

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? 42

Several authors have expressed this concern. For example, Brody (1988) writes: 43 44 45

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 46 47 48 49 50 51 52 53

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. 54 55 56 57 58 59 60 61 62 63 64 65 66 67 68 69 70 71

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 72 73 74 75 76

1 the patient or her caregivers in determining death
 2 (and hence, using medical resources on a brain-
 3 dead individual). The New York State Department
 4 of Health's *Guidelines for Determining Brain Death*
 5 (2005, 2–3), for example, includes the following
 6 clause:

7 Hospitals must establish written procedures
 8 for the reasonable accommodation of the indi-
 9 vidual's religious or moral objections to use of
 10 the brain death standard to determine death
 11 when such an objection has been expressed by
 12 the patient prior to the loss of decision-making
 13 capacity, or by the next of kin or other person
 14 closest to the individual. Policies may include
 15 specific accommodations, such as the continu-
 16 ation of artificial respiration under certain
 17 circumstances, as well as guidance on limits to
 18 accommodation.

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

22 The death of an individual shall not be declared
 23 upon the basis of neurological criteria pursu-
 24 ant to sections 3 and 4 of this act when the
 25 licensed physician authorized to declare death,
 26 has reason to believe, on the basis of information
 27 in the individual's available medical records, or
 28 information provided by a member of the indi-
 29 vidual's family or any other person knowledg-
 30 eable about the individual's personal religious
 31 beliefs that such a declaration would violate the
 32 personal religious beliefs of the individual. In
 33 these cases, death shall be declared, and the
 34 time of death fixed, solely upon the basis of
 35 cardio-respiratory criteria pursuant to section
 36 2 of this act. (*New Jersey Declaration of Death*
 37 *Act 1991, c. 90, s. 5*)

38 Given the large amount of resources necessary
 39 to maintain a brain-dead individual—an ICU
 40 bed, a ventilator, and a large time commitment
 41 from ICU nursing staff—it is plausible to won-
 42 der whether social justice demands that scarce
 43 resources not be used in such a way. In this chap-
 44 ter we shall explore the issue of distributive justice
 45 as it arises in these contexts of profound neuro-
 46 logical impairment and brain death. We begin
 47 with a brief review of the medical/clinical back-
 48 ground on VS, brain death, and related states, and
 49 then move to the ethics of health care resource
 50 distribution. Ultimately, we argue that a position

of tolerance is the optimal one in these circum- 51
 stances. 52

MEDICAL BACKGROUND: 53
COMA, BRAIN DEATH, 54
VEGETATIVE STATE, 55
MINIMALLY CONSCIOUS 56
STATE, AND THE 57
LOCKED-IN STATE 58

We begin by distinguishing wakefulness from 59
 awareness. Wakefulness is linked to arousal, alert- 60
 ness, or the absence of sleep, but its presence does 61
 not imply cognition, mental content, or awareness 62
 of self or environment. While extremely rough, 63
 we trust that the intuitive distinction between 64
 being awake but not aware, and being aware of 65
 one's self and environment, is relatively clear. This 66
 distinction is the basis for much of what follows. 67

Coma is a pathological state of eyes-closed 68
 unresponsiveness; comatose patients have a sleep- 69
 like appearance and do not respond to sensory 70
 or noxious stimuli. Wakefulness is absent and, 71
 presumably, awareness is absent as well. True 72
 sleep-like coma almost never lasts for more than 73
 2 to 4 weeks (Bernat 2006, 1181–1182; Plum & 74
 Posner 1980, 3), before progressing to the vegeta- 75
 tive or minimally conscious state, to recovery, or 76
 to death. 77

Brain death is, in essence, a form of coma. In 78
 brain death, all functions of the brain have ceased 79
 irreversibly. The patient is in a state of eyes-closed 80
 unresponsiveness, is apneic, and lacks all cranial 81
 nerve reflexes. A brain-dead patient, if mechani- 82
 cally ventilated, can maintain spontaneous circula- 83
 tion, cellular respiration, and spinal reflexes, but 84
 cannot carry out brain stem-mediated autonomic 85
 functions such as thermal regulation and blood 86
 pressure control. It is widely maintained that a 87
 brain dead-individual is dead,² although it is also 88
 well understood that some biological functions, 89
 such as those mentioned above, do remain. Brain 90
 death is not typically described as a form of coma, 91
 of course, because comatose patients are alive 92
 whereas brain-dead patients are thought to be 93
 dead. 94

The non-brain-dead comatose patient who 95
 does not recover awareness typically progresses to 96
 VS, which is a state of wakefulness in the absence 97
 of awareness. The vegetative patient exhibits irreg- 98
 ular sleep–wake cycles, lies with her eyes open 99
 while awake, and breathes spontaneously. She has 100
 preserved autonomic and hypothalamic function 101
 and cranial nerve reflexes, but does not exhibit 102
 any evidence of awareness of self or environment 103

1 through sustained, reproducible, apparently pur- 54
 2 poseful or voluntary behavior in response to stim- 55
 3 uli. Importantly, even though a VS patient may lie 56
 4 with her eyes open, responses to visual cues are 57
 5 absent. Consistent, sustained, reproducible visual 58
 6 tracking is considered evidence inconsistent with 59
 7 VS (Jennett & Plum 1972; Multi-Society Task 60
 8 Force on PVS 1994a, 1994b). 61

9 Some patients progress, either from VS or 62
 10 directly from coma, to a state of severely impaired 63
 11 responsiveness resembling VS, except that they 64
 12 show some limited evidence of awareness. This is 65
 13 known as the *minimally conscious state* (MCS). 66
 14 The patient in an MCS, like that in VS, exhibits 67
 15 sleep–wake cycles, spontaneous breathing, pre- 68
 16 served autonomic and hypothalamic functions, 69
 17 and cranial nerve reflexes. Additionally, she is able 70
 18 to gesture yes/no answers, show reproducible visual 71
 19 tracking, or reach for or grasp objects in a way 72
 20 demonstrating a cognitive association between 73
 21 the object’s size, shape, or location, relative to the 74
 22 patient (Giacino 2004; Giacino et al. 2002). Thus, 75
 23 the MCS patient does exhibit limited evidence of 76
 24 awareness of self and environment, in addition 77
 25 to wakefulness. 78

26 Finally, a distinct neurological disorder that 79
 27 is sometimes confused with coma, VS, or MCS is 80
 28 known as the *locked-in state*. This is not a disorder 81
 29 of consciousness at all; it is instead a movement 82
 30 disorder characterized by nearly complete paraly- 83
 31 sis. However, the patient does retain the capacity 84
 32 for vertical eye movements and eye opening when 85
 33 asked, and maintains normal cognitive function 86
 34 (Bernat 2006, 1184). 87

35 **DESCRIPTIVE**
 36 **DISTINCTIONS AND**
 37 **NORMATIVE**
 38 **CONCLUSIONS**

39 In theory, there is a great difference between the 93
 40 vegetative and minimally conscious patient. While 94
 41 the vegetative patient maintains sleep–wake cycles 95
 42 and some primitive neurological functions, pre- 96
 43 sumably she is also entirely unaware of herself and 97
 44 her surroundings. She lacks all thought and all 98
 45 mental content; she has no goals or desires, no 99
 46 fears, no pain, and no interests whatsoever. The 100
 47 *person*, the subject of experience or the experienc- 101
 48 ing self, no longer exists.³ There is, as one might 102
 49 say, “no one there.” 103

50 By contrast, the minimally conscious patient 104
 51 does show some limited evidence of awareness. 105
 52 She is able to follow some simple commands and 106
 53 respond to her environment in some meaningful 107

ways. Therefore we may presume a limited amount 54
 of thought or other psychological states, and hence, 55
 at least in the psychological sense of the term, we 56
 should conclude that the *person*, that locus of 57
 experience or psychological states, exists. 58

The presumed difference between the VS and 59
 MCS patient lies in the absence or presence of 60
 psychological states, which is a descriptive, non- 61
 normative distinction. However, supposing this 62
 distinction to be accurate, the normative concerns 63
 about social justice and the distribution of 64
 resources mentioned at the outset of this chapter 65
 become pressing. Namely, if the VS patient lacks 66
 all psychological states, then she feels no pain, has 67
 no capacity for awareness of self or others, and has 68
 no memory, desires, or thoughts. Therefore pre- 69
 sumably she has no interests and is no longer a 70
 locus of moral value, at least not in the same way 71
 that a non-VS individual is a locus of moral value. 72
 As a result, there is *prima facie* reason to suggest 73
 that justice demands that resources not be allo- 74
 cated to the VS patient. On the other hand, there 75
 is less reason to suggest this with respect to the 76
 MCS patient, since she does enjoy some psycho- 77
 logical states, and so presumably has interests, 78
 at the very least in not feeling bodily pain, and 79
 perhaps she has further interests in fulfilling her 80
 goals.⁴ 81

We need not adjudicate here whether the 82
 normative conclusion—that VS patients have no 83
 interests and are *prima facie* entitled to fewer or 84
 no resources on these grounds—follows from the 85
 descriptive distinction between the presence and 86
 absence of psychological states. Instead, we sug- 87
 gest that for this basic argument to direct practical 88
 decision-making on resource allocation, there 89
 should be at least a reasonable (but not absolute) 90
 level of confidence in the claim that patients diag- 91
 nosed as VS do in fact lack all psychological states. 92
 If we cannot make that claim with reasonable 93
 confidence, then the normative conclusions sug- 94
 gested above have no practical import in actual 95
 decision-making. 96

There are two reasons why we should cur- 97
 rently lack such confidence. First, we don’t yet 98
 know enough about the many forms of conscious- 99
 ness and their neurological substrates in general, 100
 nor the specific pathology of VS in particular, to 101
 ground practical allocation decisions.⁵ Second, 102
 the misdiagnosis rate for VS is unacceptably high. 103
 We shall begin with the former concern. 104

There are many different aspects of conscious- 105
 ness, and the medical term “awareness” seems to 106
 capture a conglomeration of several. Specifically, it 107

1 seems to involve *phenomenal consciousness*, which
 2 involves the qualitative “raw feel,” or the “what it is
 3 like to be” a conscious subject having a conscious
 4 experience (Block 1995, Nagel 1974). It also seems
 5 to capture *access consciousness*, or the ability to
 6 integrate sensory and mnemonic information in
 7 the guidance of goal-oriented behavior (Block
 8 1995). Additionally, the medical term “awareness”
 9 may involve both *transitive consciousness*, or con-
 10 sciousness of something, as well as *state conscious-*
 11 *ness*, which is a property of conscious mental
 12 states, not persons (Rosenthal 1997). By possibly
 13 conflating these, it isn’t clear to what the claim
 14 “VS patients lack awareness” actually amounts.
 15 Thus, more conceptual clarity is needed.

16 Further, the diagnosis of VS is made based
 17 on third-person behavioral criteria, not anatomic
 18 or neurophysiologic criteria. At its core, the diag-
 19 nosis is essentially a clinician’s determination of
 20 whether a particular patient’s behavioral reper-
 21 toire is “meaningful” or not. But this is necessarily
 22 speculative. A VS patient can grimace, blink, grunt,
 23 cry, smile, and move her limbs and eyes. The clini-
 24 cian’s responsibility is to determine whether these
 25 behaviors are purposeful or not. But when the
 26 patient is unable to communicate, if there is some
 27 purpose to any of these behaviors, or if they are in
 28 response to some internal stimuli (sadness, an
 29 itch, a pain, etc.), it will be impossible for the cli-
 30 nician to determine this. This is not to say that VS
 31 patients do in fact respond to internal stimuli, it is
 32 simply to say that there is no way to tell from
 33 behavioral criteria alone whether they do or don’t.

34 In time, anatomic pathology may assist in
 35 diagnostic assessment. At present, however, there
 36 are no pathologic criteria available to replace clin-
 37 ical assessment of “purposive” behavior. Hence,
 38 not even postmortem autopsy can confirm or
 39 refute the diagnosis. Sometimes the cortical cell
 40 bodies are destroyed as a result of anoxia second-
 41 ary to cardiac arrest. Other times there is wide-
 42 spread axonal shearing due to traumatic brain
 43 injury, with relative preservation of cortical cell
 44 bodies (Bernat 2006). Yet other times there is
 45 preservation of both the cortical cell bodies and
 46 their axonal connections, but there is damage to
 47 the thalamus, such as in the famous Karen Ann
 48 Quinlan case (Kinney et al. 1994).

49 Additionally, there are no definitive imaging
 50 or electrophysiologic modalities for making the
 51 diagnosis of VS. Instead, there is evidence sug-
 52 gesting the relative preservation of normal or
 53 close-to-normal neural activity in brain areas
 54 responsible for sensory and pain processing in the

55 brains of patients diagnosed as VS. This increases
 56 the uncertainty currently surrounding the diag-
 57 nosis of VS.

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

71 In a recent series of articles, Owen, Coleman,
 72 and colleagues have described the use of func-
 73 tional neuroimaging (fMRI) to detect neural
 74 activity in clinically diagnosed VS patients. For
 75 example, the neural correlates of speech process-
 76 ing are determined using healthy controls, then
 77 the activation patterns of VS patients, in response
 78 to the same stimuli, are compared to those of the
 79 healthy controls, and (some are) found to be sta-
 80 tistically indistinguishable (Coleman et al., 2007,
 81 2009; Owen & Coleman 2008a, 2008b; Owen,
 82 Coleman, Boly, Davis, et al. 2007; Owen, Coleman,
 83 Menon, Berry, et al. 2005; Owen, Coleman, Menon,
 84 Johnsrude, et al. 2005).

85 Other neuroimaging studies have documented
 86 the preservation of neurological responses in cor-
 87 tical primary sensory areas (Laureys et al. 2000,
 88 Laureys et al. 2002, Boly et al. 2004), as well as
 89 secondary somatosensory, insular, and anterior
 90 cingulate cortices (Kassubek et al. 2003) to a vari-
 91 ety of sensory and noxious stimuli in some VS
 92 patients. Owen and colleagues report on the
 93 case of a clinically-diagnosed VS patient who was
 94 asked to imagine playing tennis, then imagine
 95 wandering the rooms of her house, while research-
 96 ers scanned her brain using fMRI. They found
 97 neurological activity in the supplementary motor
 98 area and the parahippocampal place area, similar
 99 to healthy controls, after the instruction to imag-
 100 ine tennis and then wandering her house, respec-
 101 tively (Owen et al. 2006). Building on this
 102 methodology, Monti and colleagues were able to
 103 replicate this finding, and then, apparently, com-
 104 municate with a clinically-diagnosed VS patient,
 105 who was able to correctly answer a few personal
 106 history questions by willfully modulating brain
 107 activity, which could then be assessed using fMRI
 108 techniques (Monti et al. 2010).

1 Pain sensation is mediated by subcortical
 2 structures (Bromm & Desmedt 1995, Casey 1991).
 3 While cortical areas are also involved in pain pro-
 4 cessing, presumably there can also be intact pain
 5 sensation in the absence of cortical sensory areas
 6 (as exemplified in stroke and hemispherectomy;
 7 Brodal 1981, 89–90, 113–114; Shewmon 2004,
 8 219) and in the absence of cortical limbic areas
 9 (Bouckoms 1989; Shewmon 2004, 219). PET stud-
 10 ies have shown activation of the midbrain, thala-
 11 mus, and somatosensory cortex in response to
 12 noxious stimuli, both in the presence and absence
 13 of somatosensory cortical evoked potentials
 14 (Laureys et al. 2002). Crucially, subcortical pain
 15 pathways in VS patients are preserved; without a
 16 partially functioning brain stem the patient would
 17 be dead or brain dead, not vegetative. Thus, there
 18 is a range of evidence from different investigative
 19 paradigms suggesting the preservation of various
 20 neurological functions involving pain and sen-
 21 sory processing in the clinically diagnosed VS
 22 brain.

23 Given the above considerations, it is reason-
 24 able to adopt the weak position that, at least at
 25 this point, we don't yet know enough. We don't
 26 know enough about psychological states, the
 27 many forms of consciousness, or their neurologi-
 28 cal bases; we don't know enough about the vari-
 29 ous neuroanatomic changes and neurophysiologic
 30 deficits of VS; and we don't know enough about
 31 which elements of psychological function, pain
 32 processing, or sensory processing, if any, are pre-
 33 served in any individual VS patient. Given this
 34 much uncertainty, we conclude that we do not yet
 35 have enough confidence in the medical/descrip-
 36 tive claim that VS patients lack all psychological
 37 states to ground unilateral treatment withdrawal
 38 based on considerations of justice.

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

For both of these reasons, we conclude that 55
 the claim that VS patients lack all psychological 56
 states cannot be made with a reasonable level of 57
 confidence. As a result, the normative claim that 58
 VS patients are entitled to fewer or no resources 59
 on the grounds of their lack of psychological states 60
 should have no practical import in actual deci- 61
 sion-making. It may very well be true, but the 62
 level of uncertainty surrounding the diagnosis is 63
 far too high to ground resource allocation deci- 64
 sions. Although we acknowledge that there is 65
 extreme dysfunction in VS patients, it is more 66
 appropriate to provisionally treat VS patients as 67
 being in the same moral category as MCS patients, 68
 at least until some of the uncertainties discussed 69
 above can be sorted out. 70

COST OF CARE 71

In any allocation scheme, we should weigh the 72
 costs against the benefits of proposed interven- 73
 tions. Any intervention that is unlikely to achieve 74
 its desired aim yet carries a great cost has low effi- 75
 cacy and therefore is unlikely to be considered 76
 justly allocated in situations of scarcity. We dis- 77
 cuss the concept of efficacy and its role in resource 78
 allocation more fully below; in this section we 79
 consider the epidemiology, care needs, and cost of 80
 caring for the profoundly neurologically impaired. 81

Epidemiological information specific to VS 82
 and MCS is difficult to obtain. As Beaumont and 83
 Kenealy (2005, 184) write: 84

To establish valid epidemiological data depends 85
 critically on two principal factors: Clear, pre- 86
 cise, and universally accepted criteria for the 87
 diagnosis of a disorder, stable over time; and 88
 adequate systems for the collection of epide- 89
 miological data. Neither exists for vegetative 90
 state (VS) or for minimally conscious state 91
 (MCS). 92

Nonetheless, we do have some estimates available. 93
 Ashwal (2004) estimates worldwide prevalence of 94
 VS at 49 per million population (PMP), while 95
 Jennett (2002a, 2002b) estimates the prevalence of 96
 VS in the United States to be between 40 and 168 97
 PMP for adults, and between 16 and 60 PMP for 98
 children. The data on MCS are even less reliable; 99
 Beaumont and Kenealy (2005, 188) simply state 100
 that “the incidence and prevalence of MCS have 101
 yet to be established.” Giacino and colleagues 102
 (Giacino et al. 2002), while acknowledging that 103
 accurate estimates are unavailable, nonetheless 104
 hazard a prevalence estimate of between 48 and 105

1 96 PMP for MCS, for the combined adult and
 2 pediatric populations. By way of comparison, the
 3 prevalence of stroke in the United States is around
 4 20,700 PMP, and the prevalence of coronary artery
 5 disease in the U.S. is about 57,000 PMP (American
 6 Heart Association 2010). Thus, VS and MCS are
 7 relatively rare conditions, and this limits their
 8 overall cost.

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

19 VS and MCS patients who suffer either a
 20 traumatic or nontraumatic injury receive initial
 21 care in a hospital, typically an intensive care unit
 22 (ICU). The patient may then continue rehabilita-
 23 tion or care in an acute rehabilitation center or in
 24 a skilled nursing facility such as a nursing home.
 25 Standard medical treatment includes nursing care
 26 needs such as hygiene, bowel and bladder care,
 27 skin care, and frequent repositioning. Passive range
 28 of motion and stretching exercises are needed to
 29 prevent rigidity and contractions. A gastrostomy,
 30 or feeding tube, is necessary for about 50% of VS
 31 patients (Ashwal 2004; Kaliski, Morrison, & Meyers
 32 1985), as normal swallowing may be preserved
 33 in others. Pulmonary care is useful to prevent
 34 infections although the VS/MCS patient breathes
 35 spontaneously and is thus not on a ventilator.

36 Daily costs in a hospital are more expensive
 37 than in a long-term care facility. In an ICU with-
 38 out ventilator support (in the United States), the
 39 daily cost of care is about \$6,667 for the first
 40 day, \$3,496 for the second, and the mean daily cost
 41 is about \$3,184 thereafter (the costs are much
 42 increased when ventilator support is needed; see
 43 Dasta et al. 2005). In contrast, the cost for a pri-
 44 vate room in facilities with skilled nursing and
 45 custodial care ranges from the national average in
 46 the United States of \$219 daily to a high of \$584
 47 daily in Alaska (Metlife Mature Market Institute
 48 2009). As mentioned above, most VS patients
 49 progress from coma to the VS within 2 to 4 weeks,
 50 allowing a move from intensive care to a skilled
 51 nursing facility. This results in a cost of about
 52 \$146,000 for the first year (including ICU care
 53 and nursing facility care) and an average yearly
 54 cost of about \$79,900 for skilled nursing care

thereafter. We make these estimates based on 55
 the national average cost of nursing care and the 56
 assumption of 3 weeks of ICU use without a ven- 57
 tilator; they comport fairly well with the findings of 58
 one study by Fields et al. (1993), who estimate the 59
 cost of long-term, non-acute care for VS patients 60
 at about \$90,000 per patient per year. This was a 61
 mailed questionnaire study, based on a sample of 62
 20 pediatric patients in the United States diag- 63
 nosed with VS who had been discharged home, 64
 and whose primary costs included 10 to 12 hours 65
 of nursing care per day. 66

67 Taking the low and high prevalence estimates
 68 from above, based on a population estimate of
 69 304.5 million (U.S. Census Bureau 2008), and using
 70 \$90,000 per patient per year as a cost estimate, we
 71 get a total cost for the combined VS and MCS
 72 population (both adult and pediatric) of between
 73 \$2.9 billion and \$8.9 billion per year in the United
 74 States. This is a huge expenditure, but by way of
 75 comparison, the estimated cost of cardiovascular
 76 disease in the United States in 2010 will be \$324.1
 77 billion in direct costs (hospitals, medical profes-
 78 sionals, medications, etc.) and \$503.2 billion when
 79 the indirect cost of lost productivity is added to
 80 that estimate (American Heart Association 2010).
 81 As a word of caution when considering these cost
 82 estimates, however, we note once again that they
 83 should be considered only partially reliable at
 84 best, and are used only to get a very general idea
 85 of the amount of cost involved.

JUSTICE AND THE MORAL COMMUNITY

86 Justice involves treating like cases alike or treating
 87 similarly situated people similarly. While this
 88 formal concept of justice derived from Aristotle is
 89 clearly the backbone of all concepts of justice, it
 90 is *merely* formal, in the sense that it provides a
 91 form or structure, but lacks meaningful content.
 92 Everything in the universe is like everything else
 93 in the universe, in some respects. To understand
 94 what justice requires in any particular situation,
 95 we must understand the criteria for *relevant simi-*
 96 *larity* for that particular situation. 97
 98

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

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

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

25 One underlying motivation for determining
 26 principles of just distribution is the recognition
 27 that people have value and their interests matter.
 28 The way basic benefits and responsibilities of
 29 social cooperation are distributed, including espe-
 30 cially resources tied to health care, has a direct
 31 effect on people's life plans and expectations, their
 32 ability to pursue their goals, and hence, the satis-
 33 faction of their interests. We suggest then that a
 34 reasonable starting point is to briefly examine the
 35 more fundamental issue of the determinants of
 36 human moral worth, or value. Namely: What is it
 37 that makes an individual valuable? Examining
 38 this question will help in determining the pool of
 39 potential claimants on health care resources. We
 40 assume that having moral worth is sufficient to
 41 place one within this larger pool. We will hence-
 42 forth use the term "moral community" to refer to
 43 the group of individuals that have moral value,
 44 and in virtue of which they are potential claimants
 45 on health care resources.

46 Given a moral community, a *distribution prin-*
 47 *ciple* splits that community into categories and
 48 ranks the strength of their claims on health care
 49 resources. We can also consider distribution prin-
 50 ciples as relevance criteria, because they specify
 51 the relevant respects that determine likeness for
 52 purposes of fair resource allocation. A complete
 53 theory of distributive justice therefore requires
 54 both a theory to determine the moral community,

as well as a distribution principle, relevance crite- 55
 56 rion, or ranking scheme, which ranks the strength
 57 of each sub-category's claim against every other.
 58 Notice that being a member of the moral commu-
 59 nity gives one standing as a potential claimant but
 60 does not guarantee the right to resources, as the
 61 distribution principle might rank one's claims as
 62 having less priority than most others.

63 **POPULATING THE**
 64 **MORAL COMMUNITY:**
 65 **THREE CONCEPTS OF**
 66 **MORAL WORTH**

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

85 A different view, grounded in the utilitarian
 86 tradition, does not look to agency to confer value,
 87 but simply the ability to experience pain.⁶ Someone
 88 who has the ability to have and give reasons is
 89 responsible for her actions, and is thus a *moral*
 90 *agent* and a member of the moral community.
 91 A *moral patient* is a member of the moral com-
 92 munity, deserving of consideration by moral
 93 agents.⁷ On this view, living things that have the
 94 ability to *feel* have moral standing and deserve
 95 consideration.

96 To compare the Kantian to the utilitarian view,
 97 it is important to recognize that, while the Kantian
 98 holds the ability to be self-legislating above else as
 99 conferring intrinsic moral value, Kant would not
 100 claim that non-agents deserve no moral consider-
 101 ation. Rather, for Kant, there is a general duty of
 102 beneficence, whereby agents have the obligation
 103 of treating non-agent moral patients beneficently.
 104 The Kantian would not claim that, for example, a
 105 severely demented person should not be treated
 106 humanely. There is, however, a very crucial dis-
 107 tinction between the Kantian and utilitarian views

1 that should not be elided: Simply having the abil- 55
 2 ity to feel pain at all confers moral standing 56
 3 according to the utilitarian view, but not accord- 57
 4 ing to the Kantian. Therefore animals, humans 58
 5 with profound mental disability, infants, etc., all 59
 6 have moral standing on the former view. By distinc- 60
 7 tion, the Kantian view of moral value would 61
 8 not assign individuals in the aforementioned cat- 62
 9 egories inherent moral value.

10 A different way of thinking about human 63
 11 moral value derives from a sort of essentialist, 64
 12 exceptionalist view of humanity, which we will 65
 13 call the *biological essentialism* view. On this view, 66
 14 humans have moral value simply *qua* biologically 67
 15 functioning human being. Thus, having the 68
 16 human genome and being biologically alive (or 69
 17 even simply maintaining certain biological func- 70
 18 tions involving the maintenance of internal homeo- 71
 19 stasis and resisting entropy) confer moral value. 72
 20 This view is not explicitly tied to any particular 73
 21 tradition in moral theory; however, the idea that 74
 22 humans are special, indeed morally special, has been 75
 23 around for as long as humans have, is expressed in 76
 24 the teachings of various religious traditions, and 77
 25 is sometimes expressed in terms of the sanctity 78
 26 of human life, or human dignity. Hence, simply 79
 27 having the human genome and having some 80
 28 (unspecified) level of biological functioning confers 81
 29 moral value on the biological essentialism view. 82

30 We do not propose here to adjudicate a long- 83
 31 standing dispute between Kantians and utilitari- 84
 32 ans on such a fundamental issue as the core 85
 33 determinant of moral worth. We also do not pro- 86
 34 pose to challenge or defend the longstanding view 87
 35 that assigns moral worth to a biologically func- 88
 36 tioning human, and finds expression in some of 89
 37 the world's major religions and, perhaps, main- 90
 38 stream intuition. Instead, we shall take note of the 91
 39 following. The allocation of public resources is a 92
 40 public policy issue. The overarching goal of such 93
 41 policy is to create a system that all can acknowl- 94
 42 edge as rational, relevant, and fair, even though 95
 43 we do not all share the same basic worldview 96
 44 or value system.⁸ There is no consensus on what 97
 45 fundamentally determines human moral worth. 98
 46 However, the three conceptions canvassed above 99
 47 are commonsense, based in venerable philosophi- 100
 48 cal and religious tradition, and widely regarded as 101
 49 relevant and reasonable, even though there is no 102
 50 consensus that any one of them is superior to the 103
 51 others. Therefore we argue that each element— 104
 52 self-determination, capacity for pain, and biologi- 105
 53 cal function—is enough to determine “as if” 106
 54 moral worth. In other words, in the context of 107
 108

policy that structures a heterogeneous society, it 55
 doesn't matter whether any of these determine 56
actual moral worth. Rather, it is enough to claim 57
 that it is sensible to treat an individual that satis- 58
 fies any of these characteristics *as if* she were a 59
 member of the moral community, on the grounds 60
 that reasonable people do in fact do so, and for 61
 reasons that all can acknowledge as relevant. 62

We recommend that a quasi-pluralistic approach 63
 of tolerance is the optimal one. However, while we 64
 acknowledge the reasonableness of some level of 65
 difference in our fundamental value judgments, 66
 we neither advocate nor accept an “anything- 67
 goes,” subjectivist, nor relativist approach. We do 68
 not, for example, advocate ranking life as an over- 69
 riding value so that it trumps the patient's wishes 70
 or the surrogate's ability to discontinue life-sus- 71
 taining care. This makes our theory of the moral 72
 community “quasi” pluralist. 73

Patients with the most severe neurological 74
 impairments—even brain death—are members of 75
 the moral community, on the quasi-pluralist con- 76
 ception recommended here. The MCS patient has 77
 some limited capacity for awareness of her inter- 78
 nal and external milieu. She is able to respond 79
 with meaningful gestures and thereby to commu- 80
 nicate her desires. It is not obvious whether we 81
 should assume that the MCS patient has the 82
 capacity for self-determination in a robust sense, 83
 thereby meeting the Kantian's standard for moral 84
 standing, but she clearly has the capacity for pain 85
 and other psychological states, thereby meeting 86
 both the utilitarian's and the biological essentialist's 87
 standards. 88

The VS patient is biologically alive and contin- 89
 ues to perform a range of biological functions, 90
 albeit in the presence of profound neurological 91
 disorder. By this circumstance alone she qualifies 92
 to be treated as if she were a member of the moral 93
 community. Furthermore, we currently lack rea- 94
 sonable confidence in the claim that any individ- 95
 ual VS patient is without psychological states, for 96
 the several reasons discussed above. Therefore the 97
 VS patient may very well have some rudimentary 98
 psychological functions preserved, including espe- 99
 cially the reception and transduction of sensory 100
 and noxious stimuli. If so, this would satisfy the 101
 utilitarian's standard for moral worth as well, 102
 though not the Kantian's. 103

The brain-dead patient is also a member of 104
 the moral community. Although legally dead, the 105
 brain-dead individual continues to perform vari- 106
 ous biological functions that serve to resist entropy 107
 and maintain homeostasis. These include cellular 108

1 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.

11 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).

31 THE ROLE OF EFFICACY 32 IN RESOURCE 33 DISTRIBUTION

34 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.

46 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

54 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.

65 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.

93 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

1 capacity for self-determination, but will not do so
 2 for Schiavo. On the other hand, the biological
 3 essentialist might argue that so long as the inter-
 4 ventions have an equal likelihood of preserving
 5 biological life and returning each patient to her
 6 former state, then the treatment is equally effica-
 7 cious in both cases. Similar disagreements will
 8 arise in the context of MCS and brain death, and
 9 between utilitarians and others.

10 Again we appeal to consensus. Just about every-
 11 one agrees that preserving life, preserving auton-
 12 omy, and minimizing pain are each important
 13 goals of medicine. Therefore it is appropriate to
 14 appeal to any of them as components of the prin-
 15 ciple of efficacy. The disagreement is not about
 16 whether any of these things are important goals of
 17 medicine; rather, the disagreement is about which
 18 of them is minimally sufficient for moral stand-
 19 ing, as discussed above. The Kantian takes only
 20 the capacity for self-government to be minimally
 21 sufficient, the utilitarian takes the capacity for
 22 pain to be minimally sufficient, and the biological
 23 essentialist takes biological functioning to be mini-
 24 mally sufficient. But everyone agrees that, if it is
 25 possible to preserve life while minimizing pain
 26 and preserving or restoring autonomy—in other
 27 words, if it is possible to achieve all three—then
 28 that is clearly the optimal outcome.

29 For practical allocation decisions, the Kantian
 30 would be wrong were she to claim that only pre-
 31 serving autonomy makes for an efficacious medi-
 32 cal treatment, but the biological essentialist would
 33 similarly be wrong were she to claim that preserv-
 34 ing life and autonomy is equally efficacious as pre-
 35 serving life in the absence of autonomy. Instead,
 36 the best answer for real-world policy is some-
 37 where in the middle of these two extremes. It is
 38 efficacious to treat a VS patient, because doing so
 39 can achieve one of the several obvious goals of
 40 medicine, which is to preserve life. It is also effica-
 41 cious to treat a non-VS patient in similar circum-
 42 stances, because doing so can achieve the goals of
 43 preserving life and preserving autonomy. However,
 44 if it becomes necessary to compare the efficacy of
 45 a given treatment when provided to two patients,
 46 one for whom self-determination can be pre-
 47 served and another for whom it cannot, then it
 48 would be more efficacious to treat the former. This
 49 is justified on the simple ground that more of the
 50 widely accepted goals of medicine can be achieved
 51 for the former than for the latter.

52 We now apply these considerations to discuss
 53 resource allocation and reasonable accommoda-
 54 tion in brain death, VS, and MCS.

**BRAIN DEATH AND
 REASONABLE
 ACCOMMODATION** 55
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 57

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

AU: Please c

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 dis-
 tinctions in the moral realm. 62
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The biological notion of death involves the cessa-
 tion 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). 68
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The legal definition of “death” is stipulative,
 and thus true by definition. It reflects sociopoliti-
 cal, 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 sup-
 port of either the whole-brain or brain stem for-
 mulation, which states that an individual is legally
 dead when all functions of her brain (or brain
 stem) have ceased irreversibly. 76
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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 mem-
 bers and may choose an option that best fits the
 family’s situation. Still, the physician remains the
 final arbiter. 86
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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 cer-
 tifying 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). 97
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1 In such circumstances, New York permits the
2 expenditure of resources on brain-dead patients.
3 The guideline does not permit absolute accom-
4 modation, however, as a hospital is not required
5 to continue ventilation indefinitely. In effect, the
6 policy establishes a legal side-constraint on allo-
7 cation decisions by the hospital or medical team
8 without insisting on an inviolable requirement.

9 The New Jersey Declaration of Death Act (*New*
10 *Jersey Declaration of Death Act* 1991) similarly
11 allows family members the discretion for deter-
12 mining death according to cardiorespiratory cri-
13 teria, based on the moral or religious beliefs of the
14 patient. New Jersey's legislation favors respecting
15 beliefs about death so that the patient's family can
16 insist that the hospital continue expending medi-
17 cal resources even when the patient would be
18 determined legally dead according to the brain
19 death protocol.

20 Some seek to expand the New Jersey exemp-
21 tion as a general right (Veatch 1999) and to treat
22 the *New Jersey Declaration of Death Act* as signal-
23 ing a new direction for developing public policy
24 (Olick 1991). From the recognition that individu-
25 als have alternative conceptions of death, the posi-
26 tion presumes that whether a person is dead is a
27 moral rather than a scientific matter. As such, it
28 should be left to the patient's beliefs which of the
29 two alternatives should be used by the medical
30 profession in determining and certifying death.

31 Our quasi-pluralist conception of the moral
32 community explains and justifies the New York
33 and New Jersey brain death policies. We accept
34 the reasonableness of some religious views that
35 accord moral value to a brain-dead but biologi-
36 cally functioning individual because, implicitly at
37 least, we accept that the biological essentialism
38 view is at least one of a range of reasonable, funda-
39 mental views about human moral value; or, it is at
40 least *not unreasonable* to make this fundamental
41 value judgment. Furthermore, reasonable accom-
42 modation is not a radical departure from common
43 practice. Treatment and care continue to be
44 evidence-based, and patient or proxy requests for
45 uncommon treatment (e.g., deep-brain stimula-
46 tion for prolonged VS patients) or non-standard
47 treatment (e.g., homeopathy) can be refused.
48 Reasonable accommodation forestalls decisions
49 by the hospital or medical team to discontinue or
50 reduce treatment, but need not supplant those
51 decisions.

52 Additionally, we acknowledge the importance
53 of the voices of the medical profession in deter-
54 mining the appropriateness of certain medical

55 interventions, such as maintaining a brain-dead
56 individual through intensive life support. Although
57 there are many individual physicians who oppose
58 brain death as a criterion for death, nonetheless
59 no professional medical organization rejects it.
60 By forestalling but not preventing physicians from
61 declaring a patient dead by neurological criteria,
62 which is an accepted and standard practice,
63 New York's reasonable accommodation policy
64 preserves the integrity of the profession while also
65 acknowledging the reasonableness of different
66 value judgments.

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

83 We therefore argue that it is an appropriate
84 institutional, state, or federal policy to allow indi-
85 viduals to be accorded reasonable accommoda-
86 tion from the brain death standard for death if
87 they or their surrogates object on moral grounds
88 (i.e., if they attach moral value to a biologically
89 functioning human). However, in the face of scar-
90 city, efficacy plays an important role here as it
91 does elsewhere. When an individual doctor or
92 hospital administrator is faced with the choice of
93 either removing a brain-dead individual from a
94 ventilator or ICU bed, or denying that resource
95 to someone else who isn't brain dead, the choice
96 should always go in favor of the non-brain-dead
97 patient. This is justified on the grounds of efficacy:
98 The brain-dead patient might be maintained in a
99 state of minimal biological function for some brief
100 period of time, but she cannot be restored to ratio-
101 nal agency, nor even to a state in which any psy-
102 chological states occur at all. Since the level of
103 biological functioning is so minimal and cannot
104 be restored to anything near normal functioning,
105 scarce resources would be allocated unfairly if
106 another patient is denied resources in favor of the
107 brain-dead patient, on the grounds of the low effi-
108 cacy of maintaining the brain-dead patient.

1 The “reasonable” in “reasonable accommoda- 54
 2 tion” should be understood in terms of resource 55
 3 availability, and the local hospital administrator 56
 4 should have the final word on when the ICU bed, 57
 5 ventilator, or expert nursing staff are urgently 58
 6 needed elsewhere. If these resources can be used 59
 7 to maintain a brain-dead individual who invokes 60
 8 the reasonable accommodation clause without 61
 9 putting someone else at risk of death or perma- 62
 10 nent disability, then they should be used for that 63
 11 purpose, and this can be a just allocation of resources. 64
 12 If, however, someone else urgently needs them, 65
 13 then the brain-dead individual should be denied 66
 14 those resources, even if it means removal of the 67
 15 ventilator over objection. This is also just because 68
 16 resource allocation is relative to supply and 69
 17 demand. 70

18 **RESOURCE ALLOCATION**
 19 **FOR VS AND MCS**
 20 **PATIENTS**

21 Brain death is distinct from VS and MCS, medi- 71
 22 cally, legally, and morally. Medically, the brain-dead 72
 23 patient cannot perform the “vegetative” functions 73
 24 still performed by the VS patient, such as regula- 74
 25 tion of hormones and blood pressure, control of 75
 26 respiration, or cranial nerve reflexes. The brain- 76
 27 dead patient is on a ventilator, whereas most VS 77
 28 patients are not. Legally, the brain-dead patient is 78
 29 dead whereas the VS or MCS patient is alive. 79

30 Morally, there are a range of differences. 80
 31 Because there is so much uncertainty surround- 81
 32 ing the diagnosis of VS, both in terms of our 82
 33 understanding of the illness and sensory or psy- 83
 34 chological functions that may or may not be pre- 84
 35 served, as well as the high rate of misdiagnosis of 85
 36 VS, it is inappropriate to treat any individual VS 86
 37 patient as being in a different moral category than 87
 38 the MCS population. That is, we lack a reasonable 88
 39 level of confidence in the claim that any individual 89
 40 VS patient lacks all psychological states. Therefore 90
 41 we ought to take the safer route and treat VS 91
 42 patients as MCS patients for moral purposes. 92
 43 MCS patients are severely disabled but nonethe- 93
 44 less experience some psychological states. They 94
 45 respond to stimuli in apparently purposeful ways 95
 46 and they communicate, albeit inconsistently. 96
 47 Therefore we should presume that they experi- 97
 48 ence pain and discomfort at least, and possibly 98
 49 have desires that may be fulfilled or frustrated. 99
 50 This puts the MCS/VS population into a different 100
 51 moral category than the brain dead, since the 101
 52 brain dead do not experience pain and do not 102
 53 have any desires to be satisfied or frustrated. 103

Therefore the brain dead have no interests, 54
 whereas the MCS/VS patient has, minimally, an 55
 interest in not feeling bodily pain and possibly 56
 also interests in having her desires fulfilled. 57

Since there is this important moral distinction 58
 between the brain dead and the nearly brain dead 59
 such as the MCS and VS, resources ought to be 60
 allocated in a way that reflects that difference. 61
 Namely, it should be very easy to prioritize against 62
 the brain dead on grounds of the low efficacy of 63
 any medical treatment, but less easy to do so 64
 against the VS/MCS patient. The VS/MCS patient 65
 is legally and biologically alive and possibly a sub- 66
 ject of some sensory experiences and other psy- 67
 chological states. Therefore treating such a patient 68
 can achieve the goals of providing comfort care 69
 and maintaining life, although not preserving 70
 autonomy. In situations of extreme scarcity, how- 71
 ever, it would be unfair to prioritize against a 72
 non-VS/MCS patient so as to treat the VS/MCS 73
 patient, based on the same considerations of effi- 74
 cacy. To clarify our claims, we will discuss these 75
 issues in the context of two cases that follow. 76

First, recall Teresa Schiavo. This is a young 77
 woman in a prolonged, 17-year VS whose family 78
 disagreed about the best course of care for her, 79
 and their difficult family struggle made its way 80
 into the arena of public debate through multiple 81
 court cases, gubernatorial and legislative inter- 82
 vention, and widespread media coverage (Caplan, 83
 McCartney, & Sisti 2006). The moral and legal 84
 questions most often discussed with respect to the 85
 Schiavo case involve the sanctity of human life 86
 and the right to die, the right to self-determina- 87
 tion or non-interference, and more generally, 88
 respect for the decisions of legal surrogates. 89

In addition to the above considerations, dis- 90
 tributive justice is always relevant. To begin, con- 91
 sider that Ms. Schiavo was in need of supportive 92
 care for all of her basic needs. As mentioned 93
 above, this includes important nursing care needs 94
 such as hygiene, bowel and bladder care, skin 95
 care, frequent repositioning, and passive range of 96
 motion and stretching exercises. While a feeding 97
 tube is necessary for about 50% of VS patients, 98
 this was not necessary in Ms. Schiavo’s case, nor 99
 was she on a ventilator. These basic care needs can 100
 be expensive, as discussed above. Given the severe 101
 disability and high cost, does social justice demand 102
 that patients like Ms. Schiavo be denied care? 103

We argue that it does not. Ms. Schiavo and 104
 other VS patients ought to be provided the stan- 105
 dard medical and nursing care mentioned above, 106
 with public funds if necessary. As we’ve argued 107

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

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

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

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

51 Similarly, if Ms. Schiavo had developed organ
52 failure and was in need of a transplant, she should
53 not have been placed on a transplant waiting list,
54 nor should she have received scarce vaccines, as in

the recent H1N1 flu virus outbreak. Although 55
she should be treated as a member of the moral 56
community and therefore a potential claimant 57
on resources, in these types of circumstances, 58
resources are so scarce that providing a unit of 59
that resource to one individual means that another 60
individual must be denied that very same resource. 61
Obviously in a very broad sense, giving anyone 62
any care means someone else is missing some- 63
thing, but in a more tangible and direct way, giving 64
the organ to Ms. Schiavo means that that particu- 65
lar organ doesn't go to the next person on the list, 66
and so on, until the very next person on the list 67
that does not get an organ, dies. Although it would 68
be efficacious to provide a transplanted organ to 69
Ms. Schiavo because it could help to achieve the 70
legitimate medical goal of preserving biological 71
life, it would be *more* efficacious to transplant that 72
same organ to a different patient who is not in 73
a VS because it could preserve both life and 74
autonomy. 75

Let us consider a more recent case. Ruben 76
Betancourt was a 73-year-old man who, after pro- 77
longed oxygen deprivation as a result of complica- 78
tions surrounding surgery, developed anoxic 79
encephalopathy in January 2008. He lapsed into 80
unconsciousness, was placed on a ventilator, and 81
was diagnosed as being in a VS. Six months after 82
the initial anoxic insult, Mr. Betancourt was diag- 83
nosed with renal failure and given thrice-weekly 84
dialysis treatments. Six months after that, the 85
treating hospital, Trinitas Regional Medical 86
Hospital in Elizabeth, NJ, advised Mr. Betancourt's 87
family that they felt that further treatment was 88
medically inappropriate and sought to discon- 89
tinue dialysis and remove him from the ventilator, 90
which would result in his death. The family sought 91
and received a restraining order in April 2009 92
from the Superior Court of New Jersey, prohibiting 93
the hospital from discontinuing treatment without 94
the consent of the daughter, Mr. Betancourt's legal 95
surrogate. The hospital appealed, but before fur- 96
ther arguments could be heard Mr. Betancourt 97
died, in May 2009. 98

Trinitas physicians argued that Mr. Betancourt 99
was in a persistent, irreversible VS and would not 100
recover. They further argued that dialysis treat- 101
ment should be discontinued as further care would 102
achieve no medical goal. As a result, they sought to 103
discontinue all treatment, including dialysis, arti- 104
ficial nutrition and hydration, and ventilation, 105
over the family's objection. Family members 106
argued that the Trinitas medical personnel were 107
incorrect in their assessment, disputing the claim 108

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

11 Futility, however, is the inverse of efficacy;
 12 thus it is relative to some particular outcome to be
 13 achieved. For the goal of discharge or return to
 14 Mr. Betancourt's former state of functioning, dial-
 15 ysis and other treatments *are* futile; that is, their
 16 likelihood of achieving this outcome is vanish-
 17 ingly slim. But on the other hand, dialysis treat-
 18 ments served to prevent electrolyte imbalances
 19 that would have resulted in cardiac arrest; they
 20 thereby furthered the goal of preserving Mr.
 21 Betancourt's life, for 6 extra months, and so were
 22 not futile for achieving this other goal. Thus,
 23 whether treatment is futile depends on what is
 24 considered an appropriate goal of medical treat-
 25 ment. As above, we suggest that a quasi-pluralist
 26 position of tolerance is appropriate here. Both the
 27 family and the treating nephrologist felt that the
 28 goal of extending biological life was an important
 29 goal, and dialysis did help to achieve that.¹⁰
 30 However, we may still ask whether this use of
 31 resources was just.

32 Dialysis treatment is expensive; one study
 33 found the average annual cost of in-hospital dialy-
 34 sis treatments for end-stage renal disease to be
 35 \$51,252 (Lee et al. 2002). Further, the average cost
 36 of a single day in an ICU with ventilator support is
 37 over \$10,000 for the first day, near \$4,700 for the
 38 second day, and around \$4,000 per day thereafter
 39 (Dasta et al. 2005). With this great cost, it is not
 40 surprising that Mr. Betancourt's unpaid hospital
 41 bill reached \$1.6 million before Trinitas sought to
 42 discontinue his treatment over the family's objec-
 43 tion (Toutant 2010). Is it fair to use this amount of
 44 resources on a ventilated patient with end-stage
 45 renal failure in an irreversible VS, when there are
 46 so many others in need of care, and who could
 47 benefit so much more?

48 We suggest that it is. Dialysis is certainly
 49 expensive, but it is not so scarce a resource that
 50 using a dialysis machine to treat Betancourt
 51 means that someone else will not get dialysis and
 52 hence die. Dialysis is an efficacious (and hence
 53 medically appropriate) treatment because it can
 54 help to keep Mr. Betancourt alive by preventing

fatal electrolyte imbalances. Given that the family
 55 believed Mr. Betancourt would have wanted to
 56 stay alive in this state, providing treatment further
 57 achieves the goal of respecting the wishes of
 58 autonomous agents through respecting their sur-
 59 rogates' decisions. As we argued above, there is no
 60 consensus on what fundamentally determines moral
 61 standing, but the three aspects of self-determination,
 62 minimization of pain, and preservation of bio-
 63 logical life are all widely accepted as relevant con-
 64 siderations in this regard. Since it is reasonable to
 65 value biological life, even though not everyone
 66 values it in the same way, it is a sensible and fair
 67 allocation to use resources in order to preserve
 68 life, even in the absence of preserving autonomy.
 69

70 As with Ms. Schiavo, there should also be
 71 limits. While we argue that it is just to use public
 72 funds to provide ventilation, dialysis, and artifi-
 73 cial nutrition and hydration to Mr. Betancourt, it
 74 would not be just to put him on a kidney trans-
 75 plant list. In this circumstance, the scarcity of
 76 resources is not a scarcity of *funds*, but a scarcity
 77 of *kidneys*. As we argued with Ms. Schiavo, while
 78 it would be efficacious to transplant a kidney into
 79 Mr. Betancourt for its likelihood of preserving life
 80 for a while longer, it would not return him to a
 81 state of autonomous self-determination. By pre-
 82 venting death for some other (non-VS) patient in
 83 need of a kidney, on the other hand, the transplant
 84 would preserve both life and autonomy, and
 85 therefore the intervention would be more effica-
 86 cious if given to the non-VS patient. Distributive
 87 justice therefore demands that patients such as
 88 Mr. Betancourt or Ms. Schiavo not be placed on
 89 organ transplant waiting lists, because the scarcity
 90 of resources in that circumstance is far more
 91 acute.

92 Finally, many of these well-known cases
 93 revolve around families that claim that the clini-
 94 cally diagnosed VS patient does respond in pur-
 95 poseful ways, opposing the physicians who claim
 96 that the patient is permanently unconscious. This
 97 occurred in both Ms. Schiavo and Mr. Betancourt's
 98 case. These claims from the family should not
 99 be ignored or dismissed as wishful thinking. The
 100 diagnosis of the VS is problematic and suffers
 101 many flaws, as discussed above. Not least of these
 102 flaws, the misdiagnosis rate is around 40%; both
 103 Mr. Betancourt and Ms. Schiavo had a 2 in 5
 104 chance of not being in a VS, despite their having
 105 received that diagnosis.

106 Further, recall that the diagnosis can be nei-
 107 ther confirmed nor refuted by postmortem autopsy,
 108 by imaging tests, or by electrophysiologic tests.

1 The diagnosis is essentially a clinician's deter- 54
 2 mination that the behavioral repertoire of some 55
 3 particular patient, which can include blinking, 56
 4 grunting, crying, smiling, movement of eyes and 57
 5 extremities, and more, is not "purposeful." If the 58
 6 family, who spends far more time with the patient, 59
 7 believes that the patient is exhibiting some signs 60
 8 of awareness, this should not be ignored. Of 61
 9 course it might very well be wishful thinking on 62
 10 the part of the family, and the well-trained clini- 63
 11 cian's observational skills should ordinarily be 64
 12 trusted more than the non-clinician's. Nevertheless, 65
 13 as we've argued above, there is far too much 66
 14 uncertainty surrounding the diagnosis to assert a 67
 15 stark contrast between the VS and MCS patient; 68
 16 and the MCS patient *is* a subject of experiences. 69
 17 Given these uncertainties, we should not presume 70
 18 that Mr. Betancourt was completely lacking in all 71
 19 experiences, nor that he lacked all psychological 72
 20 states. *A fortiori*, we should not base normative 73
 21 conclusions about resource allocation on this 74
 22 uncertain medical/descriptive claim. 75

23 **CONCLUSION**

24 The impairments associated with the nearly brain 76
 25 dead such as those in a vegetative or minimally 77
 26 conscious state are profound, and result in the 78
 27 complete or near-complete loss of all cognitive 79
 28 function as well as total dependence on caregivers 80
 29 for all basic needs. This situation of extraordinary 81
 30 cognitive dysfunction (or complete lack of func- 82
 31 tion), coupled with the presence of some remain- 83
 32 ing biological function, might plausibly lead one 84
 33 to wonder if it would be unjust to allocate scarce 85
 34 medical resources in the maintenance of such a 86
 35 patient, when there are so many others who could 87
 36 presumably benefit more. Furthermore, using 88
 37 resources to maintain a brain-dead individual— 89
 38 who is legally dead—can plausibly seem even more 90
 39 unjust for the same reason. 91

40 In this chapter we have argued that this is 92
 41 not so, or at least, it is not always so. Social policy 93
 42 on health care resource distribution should be 94
 43 guided by the understanding that we do not all 95
 44 share the same basic worldview or value system, but 96
 45 nonetheless must decide how to allocate resources 97
 46 in a way that all can recognize as reasonable and 98
 47 based on relevant considerations. One way of doing 99
 48 this is to begin with a pool of potential claimants 100
 49 on resources, the moral community, and then 101
 50 split and rank that pool according to well-accepted 102
 51 principles. While there is no consensus on the 103
 52 fundamental determinants of human moral worth, 104
 53 all three of the components discussed above are 105

intuitive, widely endorsed, and based in long- 54
 standing philosophical and religious tradition. 55
 Since even the most profoundly impaired (includ- 56
 ing the brain dead) satisfy at least one of those 57
 criteria, we argue that they should be treated "as 58
 if" they are members of the moral community, on 59
 the grounds of tolerance, the lack of consensus 60
 on what determines moral standing, and on the 61
 ground that reasonable people do in fact treat them 62
 as having moral standing, for reasons that all can 63
 at least acknowledge as relevant. Therefore they 64
 are potential claimants on health care resources. 65
 As a result, resources such as skilled nursing care, 66
 antibiotics, and even dialysis ought to be allocated 67
 to the profoundly neurologically impaired, should 68
 this be the decision made by an appropriate sur- 69
 rogate, and this is a just use of resources.¹¹ 70

71 However, it is also well accepted that in the 71
 72 face of extreme scarcity of medical resources, 72
 73 efficacy is relevant. While "standard" medical 73
 74 treatments such as those mentioned above can be 74
 75 justly allocated to those with profound neurologi- 75
 76 cal impairments, it would not be just to allocate 76
 77 extremely scarce resources to them, such as trans- 77
 78 plantable organs. In this circumstance, efficacy 78
 79 should be one of the guiding principles of resource 79
 80 distribution. Since it would be more efficacious to 80
 81 transplant an organ into a patient for whom both 81
 82 life and autonomy can be preserved, than a patient 82
 83 for whom only biological life can be preserved, 83
 84 justice demands that the organ go to the former. 84

85 **Notes**

86 1. In the context of the cited paper, Brody is in the 86
 87 midst of a general discussion of several different ethical 87
 88 questions raised by the vegetative patient, providing a 88
 89 broad overview of different positions that one might 89
 90 take. The position on justice stated above is only one 90
 91 of them. 91

92 2. Nair-Collins has argued elsewhere (Collins 2009; 92
 93 2010b; Nair-Collins 2010) that the orthodox view is 93
 94 mistaken: brain-dead individuals are biologically alive. 94
 95 Many other authors have challenged the orthodox view 95
 96 as well. For the orthodox view, see Bernat 1998; Bernat, 96
 97 Culver, and Gert 1981; and President's Commission 97
 98 1981. 98

99 3. Some use the word "person" to mean something 99
 100 like rational, autonomous, moral agent, capable of 100
 101 having and giving reasons, of guiding her behavior in 101
 102 order to achieve her goals in light of her reasons, and 102
 103 able to be held morally responsible for her behavior. 103
 104 Such a person would be competent to accept or forgo a 104
 105 medical procedure. Here we use the terms "moral 105
 106 agent" or "agent" to mark this category, and "person" in 106
 107 a weaker sense, as the locus of psychological states, or 107

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

6 4. Since the MCS patient is able to follow com-
 7 mands and gesture yes/no answers, thereby communi-
 8 cating, it is reasonable to suppose that she might have
 9 some rudimentary goals or desires.

10 5. As an aside, we should note that we do not base this
 11 claim on vague worries about the ineffability of conscious-
 12 ness, nor on the presumed non-reducibility of psycho-
 13 logical states, nor on the ancient problem of other minds.
 14 We are fully confident that consciousness, intentionality,
 15 and all other mental capacities can be eventually reduc-
 16 tively explained in naturalistic terms, and in particular, in
 17 terms of neurological states. See Collins (2010a) for one of
 18 our views on naturalistic explanations of mind.

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

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

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

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

46 10. In their influential account of futility,
 47 Schneiderman, Jecker, and Jonsen (1990) argue that
 48 treatment for patients in VS is qualitatively futile; that
 49 is, some measurable outcome might be achieved, but
 50 no benefit to the patient can be appreciated by the
 51 patient, since she is unconscious. This depends on,
 52 first, the descriptive claim that every patient diagnosed
 53 as VS is indeed entirely unconscious, a claim that we
 54 believe should be qualified to a more agnostic one of
 55 uncertainty about the presence of psychological states,
 56 as discussed above. But furthermore, it also depends

on a normative claim about the appropriate goals of 57
 medical care. While the views of Schneiderman et al. 58
 are certainly among the range of reasonable views on 59
 this issue, the preservation of biological life is also 60
 among that range. In a pluralistic society, we should be 61
 willing to accept different fundamental value judg- 62
 ments, while accounting for constraints of reasonable- 63
 ness and fair use of resources. 64

11. It is worth noting that nothing that we have said 65
 here should be construed as asserting that treatment 66
 should be forced upon patients or surrogates who do 67
 not wish it. 68

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