impossible for the clinician to determine this. This is not to say that VS patients do in fact respond to internal stimuli, it is simply to say that there is no way to tell from behavioral criteria alone whether they do or don't.

In time, anatomic pathology may assist in diagnostic assessment. At present, however, there are no pathologic criteria available to replace clinical assessment of "purposive" behavior. Hence, not even postmortem autopsy can confirm or refute the diagnosis. Sometimes the cortical cell bodies are destroyed as a result of anoxia secondary to cardiac arrest. Other times there is widespread axonal shearing due to traumatic brain injury, with relative preservation of cortical cell bodies (Bernat 2006). Yet other times there is preservation of both the cortical cell bodies and their axonal connections, but there is damage to the thalamus, such as in the famous Karen Ann Quinlan case (Kinney et al. 1994).

Additionally, there are no definitive imaging or electrophysiologic modalities for making the diagnosis of VS. Instead, there is evidence suggesting the relative preservation of normal or close-to-normal neural activity in brain areas responsible for sensory and pain processing in the brains of patients diagnosed as VS. This increases the uncertainty currently surrounding the diagnosis of VS.

Electrophysiologic studies have shown that brain stem auditory evoked responses are typically preserved (Bernat 2006). Cortical somatosensory and auditory evoked potentials may be preserved (Jones et al. 2000, Marosi et al. 1993, Rappaport et al. 1991), showing evidence of intact primary sensory areas (Boly et al. 2004). Other studies have shown preservation of what are known as "cognitive" evoked potentials in VS patients (De Giorgio, Rabinowicz, & Gott 1993; Glass, Sazbon, & Groswasser 1998; Gott, Rabinowicz, & DeGiorgio 1991; Yingling, Hosobuchi, & Harrington 1990).

In a recent series of articles, Owen, Coleman, and colleagues have described the use of functional neuroimaging (fMRI) to detect neural activity in clinically diagnosed VS patients. For example, the neural correlates of speech processing are determined using healthy controls, then the activation patterns of VS patients, in response to the same stimuli, are compared to those of the healthy controls, and (some are) found to be statistically indistinguishable (Coleman et al., 2007, 2009; Owen & Coleman 2008a, 2008b; Owen, Coleman, Boly, Davis, et al. 2007; Owen, Coleman, Menon, Berry, et al. 2005; Owen, Coleman, Menon, Johnsrude, et al. 2005).

Other neuroimaging studies have documented the preservation of neurological responses in cortical primary sensory areas (Laureys et al. 2000, Laureys et al. 2002, Boly et al. 2004), as well as secondary somatosensory, insular, and anterior cingulate cortices (Kassubek et al. 2003) to a variety of sensory and noxious stimuli in some VS patients. Owen and colleagues report on the case of a clinically-diagnosed VS patient who was asked to imagine playing tennis, then imagine wandering the rooms of her house, while researchers scanned her brain using fMRI. They found neurological activity in the supplementary motor area and the parahippocampal place area, similar to healthy controls, after the instruction to imagine tennis and then wandering her house, respectively (Owen et al. 2006). Building on this methodology, Monti and colleagues were able to replicate this finding, and then, apparently, communicate with a clinically-diagnosed VS patient, who was able to correctly answer a few personal history questions by willfully modulating brain activity, which could then be assessed using fMRI techniques (Monti et al. 2010).

Pain sensation is mediated by subcortical structures (Bromm & Desmedt 1995, Casey 1991). While cortical areas are also involved in pain processing, presumably there can also be intact pain sensation in the absence of cortical sensory areas (as exemplified in stroke and hemispherectomy; Brodal 1981, 89–90, 113–114; Shewmon 2004, 219) and in the absence of cortical limbic areas (Bouckoms 1989; Shewmon 2004, 219). PET studies have shown activation of the midbrain, thalamus, and somatosensory cortex in response to noxious stimuli, both in the presence and absence of somatosensory cortical evoked potentials (Laureys et al. 2002). Crucially, subcortical pain pathways in VS patients are preserved; without a partially functioning brain stem the patient would be dead or brain dead, not vegetative. Thus, there is a range of evidence from different investigative paradigms suggesting the preservation of various neurological functions involving pain and sensory processing in the clinically diagnosed VS brain.

Given the above considerations, it is reasonable to adopt the weak position that, at least at this point, we don't yet know enough. We don't know enough about psychological states, the many forms of consciousness, or their neurological bases; we don't know enough about the various neuroanatomic changes and neurophysiologic deficits of VS; and we don't know enough about which elements of psychological function, pain processing, or sensory processing, if any, are preserved in any individual VS patient. Given this much uncertainty, we conclude that we do not yet have enough confidence in the medical/descriptive claim that VS patients lack all psychological states to ground unilateral treatment withdrawal based on considerations of justice.

Even if all of the above uncertainty were clarified, there is a further concern that is perhaps even more pressing: VS is consistently misdiagnosed at a very high rate. Early studies found behavioral evidence of awareness in 37% to 43% of patients diagnosed as VS (Andrews et al. 1996; Childs, Mercer, & Childs 1993). More recently, Schnakers et al. (2009) found a misdiagnosis rate of 41% for patients in VS and 10% for patients in MCS (those misdiagnosed as VS were determined to be in MCS; those misdiagnosed in MCS were determined to have emerged from MCS). With a consistent misdiagnosis rate of around 40% over the past 15 years, it would be irresponsible to assume, because a patient has been diagnosed as VS, that she lacks psychological states.

For both of these reasons, we conclude that the claim that VS patients lack all psychological states cannot be made with a reasonable level of confidence. As a result, the normative claim that VS patients are entitled to fewer or no resources on the grounds of their lack of psychological states should have no practical import in actual decision-making. It may very well be true, but the level of uncertainty surrounding the diagnosis is far too high to ground resource allocation decisions. Although we acknowledge that there is extreme dysfunction in VS patients, it is more appropriate to provisionally treat VS patients as being in the same moral category as MCS patients, at least until some of the uncertainties discussed above can be sorted out.

COST OF CARE

In any allocation scheme, we should weigh the costs against the benefits of proposed interventions. Any intervention that is unlikely to achieve its desired aim yet carries a great cost has low efficacy and therefore is unlikely to be considered justly allocated in situations of scarcity. We discuss the concept of efficacy and its role in resource allocation more fully below; in this section we consider the epidemiology, care needs, and cost of caring for the profoundly neurologically impaired.

Epidemiological information specific to VS and MCS is difficult to obtain. As Beaumont and Kenealy (2005, 184) write:

> To establish valid epidemiological data depends critically on two principal factors: Clear, precise, and universally accepted criteria for the diagnosis of a disorder, stable over time; and adequate systems for the collection of epidemiological data. Neither exists for vegetative state (VS) or for minimally conscious state (MCS).

Nonetheless, we do have some estimates available. Ashwal (2004) estimates worldwide prevalence of VS at 49 per million population (PMP), while Jennett (2002a, 2002b) estimates the prevalence of VS in the United States to be between 40 and 168 PMP for adults, and between 16 and 60 PMP for children. The data on MCS are even less reliable; Beaumont and Kenealy (2005, 188) simply state that "the incidence and prevalence of MCS have yet to be established." Giacino and colleagues (Giacino et al. 2002), while acknowledging that accurate estimates are unavailable, nonetheless hazard a prevalence estimate of between 48 and

96 PMP for MCS, for the combined adult and pediatric populations. By way of comparison, the prevalence of stroke in the United States is around 20,700 PMP, and the prevalence of coronary artery disease in the U.S. is about 57,000 PMP (American Heart Association 2010). Thus, VS and MCS are relatively rare conditions, and this limits their overall cost.

The difficulties and ambiguities in diagnosing these conditions result in unreliable epidemiological statistics, as mentioned above. It also results in difficulties establishing cost of care estimates, since this depends on reliable diagnostic criteria and reliable epidemiology. However, although precise information specific to VS and MCS is difficult to come by, nonetheless we can consider more general cost estimates based on the kinds of care required, which we discuss below.

VS and MCS patients who suffer either a traumatic or nontraumatic injury receive initial care in a hospital, typically an intensive care unit (ICU). The patient may then continue rehabilitation or care in an acute rehabilitation center or in a skilled nursing facility such as a nursing home. Standard medical treatment includes nursing care needs such as hygiene, bowel and bladder care, skin care, and frequent repositioning. Passive range of motion and stretching exercises are needed to prevent rigidity and contractions. A gastrostomy, or feeding tube, is necessary for about 50% of VS patients (Ashwal 2004; Kaliski, Morrison, & Meyers 1985), as normal swallowing may be preserved in others. Pulmonary care is useful to prevent infections although the VS/MCS patient breathes spontaneously and is thus not on a ventilator.

Daily costs in a hospital are more expensive than in a long-term care facility. In an ICU without ventilator support (in the United States), the daily cost of care is about $6,667 for the first day,$3,496 for the second, and the mean daily cost is about $3,184 thereafter (the costs are much increased when ventilator support is needed; see Dasta et al. 2005). In contrast, the cost for a private room in facilities with skilled nursing and custodial care ranges from the national average in the United States of $219 daily to a high of $584 daily in Alaska (Metlife Mature Market Institute 2009). As mentioned above, most VS patients progress from coma to the VS within 2 to 4 weeks, allowing a move from intensive care to a skilled nursing facility. This results in a cost of about $146,000 for the first year (including ICU care and nursing facility care) and an average yearly cost of about $79,900 for skilled nursing care thereafter. We make these estimates based on the national average cost of nursing care and the assumption of 3 weeks of ICU use without a ventilator; they comport fairly well with the findings of one study by Fields et al. (1993), who estimate the cost of long-term, non-acute care for VS patients at about $90,000 per patient per year. This was a mailed questionnaire study, based on a sample of 20 pediatric patients in the United States diagnosed with VS who had been discharged home, and whose primary costs included 10 to 12 hours of nursing care per day.

Taking the low and high prevalence estimates from above, based on a population estimate of 304.5 million (U.S. Census Bureau 2008), and using $90,000 per patient per year as a cost estimate, we get a total cost for the combined VS and MCS population (both adult and pediatric) of between $2.9 billion and $8.9 billion per year in the United States. This is a huge expenditure, but by way of comparison, the estimated cost of cardiovascular disease in the United States in 2010 will be $324.1 billion in direct costs (hospitals, medical professionals, medications, etc.) and $503.2 billion when the indirect cost of lost productivity is added to that estimate (American Heart Association 2010). As a word of caution when considering these cost estimates, however, we note once again that they should be considered only partially reliable at best, and are used only to get a very general idea of the amount of cost involved.

JUSTICE AND THE MORAL COMMUNITY

Justice involves treating like cases alike or treating similarly situated people similarly. While this formal concept of justice derived from Aristotle is clearly the backbone of all concepts of justice, it is *merely* formal, in the sense that it provides a form or structure, but lacks meaningful content. Everything in the universe is like everything else in the universe, in some respects. To understand what justice requires in any particular situation, we must understand the criteria for *relevant similarity* for that particular situation.

Different distribution schemes—libertarian, utilitarian, egalitarian, prioritarian, need, urgency, efficacy, and so forth—are at bottom criteria for determining relevant similarity. If two people are similar in need, urgency, and efficacy, for example, then according to Rhodes' account of *clinical justice* (Rhodes 2005; 2007, 1186), they are relevantly similar and hence should be treated similarly. By contrast, if two people require different amounts

of resources in order to preserve or restore normal or species-typical functioning so that their opportunities can be equalized, then according to Daniels' egalitarian, equality of opportunity account (Daniels 1985, Chapter 1), those two should be treated differently, because they are relevantly dissimilar.

To understand fair resource allocation in practical terms, we should answer two questions. First: Who gets consideration at all? That is, we start with a pool of *potential* claimants, without yet prioritizing their claims on health care resources. Second: Given that pool, how do we split it into categories and then prioritize the categories (cf. Beauchamp & Childress 2009, 275–279)? In this way, each member of each category is relevantly similar to every other member of that category, and justice is served when all members of that category are treated alike; however, the categories themselves get ranked in order of priority. This takes into account that resource distribution is relative to supply and demand, and ranks the strength of each group's claim on resources against one another.

One underlying motivation for determining principles of just distribution is the recognition that people have value and their interests matter. The way basic benefits and responsibilities of social cooperation are distributed, including especially resources tied to health care, has a direct effect on people's life plans and expectations, their ability to pursue their goals, and hence, the satisfaction of their interests. We suggest then that a reasonable starting point is to briefly examine the more fundamental issue of the determinants of human moral worth, or value. Namely: What is it that makes an individual valuable? Examining this question will help in determining the pool of potential claimants on health care resources. We assume that having moral worth is sufficient to place one within this larger pool. We will henceforth use the term "moral community" to refer to the group of individuals that have moral value, and in virtue of which they are potential claimants on health care resources.

Given a moral community, a *distribution principle* splits that community into categories and ranks the strength of their claims on health care resources. We can also consider distribution principles as relevance criteria, because they specify the relevant respects that determine likeness for purposes of fair resource allocation. A complete theory of distributive justice therefore requires both a theory to determine the moral community, as well as a distribution principle, relevance criterion, or ranking scheme, which ranks the strength of each sub-category's claim against every other. Notice that being a member of the moral community gives one standing as a potential claimant but does not guarantee the right to resources, as the distribution principle might rank one's claims as having less priority than most others.

POPULATING THE MORAL COMMUNITY: THREE CONCEPTS OF MORAL WORTH

The Kantian view is that rational *agents* have intrinsic moral value; everything else that has value only does so relative to the value attributed it by a rational agent. To be an agent is to be able to have and give reasons, and to autonomously guide and direct one's behavior in light of one's goals and reasons. As a result, rational agents are *moral agents*, in the sense that they can be held morally responsible. This Kantian view of personhood and moral value is deeply ingrained in our common law traditions, via notions such as respect for privacy, personal liberty, and the right of self-determination, as well as culpability, negligence, and malpractice. It is also deeply ingrained in health care ethics, as the well-regarded principle of respect for autonomy. On this view, humans are morally valuable because they have the ability to guide and direct their behavior based on reasons.

A different view, grounded in the utilitarian tradition, does not look to agency to confer value, but simply the ability to experience pain.[6] Someone who has the ability to have and give reasons is responsible for her actions, and is thus a *moral agent* and a member of the moral community. A *moral patient* is a member of the moral community, deserving of consideration by moral agents.[7] On this view, living things that have the ability to *feel* have moral standing and deserve consideration.

To compare the Kantian to the utilitarian view, it is important to recognize that, while the Kantian holds the ability to be self-legislating above else as conferring intrinsic moral value, Kant would not claim that non-agents deserve no moral consideration. Rather, for Kant, there is a general duty of beneficence, whereby agents have the obligation of treating non-agent moral patients beneficently. The Kantian would not claim that, for example, a severely demented person should not be treated humanely. There is, however, a very crucial distinction between the Kantian and utilitarian views

that should not be elided: Simply having the ability to feel pain at all confers moral standing according to the utilitarian view, but not according to the Kantian. Therefore animals, humans with profound mental disability, infants, etc., all have moral standing on the former view. By distinction, the Kantian view of moral value would not assign individuals in the aforementioned categories inherent moral value.

A different way of thinking about human moral value derives from a sort of essentialist, exceptionalist view of humanity, which we will call the *biological essentialism* view. On this view, humans have moral value simply *qua* biologically functioning human being. Thus, having the human genome and being biologically alive (or even simply maintaining certain biological functions involving the maintenance of internal homeostasis and resisting entropy) confer moral value. This view is not explicitly tied to any particular tradition in moral theory; however, the idea that humans are special, indeed morally special, has been around for as long as humans have, is expressed in the teachings of various religious traditions, and is sometimes expressed in terms of the sanctity of human life, or human dignity. Hence, simply having the human genome and having some (unspecified) level of biological functioning confers moral value on the biological essentialism view.

We do not propose here to adjudicate a longstanding dispute between Kantians and utilitarians on such a fundamental issue as the core determinant of moral worth. We also do not propose to challenge or defend the longstanding view that assigns moral worth to a biologically functioning human, and finds expression in some of the world's major religions and, perhaps, mainstream intuition. Instead, we shall take note of the following. The allocation of public resources is a public policy issue. The overarching goal of such policy is to create a system that all can acknowledge as rational, relevant, and fair, even though we do not all share the same basic worldview or value system.[8] There is no consensus on what fundamentally determines human moral worth. However, the three conceptions canvassed above are commonsense, based in venerable philosophical and religious tradition, and widely regarded as relevant and reasonable, even though there is no consensus that any one of them is superior to the others. Therefore we argue that each element—self-determination, capacity for pain, and biological function—is enough to determine "as if" moral worth. In other words, in the context of policy that structures a heterogeneous society, it doesn't matter whether any of these determine *actual* moral worth. Rather, it is enough to claim that it is sensible to treat an individual that satisfies any of these characteristics *as if* she were a member of the moral community, on the grounds that reasonable people do in fact do so, and for reasons that all can acknowledge as relevant.

We recommend that a quasi-pluralistic approach of tolerance is the optimal one. However, while we acknowledge the reasonableness of some level of difference in our fundamental value judgments, we neither advocate nor accept an "anything-goes," subjectivist, nor relativist approach. We do not, for example, advocate ranking life as an overriding value so that it trumps the patient's wishes or the surrogate's ability to discontinue life-sustaining care. This makes our theory of the moral community "quasi" pluralist.

Patients with the most severe neurological impairments—even brain death—are members of the moral community, on the quasi-pluralist conception recommended here. The MCS patient has some limited capacity for awareness of her internal and external milieu. She is able to respond with meaningful gestures and thereby to communicate her desires. It is not obvious whether we should assume that the MCS patient has the capacity for self-determination in a robust sense, thereby meeting the Kantian's standard for moral standing, but she clearly has the capacity for pain and other psychological states, thereby meeting both the utilitarian's and the biological essentialist's standards.

The VS patient is biologically alive and continues to perform a range of biological functions, albeit in the presence of profound neurological disorder. By this circumstance alone she qualifies to be treated as if she were a member of the moral community. Furthermore, we currently lack reasonable confidence in the claim that any individual VS patient is without psychological states, for the several reasons discussed above. Therefore the VS patient may very well have some rudimentary psychological functions preserved, including especially the reception and transduction of sensory and noxious stimuli. If so, this would satisfy the utilitarian's standard for moral worth as well, though not the Kantian's.

The brain-dead patient is also a member of the moral community. Although legally dead, the brain-dead individual continues to perform various biological functions that serve to resist entropy and maintain homeostasis. These include cellular

respiration, circulation, gas exchange at the alveoli, and many others. As a result, the brain-dead individual is a minimally biologically functioning human, and therefore qualifies to be treated *as if* she were a member of the moral community, on the grounds that we have mentioned above: Reasonable people do in fact value these individuals as having intrinsic moral worth, and for reasons that all can acknowledge as relevant even though not all will accept these reasons as sufficient.

We urge a tolerant, quasi-pluralistic conception of the moral community that makes room for differing fundamental judgments on the determinants of moral worth. A consequence of this view is that even the most severely neurologically impaired individuals (indeed, even the brain dead, who are legally dead) deserve to be treated as if they are loci of intrinsic moral worth, and are therefore *potential* claimants on health care resources. However, recall that distributive justice requires, in addition to a conception of the moral community, a distribution principle or ranking scheme. This distribution principle will split the pool of potential claimants into smaller categories, and prioritize them according to some ranking scheme. It is consistent with what we have argued here that different principles should be applied in different scenarios (say, in the context of scarce organs for transplant as opposed to relatively abundant resources like some antibiotics).

THE ROLE OF EFFICACY IN RESOURCE DISTRIBUTION

There are many different criteria that might be used as distribution principles that categorize and rank the members of the moral community for purposes of health care resource distribution. These criteria are usually based in large-scale theories of social justice, such as egalitarianism, prioritarianism, utilitarianism, libertarianism, and so forth. As above, we will not attempt to arbitrate such large-scale and fundamental theories in a single chapter. Instead, we urge that a focus on consensus and compromise is appropriate in making policy decisions.

While there are many entrenched and sometimes opposing views on what constitutes a fair distribution of resources, in situations of scarcity in medicine, the importance of the principle of efficacy is well accepted. When resources are scarce, the assumption behind appealing to efficacy is that, if some particular resource is not likely to help the person to whom it might be given, then it should not be given to that person when it might help another. For example, it seems unjustified to transplant a heart into a patient who already has multiple organ failure and is unlikely to survive even with the heart transplant, because by doing so, some other patient with a much higher chance of survival gets denied, and the end result is that both patients die when one could have been saved. However, while the appeal to efficacy during scarcity enjoys widespread acceptance, the principle itself needs explication.

Efficacy is the likelihood that a particular intervention will have its desired effect. However, an important and open question is: What *should* be the desired effect? While assessing the likelihood of a desired medical outcome given some intervention is a non-normative matter for science to grapple with, deciding on what the benefit should be is a normative matter. Embedded within the principle of efficacy in resource distribution is a value judgment about what benefits are the most important. For example, consider the classic battlefield triage case. Many soldiers are badly wounded, and supplies, including the medic's time and availability, are limited. In this case of extreme scarcity, those who are highly likely to die even if treated are prioritized against, so that the medic is able to treat those who have a reasonable likelihood of survival. The embedded value judgment is that life is the most important good, and if treatment will not have the desired effect of preserving life for some individual soldier, then treatment should not be allocated to her. However, while the preservation of life is an obvious good, there are others that should also be considered. Freedom of movement, the preservation of functional limbs, the preservation of cognitive capacities, and relief of pain are some other moral goods that might be appealed to as components of the principle of efficacy.

Indeed, there is an important connection between the concepts of moral worth discussed above, efficacy, and the profound neurological impairments under consideration here. Specifically, whether some intervention made on behalf of a patient with VS is efficacious depends on one's underlying views about what the goals of treatment are or should be. For example, imagine a VS patient such as Terri Schiavo with severe pneumonia and in need of a ventilator and antibiotics, as compared to a non-VS patient in similar circumstances. A Kantian would argue that the treatments are more efficacious for the non-VS patient than for the VS patient: The interventions are likely to restore or preserve the non-VS patient's

capacity for self-determination, but will not do so for Schiavo. On the other hand, the biological essentialist might argue that so long as the interventions have an equal likelihood of preserving biological life and returning each patient to her former state, then the treatment is equally efficacious in both cases. Similar disagreements will arise in the context of MCS and brain death, and between utilitarians and others.

Again we appeal to consensus. Just about everyone agrees that preserving life, preserving autonomy, and minimizing pain are each important goals of medicine. Therefore it is appropriate to appeal to any of them as components of the principle of efficacy. The disagreement is not about whether any of these things are important goals of medicine; rather, the disagreement is about which of them is minimally sufficient for moral standing, as discussed above. The Kantian takes only the capacity for self-government to be minimally sufficient, the utilitarian takes the capacity for pain to be minimally sufficient, and the biological essentialist takes biological functioning to be minimally sufficient. But everyone agrees that, if it is possible to preserve life while minimizing pain and preserving or restoring autonomy—in other words, if it is possible to achieve all three—then that is clearly the optimal outcome.

For practical allocation decisions, the Kantian would be wrong were she to claim that only preserving autonomy makes for an efficacious medical treatment, but the biological essentialist would similarly be wrong were she to claim that preserving life and autonomy is equally efficacious as preserving life in the absence of autonomy. Instead, the best answer for real-world policy is somewhere in the middle of these two extremes. It *is* efficacious to treat a VS patient, because doing so can achieve one of the several obvious goals of medicine, which is to preserve life. It is also efficacious to treat a non-VS patient in similar circumstances, because doing so can achieve the goals of preserving life and preserving autonomy. However, if it becomes necessary to compare the efficacy of a given treatment when provided to two patients, one for whom self-determination can be preserved and another for whom it cannot, then it would be more efficacious to treat the former. This is justified on the simple ground that more of the widely accepted goals of medicine can be achieved for the former than for the latter.

We now apply these considerations to discuss resource allocation and reasonable accommodation in brain death, VS, and MCS.

BRAIN DEATH AND REASONABLE ACCOMMODATION

The concept of *death* is both vague and ambiguous, and the word "death" has evolved to take on several meanings. Rhodes (2001, 1), for example, notes the following:

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> While it may not always have been so, today the word 'death' has three distinct senses. 'Death' is a rough marker for a complex biological event. 'Death' is also an important marker in the social/legal/political realm. And 'death' indicates distinctions in the moral realm.

The biological notion of death involves the cessation of the functioning of the organism as a whole; or, it involves the loss of the integrative unity of the organism. In this context, "functioning" is typically taken to mean the resistance of entropy and the maintenance of internal homeostasis (Bernat, Culver, & Gert 1981; Korein & Machado 2004).

The legal definition of "death" is stipulative, and thus true by definition. It reflects sociopolitical, legal, and moral reasons for saying that an individual is *legally dead*, so that the legal and social status accorded to living humans ceases. Currently, there is international consensus in support of either the whole-brain or brain stem formulation, which states that an individual is legally dead when all functions of her brain (or brain stem) have ceased irreversibly.

In every state of the United States except New Jersey and New York, discretion for determining death by either brain death or cardiorespiratory arrest resides with the physician. Family members do not have legal authority to prevent or forestall the determination of death by the brain death protocol. Physicians may of course be sensitive to the concerns, worries, and plight of family members and may choose an option that best fits the family's situation. Still, the physician remains the final arbiter.

By contrast, in New York and New Jersey, the family's or patient's prior moral beliefs regarding death and brain death play a more prominent role in the determination and certification of death, and hence in resource usage. In New York, after the determination of brain death but prior to certifying death, if it is known that the patient had moral objections to the brain death standard, the hospital must provide reasonable accommodation (New York State Department of Health 2005).

In such circumstances, New York permits the expenditure of resources on brain-dead patients. The guideline does not permit absolute accommodation, however, as a hospital is not required to continue ventilation indefinitely. In effect, the policy establishes a legal side-constraint on allocation decisions by the hospital or medical team without insisting on an inviolable requirement.

The New Jersey Declaration of Death Act (*New Jersey Declaration of Death Act* 1991) similarly allows family members the discretion for determining death according to cardiorespiratory criteria, based on the moral or religious beliefs of the patient. New Jersey's legislation favors respecting beliefs about death so that the patient's family can insist that the hospital continue expending medical resources even when the patient would be determined legally dead according to the brain death protocol.

Some seek to expand the New Jersey exemption as a general right (Veatch 1999) and to treat the *New Jersey Declaration of Death Act* as signaling a new direction for developing public policy (Olick 1991). From the recognition that individuals have alternative conceptions of death, the position presumes that whether a person is dead is a moral rather than a scientific matter. As such, it should be left to the patient's beliefs which of the two alternatives should be used by the medical profession in determining and certifying death.

Our quasi-pluralist conception of the moral community explains and justifies the New York and New Jersey brain death policies. We accept the reasonableness of some religious views that accord moral value to a brain-dead but biologically functioning individual because, implicitly at least, we accept that the biological essentialism view is at least one of a range of reasonable, fundamental views about human moral value; or, it is at least *not un*reasonable to make this fundamental value judgment. Furthermore, reasonable accommodation is not a radical departure from common practice. Treatment and care continue to be evidence-based, and patient or proxy requests for uncommon treatment (e.g., deep-brain stimulation for prolonged VS patients) or non-standard treatment (e.g., homeopathy) can be refused. Reasonable accommodation forestalls decisions by the hospital or medical team to discontinue or reduce treatment, but need not supplant those decisions.

Additionally, we acknowledge the importance of the voices of the medical profession in determining the appropriateness of certain medical interventions, such as maintaining a brain-dead individual through intensive life support. Although there are many individual physicians who oppose brain death as a criterion for death, nonetheless no professional medical organization rejects it. By forestalling but not preventing physicians from declaring a patient dead by neurological criteria, which is an accepted and standard practice, New York's reasonable accommodation policy preserves the integrity of the profession while also acknowledging the reasonableness of different value judgments.

While we allow a quasi-pluralist conception of value, we neither advocate nor accept an "anything-goes" approach either. We do not and should not, for example, make accommodations for a religious view that doesn't accept cardiac death as death. If *all* biological functions have ceased, we do not make exceptions if someone were to claim that her religion demands that the body be kept on a ventilator or even in a hospital bed. Furthermore, we acknowledge that the *legal* definition of "death" is a stipulative one that reflects sociopolitical, legal, and moral reasons for saying that an individual is legally dead. As such, there is a value judgment embedded within it, and therefore it is appropriate to allow for reasonable accommodation of other, different value judgments.

We therefore argue that it is an appropriate institutional, state, or federal policy to allow individuals to be accorded reasonable accommodation from the brain death standard for death if they or their surrogates object on moral grounds (i.e., if they attach moral value to a biologically functioning human). However, in the face of scarcity, efficacy plays an important role here as it does elsewhere. When an individual doctor or hospital administrator is faced with the choice of either removing a brain-dead individual from a ventilator or ICU bed, or denying that resource to someone else who isn't brain dead, the choice should always go in favor of the non-brain-dead patient. This is justified on the grounds of efficacy: The brain-dead patient might be maintained in a state of minimal biological function for some brief period of time, but she cannot be restored to rational agency, nor even to a state in which any psychological states occur at all. Since the level of biological functioning is so minimal and cannot be restored to anything near normal functioning, scarce resources would be allocated unfairly if another patient is denied resources in favor of the brain-dead patient, on the grounds of the low efficacy of maintaining the brain-dead patient.

The "reasonable" in "reasonable accommodation" should be understood in terms of resource availability, and the local hospital administrator should have the final word on when the ICU bed, ventilator, or expert nursing staff are urgently needed elsewhere. If these resources can be used to maintain a brain-dead individual who invokes the reasonable accommodation clause without putting someone else at risk of death or permanent disability, then they should be used for that purpose, and this can be a just allocation of resources. If, however, someone else urgently needs them, then the brain-dead individual should be denied those resources, even if it means removal of the ventilator over objection. This is also just because resource allocation is relative to supply and demand.

RESOURCE ALLOCATION FOR VS AND MCS PATIENTS

Brain death is distinct from VS and MCS, medically, legally, and morally. Medically, the brain-dead patient cannot perform the "vegetative" functions still performed by the VS patient, such as regulation of hormones and blood pressure, control of respiration, or cranial nerve reflexes. The brain-dead patient is on a ventilator, whereas most VS patients are not. Legally, the brain-dead patient is dead whereas the VS or MCS patient is alive.

Morally, there are a range of differences. Because there is so much uncertainty surrounding the diagnosis of VS, both in terms of our understanding of the illness and sensory or psychological functions that may or may not be preserved, as well as the high rate of misdiagnosis of VS, it is inappropriate to treat any individual VS patient as being in a different moral category than the MCS population. That is, we lack a reasonable level of confidence in the claim that any individual VS patient lacks all psychological states. Therefore we ought to take the safer route and treat VS patients as MCS patients for moral purposes. MCS patients are severely disabled but nonetheless experience some psychological states. They respond to stimuli in apparently purposeful ways and they communicate, albeit inconsistently. Therefore we should presume that they experience pain and discomfort at least, and possibly have desires that may be fulfilled or frustrated. This puts the MCS/VS population into a different moral category than the brain dead, since the brain dead do not experience pain and do not have any desires to be satisfied or frustrated. Therefore the brain dead have no interests, whereas the MCS/VS patient has, minimally, an interest in not feeling bodily pain and possibly also interests in having her desires fulfilled.

Since there is this important moral distinction between the brain dead and the nearly brain dead such as the MCS and VS, resources ought to be allocated in a way that reflects that difference. Namely, it should be very easy to prioritize against the brain dead on grounds of the low efficacy of any medical treatment, but less easy to do so against the VS/MCS patient. The VS/MCS patient is legally and biologically alive and possibly a subject of some sensory experiences and other psychological states. Therefore treating such a patient can achieve the goals of providing comfort care and maintaining life, although not preserving autonomy. In situations of extreme scarcity, however, it would be unfair to prioritize against a non-VS/MCS patient so as to treat the VS/MCS patient, based on the same considerations of efficacy. To clarify our claims, we will discuss these issues in the context of two cases that follow.

First, recall Teresa Schiavo. This is a young woman in a prolonged, 17-year VS whose family disagreed about the best course of care for her, and their difficult family struggle made its way into the arena of public debate through multiple court cases, gubernatorial and legislative intervention, and widespread media coverage (Caplan, McCartney, & Sisti 2006). The moral and legal questions most often discussed with respect to the Schiavo case involve the sanctity of human life and the right to die, the right to self-determination or non-interference, and more generally, respect for the decisions of legal surrogates.

In addition to the above considerations, distributive justice is always relevant. To begin, consider that Ms. Schiavo was in need of supportive care for all of her basic needs. As mentioned above, this includes important nursing care needs such as hygiene, bowel and bladder care, skin care, frequent repositioning, and passive range of motion and stretching exercises. While a feeding tube is necessary for about 50% of VS patients, this was not necessary in Ms. Schiavo's case, nor was she on a ventilator. These basic care needs can be expensive, as discussed above. Given the severe disability and high cost, does social justice demand that patients like Ms. Schiavo be denied care?

We argue that it does not. Ms. Schiavo and other VS patients ought to be provided the standard medical and nursing care mentioned above, with public funds if necessary. As we've argued

above, these patients are members of the moral community, or, minimally, they should be treated as if they are members of the moral community. Therefore they are potential claimants on health care resources because they have moral standing. Although there is always some amount of scarcity, the resources required for basic needs mentioned above are not so scarce that, by giving care to Ms. Schiavo and others like her, someone else would have to be denied the very same intervention and thereby be put at risk of death or disability.

However, circumstances could arise in which this would change. Imagine for example that Ms. Schiavo contracted severe pneumonia and was in need of an ICU bed and ventilator. Imagine further that the ICU has only one available bed, and at the same time, Ms. Smith, a different patient of the same age, say with a history of asthma but no other major ailments, also contracted pneumonia and needed that ICU bed. (Imagine further that there are no nearby hospitals with ICU space available either.) Some individual physician or hospital administrator must make the difficult decision to give the last ICU bed to either Ms. Schiavo or Ms. Smith, with the consequence that whoever does not get the ICU bed will be sent to a standard unit, and be far more likely to succumb to her pneumonia.

This circumstance involves a triage context, where efficacy becomes relevant. By all accounts, after 17 years in a VS, Schiavo's mental function cannot be restored; her status as a moral agent is forever lost. The best that can be done for her is to preserve biological functioning, and, possibly, maintain a state of relative comfort.[9] By contrast, Smith is a moral agent and if the pneumonia is treated aggressively, she can be restored to a state of autonomous agency and preservation of species-typical biological functioning, and her pain from the pneumonia can be alleviated.

Both Smith and Schiavo are loci of intrinsic moral worth, both are members of the moral community, and providing health care to each is a matter of justice and desert, not beneficence or charity. However, the reality of limited resources, especially in a micro-allocation context, forces a decision with distressing consequences. Justice demands that like cases be treated alike, but Smith and Schiavo are not alike, at least for this allocation decision.

Similarly, if Ms. Schiavo had developed organ failure and was in need of a transplant, she should not have been placed on a transplant waiting list, nor should she have received scarce vaccines, as in the recent H1N1 flu virus outbreak. Although she should be treated as a member of the moral community and therefore a potential claimant on resources, in these types of circumstances, resources are so scarce that providing a unit of that resource to one individual means that another individual must be denied that very same resource. Obviously in a very broad sense, giving anyone any care means someone else is missing something, but in a more tangible and direct way, giving the organ to Ms. Schiavo means that that particular organ doesn't go to the next person on the list, and so on, until the very next person on the list that does not get an organ, dies. Although it would be efficacious to provide a transplanted organ to Ms. Schiavo because it could help to achieve the legitimate medical goal of preserving biological life, it would be *more* efficacious to transplant that same organ to a different patient who is not in a VS because it could preserve both life and autonomy.

Let us consider a more recent case. Ruben Betancourt was a 73-year-old man who, after prolonged oxygen deprivation as a result of complications surrounding surgery, developed anoxic encephalopathy in January 2008. He lapsed into unconsciousness, was placed on a ventilator, and was diagnosed as being in a VS. Six months after the initial anoxic insult, Mr. Betancourt was diagnosed with renal failure and given thrice-weekly dialysis treatments. Six months after that, the treating hospital, Trinitas Regional Medical Hospital in Elizabeth, NJ, advised Mr. Betancourt's family that they felt that further treatment was medically inappropriate and sought to discontinue dialysis and remove him from the ventilator, which would result in his death. The family sought and received a restraining order in April 2009 from the Superior Court of New Jersey, prohibiting the hospital from discontinuing treatment without the consent of the daughter, Mr. Betancourt's legal surrogate. The hospital appealed, but before further arguments could be heard Mr. Betancourt died, in May 2009.

Trinitas physicians argued that Mr. Betancourt was in a persistent, irreversible VS and would not recover. They further argued that dialysis treatment should be discontinued as further care would achieve no medical goal. As a result, they sought to discontinue all treatment, including dialysis, artificial nutrition and hydration, and ventilation, over the family's objection. Family members argued that the Trinitas medical personnel were incorrect in their assessment, disputing the claim

that Mr. Betancourt was in an unresponsive, persistent VS. They argued that he would open his eyes or turn his head in response to certain voices, and would recoil when medical personnel approached, anticipating treatment. They, along with Mr. Betancourt's nephrologist, also disputed the claim that dialysis treatment was futile or harmful, arguing that it is the standard of care for end-stage renal failure (*Betancourt v. Trinitas Regional Medical Hospital* 2009).

Futility, however, is the inverse of efficacy; thus it is relative to some particular outcome to be achieved. For the goal of discharge or return to Mr. Betancourt's former state of functioning, dialysis and other treatments *are* futile; that is, their likelihood of achieving this outcome is vanishingly slim. But on the other hand, dialysis treatments served to prevent electrolyte imbalances that would have resulted in cardiac arrest; they thereby furthered the goal of preserving Mr. Betancourt's life, for 6 extra months, and so were not futile for achieving this other goal. Thus, whether treatment is futile depends on what is considered an appropriate goal of medical treatment. As above, we suggest that a quasi-pluralist position of tolerance is appropriate here. Both the family and the treating nephrologist felt that the goal of extending biological life was an important goal, and dialysis did help to achieve that.[10] However, we may still ask whether this use of resources was just.

Dialysis treatment is expensive; one study found the average annual cost of in-hospital dialysis treatments for end-stage renal disease to be $51,252 (Lee et al. 2002). Further, the average cost of a single day in an ICU with ventilator support is over $10,000 for the first day, near $4,700 for the second day, and around $4,000 per day thereafter (Dasta et al. 2005). With this great cost, it is not surprising that Mr. Betancourt's unpaid hospital bill reached $1.6 million before Trinitas sought to discontinue his treatment over the family's objection (Toutant 2010). Is it fair to use this amount of resources on a ventilated patient with end-stage renal failure in an irreversible VS, when there are so many others in need of care, and who could benefit so much more?

We suggest that it is. Dialysis is certainly expensive, but it is not so scarce a resource that using a dialysis machine to treat Betancourt means that someone else will not get dialysis and hence die. Dialysis is an efficacious (and hence medically appropriate) treatment because it can help to keep Mr. Betancourt alive by preventing fatal electrolyte imbalances. Given that the family believed Mr. Betancourt would have wanted to stay alive in this state, providing treatment further achieves the goal of respecting the wishes of autonomous agents through respecting their surrogates' decisions. As we argued above, there is no consensus on what fundamentally determines moral standing, but the three aspects of self-determination, minimization of pain, and preservation of biological life are all widely accepted as relevant considerations in this regard. Since it is reasonable to value biological life, even though not everyone values it in the same way, it is a sensible and fair allocation to use resources in order to preserve life, even in the absence of preserving autonomy.

As with Ms. Schiavo, there should also be limits. While we argue that it is just to use public funds to provide ventilation, dialysis, and artificial nutrition and hydration to Mr. Betancourt, it would not be just to put him on a kidney transplant list. In this circumstance, the scarcity of resources is not a scarcity of *funds*, but a scarcity of *kidneys*. As we argued with Ms. Schiavo, while it would be efficacious to transplant a kidney into Mr. Betancourt for its likelihood of preserving life for a while longer, it would not return him to a state of autonomous self-determination. By preventing death for some other (non-VS) patient in need of a kidney, on the other hand, the transplant would preserve both life and autonomy, and therefore the intervention would be more efficacious if given to the non-VS patient. Distributive justice therefore demands that patients such as Mr. Betancourt or Ms. Schiavo not be placed on organ transplant waiting lists, because the scarcity of resources in that circumstance is far more acute.

Finally, many of these well-known cases revolve around families that claim that the clinically diagnosed VS patient does respond in purposeful ways, opposing the physicians who claim that the patient is permanently unconscious. This occurred in both Ms. Schiavo and Mr. Betancourt's case. These claims from the family should not be ignored or dismissed as wishful thinking. The diagnosis of the VS is problematic and suffers many flaws, as discussed above. Not least of these flaws, the misdiagnosis rate is around 40%; both Mr. Betancourt and Ms. Schiavo had a 2 in 5 chance of not being in a VS, despite their having received that diagnosis.

Further, recall that the diagnosis can be neither confirmed nor refuted by postmortem autopsy, by imaging tests, or by electrophysiologic tests.

The diagnosis is essentially a clinician's determination that the behavioral repertoire of some particular patient, which can include blinking, grunting, crying, smiling, movement of eyes and extremities, and more, is not "purposeful." If the family, who spends far more time with the patient, believes that the patient is exhibiting some signs of awareness, this should not be ignored. Of course it might very well be wishful thinking on the part of the family, and the well-trained clinician's observational skills should ordinarily be trusted more than the non-clinician's. Nevertheless, as we've argued above, there is far too much uncertainty surrounding the diagnosis to assert a stark contrast between the VS and MCS patient; and the MCS patient *is* a subject of experiences. Given these uncertainties, we should not presume that Mr. Betancourt was completely lacking in all experiences, nor that he lacked all psychological states. *A fortiori*, we should not base normative conclusions about resource allocation on this uncertain medical/descriptive claim.

CONCLUSION

The impairments associated with the nearly brain dead such as those in a vegetative or minimally conscious state are profound, and result in the complete or near-complete loss of all cognitive function as well as total dependence on caregivers for all basic needs. This situation of extraordinary cognitive dysfunction (or complete lack of function), coupled with the presence of some remaining biological function, might plausibly lead one to wonder if it would be unjust to allocate scarce medical resources in the maintenance of such a patient, when there are so many others who could presumably benefit more. Furthermore, using resources to maintain a brain-dead individual—who is legally dead—can plausibly seem even more unjust for the same reason.

In this chapter we have argued that this is not so, or at least, it is not always so. Social policy on health care resource distribution should be guided by the understanding that we do not all share the same basic worldview or value system, but nonetheless must decide how to allocate resources in a way that all can recognize as reasonable and based on relevant considerations. One way of doing this is to begin with a pool of potential claimants on resources, the moral community, and then split and rank that pool according to well-accepted principles. While there is no consensus on the fundamental determinants of human moral worth, all three of the components discussed above are intuitive, widely endorsed, and based in long-standing philosophical and religious tradition. Since even the most profoundly impaired (including the brain dead) satisfy at least one of those criteria, we argue that they should be treated "as if" they are members of the moral community, on the grounds of tolerance, the lack of consensus on what determines moral standing, and on the ground that reasonable people do in fact treat them as having moral standing, for reasons that all can at least acknowledge as relevant. Therefore they are potential claimants on health care resources. As a result, resources such as skilled nursing care, antibiotics, and even dialysis ought to be allocated to the profoundly neurologically impaired, should this be the decision made by an appropriate surrogate, and this is a just use of resources.[11]

However, it is also well accepted that in the face of extreme scarcity of medical resources, efficacy is relevant. While "standard" medical treatments such as those mentioned above can be justly allocated to those with profound neurological impairments, it would not be just to allocate extremely scarce resources to them, such as transplantable organs. In this circumstance, efficacy should be one of the guiding principles of resource distribution. Since it would be more efficacious to transplant an organ into a patient for whom both life and autonomy can be preserved, than a patient for whom only biological life can be preserved, justice demands that the organ go to the former.

Notes

1. In the context of the cited paper, Brody is in the midst of a general discussion of several different ethical questions raised by the vegetative patient, providing a broad overview of different positions that one might take. The position on justice stated above is only one of them.

2. Nair-Collins has argued elsewhere (Collins 2009; 2010b; Nair-Collins 2010) that the orthodox view is mistaken: brain-dead individuals are biologically alive. Many other authors have challenged the orthodox view as well. For the orthodox view, see Bernat 1998; Bernat, Culver, and Gert 1981; and President's Commission 1981.

3. Some use the word "person" to mean something like rational, autonomous, moral agent, capable of having and giving reasons, of guiding her behavior in order to achieve her goals in light of her reasons, and able to be held morally responsible for her behavior. Such a person would be competent to accept or forgo a medical procedure. Here we use the terms "moral agent" or "agent" to mark this category, and "person" in a weaker sense, as the locus of psychological states, or

the experiencing self. Thus a severely demented person who still has psychological states (she can feel pain, for example) but is no longer capable of having and giving reasons and pursuing her goals in light of them (etc.) is not an agent, but is a person, on this use of terms.

4. Since the MCS patient is able to follow commands and gesture yes/no answers, thereby communicating, it is reasonable to suppose that she might have some rudimentary goals or desires.

5. As an aside, we should note that we do not base this claim on vague worries about the ineffability of consciousness, nor on the presumed non-reducibility of psychological states, nor on the ancient problem of other minds. We are fully confident that consciousness, intentionality, and all other mental capacities can be eventually reductively explained in naturalistic terms, and in particular, in terms of neurological states. See Collins (2010a) for one of our views on naturalistic explanations of mind.

6. In chapter XVII, section i, paragraph 4, note b of The Principles of Morals and Legislation, Jeremy Bentham writes, "What else is it that should trace the insuperable line [between those who deserve moral consideration and those who do not]? Is it the faculty of reason, or, perhaps, the faculty of discourse? But a full-grown horse or dog, is beyond comparison a more rational, as well as a more conversible animal, than an infant of a day, or a week, or even a month, old. But suppose the case were otherwise, what would it avail? the question is not, Can they reason? nor, Can they talk? but, Can they suffer? [sic] (Bentham 1996, 283)"

7. See McPherson 1984 for a discussion of the moral patient as one who can be helped or harmed by an action, or one who has either rights or interests. The concept of a moral patient is associated with the animal rights literature, as in Regan 1983 and Singer 1975, since it is a category that includes sentient animals.

8. We borrow this basic idea from Rawls's concept of an overlapping consensus (1996, 2005).

9. Although hers was a case of VS, not MCS, recall that we have argued above that the descriptive/medical distinction between the two is far too tenuous to base any normative judgments on that distinction. Thus we should treat VS cases like MCS cases for moral purposes, and that includes treatment plans that include comfort care and pain control.

10. In their influential account of futility, Schneiderman, Jecker, and Jonsen (1990) argue that treatment for patients in VS is qualitatively futile; that is, some measurable outcome might be achieved, but no benefit to the patient can be appreciated by the patient, since she is unconscious. This depends on, first, the descriptive claim that every patient diagnosed as VS is indeed entirely unconscious, a claim that we believe should be qualified to a more agnostic one of uncertainty about the presence of psychological states, as discussed above. But furthermore, it also depends on a normative claim about the appropriate goals of medical care. While the views of Schneiderman et al. are certainly among the range of reasonable views on this issue, the preservation of biological life is also among that range. In a pluralistic society, we should be willing to accept different fundamental value judgments, while accounting for constraints of reasonableness and fair use of resources.

11. It is worth noting that nothing that we have said here should be construed as asserting that treatment should be forced upon patients or surrogates who do not wish it.

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