

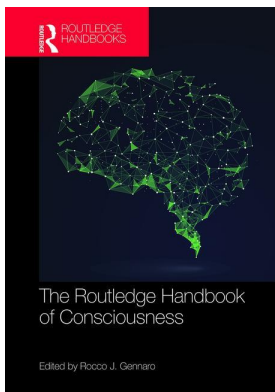
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## The Routledge Handbook Of Consciousness

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### Consciousness and End of Life Ethical Issues

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CONSCIOUSNESS AND END  
OF LIFE ETHICAL ISSUES*Adina L. Roskies*<sup>1</sup>

We can all appreciate the particular quality of the searing pain of touching a hot stove or the mouth-watering aroma of freshly-baked cookies. The capacity to experience these and other sensations, to react to them, and possibly to report on them is part of what it is to be conscious beings, beings for which it is like something to be. Against the background of normal states of consciousness, we can identify disorders of consciousness, perturbations of this awareness of self and environment that affect people as a consequence of traumatic and non-traumatic brain injury. A variety of global disorders of consciousness have been identified, including coma, persistent vegetative state (PVS), and minimally conscious state (MCS). Estimating the numbers of patients affected by these disorders is difficult, both because of difficulties in delineating and diagnosing them, and because of a lack of a formal reporting structure. However, a 2005 estimate of patients in PVS in the US ranged from 40–168 per million (Beaumont and Kenealy 2005), while another earlier estimate for PVS in the US was 14,000–35,000 (The Multi-Society Task Force on PVS, 1994). MCS prevalence was estimated to be between 45,000 and 250,000 (Fins et al. 2008). Regardless of exact numbers, it is clear that disorders of consciousness affect a great many people, few of whom are likely to regain normal consciousness. This chapter addresses the ethical issues raised by these cases.

**1 Types of Disorders of Consciousness**

Perhaps the most widely recognized disorder of consciousness is the coma, a state that occurs subsequent to brain injury. Comatose patients exhibit no evidence of wakefulness or arousal, no evidence of awareness, and no communication (Owen and Coleman 2008). They appear to be asleep, with eyes closed, but their brainwaves belie that interpretation, exhibiting no signs of normal sleep–wake patterns. Patients in comas sometimes transition to other states, occasionally regaining normal consciousness, but often transitioning to other recognized disorders of consciousness, such as PVS or MCS. A patient in PVS may open his or her eyes and appear to be awake, but nonetheless shows no evidence of awareness of self or environment, and is unable to communicate or to respond all but reflexively to stimuli. The vegetative state thus is a state of unconsciousness. PVS patients sometimes transition to a minimally conscious state. MCS differs from a vegetative state in that patients show some, albeit intermittent, signs of conscious mental activity. Patients may exhibit occasional visual tracking of stimuli, or they may respond

to people around them with gestures or words (Kahane and Savulescu 2009: 6). Patients in minimally conscious states are more likely to regain normal consciousness, and the fact that they show some evidence of consciousness suggests to many that they should be treated differently than vegetative patients.

Because disorders of consciousness are typically diagnosed clinically on the basis of *lack* of certain types of behavior (Schnackers et al. 2009; Di Perri et al. 2014: 29), it is extremely important to distinguish PVS from another condition that manifests as virtually indistinguishable, but that does not involve a disorder of consciousness. Locked-in syndrome (LIS), a state of global paralysis, may be mistaken for PVS, for patients with LIS cannot respond behaviorally to stimuli except in minute and subtle ways. LIS results from systemic injury to voluntary motor neurons, either from damage to brainstem structures or by demyelination, as in amyotrophic lateral sclerosis (ALS) (Patterson and Grabois 1986: 760; Smith and Delargy 2005: 407). Patients who have locked-in syndrome experience sleep-wake cycles, as do PVS patients, but in contrast to PVS patients they are fully conscious and mentally competent. However, due to their motor dysfunction they are completely or almost completely paralyzed. Some, but not all, of them can voluntarily move only their eyes, and thus can communicate only with eye movements (Bauer et al. 1979; Owen and Coleman 2008: 236). Locked-in syndrome is thus not a disorder of consciousness at all, but rather a physical disorder that masquerades as a disorder of consciousness.

## 2 Theories of Consciousness

One of the difficulties facing bioethicists interested in addressing the relationship between consciousness and end of life issues lies in identifying the type of phenomenon that consciousness is. Different fields have different theories or frameworks for identifying consciousness, and they are often incommensurable. In addition, because the underlying theory of the phenomenon may have bearing on its moral significance, it may not be possible for theorists to remain neutral about committing to a particular theory. Although other chapters in this volume go into greater depth regarding theories of consciousness, a brief survey of some of the major theoretical approaches is necessary here as background to the ethical discussion.

### *Medical Distinctions*

The medical community typically distinguishes between *wakefulness* and *awareness*. Wakefulness is produced by the activation and regulation of neural pathways in the brainstem, known as the *ascending reticular activating system* (Di Perri et al. 2014: 29). Mere wakefulness does not imply consciousness. Awareness, in contrast, is anatomically associated with regions in the frontoparietal cortex, and entails subjective first-person experience. In general, wakefulness precipitates awareness, but there are instances when the two can become dissociated. For example, in REM sleep one can be unawake, yet aware (one experiences one's dreams). In certain pathological states, such as the ones we discuss here, one can be awake, yet seem unaware (Di Perri et al. 2014: 28). In general, the medical term awareness maps onto what we refer to here as consciousness.

### *Philosophical and Scientific Distinctions*

Philosophers and scientists have elaborated more fine-grained concepts of consciousness. No single theory is generally accepted, let alone completely explanatory, but some distinctions have gained widespread acceptance. Because it is possible that different types of consciousness should

be accorded different levels of moral significance, careful fractionation of these concepts is an important precursor to a discussion of the ethical import of disorders of consciousness.

Perhaps the most influential taxonomy of consciousness distinguishes between “access consciousness” and “phenomenal consciousness” (Block 1995: 230–232). *Access consciousness* characterizes the availability of information in the brain that makes possible intelligent behaviors such as reasoning and executive function; it is an information-processing notion of consciousness. Contents of access consciousness are widely available and can be utilized in controlling actions or speech, and thus are “reportable.” Because it is an informational construct with behavioral implications, access consciousness (or the contents thereof) is amenable to scientific study. Although the access/phenomenal distinction is a philosophical one, similar kinds of theoretical constructs to access consciousness are evident in the psychological literature (e.g., Baars 1988). Because access consciousness is the kind of consciousness that makes possible complex and goal-directed intelligent behaviors informational and measurable, Chalmers (1995: 201) has labeled the explanation of this form of consciousness as the “easy problem” of consciousness.

In contrast, *phenomenal consciousness*, or the “what-it-is-likeness” of subjective experience, gives rise to the “hard problem” (Chalmers 1995). Examples of phenomenal experiences include sensations, feelings, thoughts, emotions, or perceptions (Block 1995: 230). Nagel famously argued that because phenomenality is essentially subjective, we cannot know the phenomenal experience of an entity unlike ourselves (Nagel 1974). Various theories attempt to explain phenomenal consciousness, or at least to identify the nature of phenomenal content. *Intentionalism* or *representationalism* holds that the representational content of a subject’s mental state determines the phenomenal character of the experience. *Phenomenalism*, on the other hand, rejects the idea that phenomenal character supervenes on representational content (Byrne 2001: 205), implying that there is something further to be said about the nature of phenomenal content.

Block contends that one can have access consciousness without phenomenal consciousness and phenomenal consciousness without access consciousness. Chalmers’ thought experiment pointing to the conceivability of philosophical zombies, beings that are behaviorally indistinguishable from normal humans yet lack subjective states, is pointed to as an argument for the former type of dissociation (Block 1995: 233). However, we need not look to far-fetched conceivability arguments to grasp intuitively this dissociation. As artificial intelligence becomes more and more powerful, we can imagine machines that have sophisticated cognitive abilities, presumably fulfilling the informational demands of access consciousness, in the (supposed) absence of phenomenal experience. Block’s other claim, that it is possible to have phenomenal consciousness in the absence of a sufficiently informationally complex organization to support access consciousness, is more contested. Tononi’s (2008) computationally and neuroscientifically-inspired theory of consciousness postulates that (phenomenal) consciousness emerges from sufficient integrated informational complexity, and thus it implies that phenomenality and access consciousness, if these can be distinguished at all in this framework, are co-emergent.

Daniel Dennett’s *Multiple Drafts Model* (MDM) of consciousness provides an alternative way of theorizing about consciousness (Dennett 1992). According to MDM, cognition involves concurrent processing of multiple streams of information that are subject to constant editing and re-editing. According to this view, there is no unitary locus or subject of consciousness, no dominant “central authority,” “homunculus,” or “Cartesian Theater” in which the contents of consciousness play out. In Dennett’s view, phenomenality does not emerge as different from access consciousness: each is the result of different kinds of behavioral probes. Some have argued, however, that rather than explaining consciousness, Dennett explains it away (Roskies and Wood 1992).

The previously described theories are first-order theories of consciousness: consciousness depends on the obtaining of certain kinds of representational mental states. Higher order thought

(HOT) theories of consciousness maintain that phenomenal consciousness requires higher order mental states, or mental states that take first order mental states as their objects (Byrne 2001: 205; Rosenthal 2005). Thus, consciousness requires mental acknowledgement of an experience. HOT theories take *self-awareness* or *self-consciousness* to be a central aspect of consciousness (Carruthers 2000). How to unpack self-consciousness is itself a matter of debate. Self-consciousness can be unpacked as awareness of oneself as a self, termed *reflective* self-consciousness, or merely as awareness of oneself as a biological body in nature, termed *pre-reflective* self-consciousness. Pre-reflective self-consciousness emerges when an individual's biological body responds to stimuli in an external environment and performs sensorimotor actions, but in a self-identification-free manner (Legrand 2006: 92). Reflective self-consciousness, in which one contemplates one's own biological self-awareness, is related to HOT theories of consciousness. Finally, a variation of higher-order theories are *reflexive theories*, which hold that self-awareness exists directly *within* the conscious state, rather than within an associated meta-state that is merely *directed* at consciousness (Kriegel and Williford 2006).

### 3 New Methods of Assessing Consciousness

New noninvasive methods for imaging brain activity have the potential to revolutionize the diagnosis, care, and treatment of patients with disorders of consciousness. An enormous body of imaging studies in normal test subjects has identified signature patterns of brain activity associated with the performance of particular cognitive tasks. For example, motor imagery (imagining moving one's body) activates regions of premotor cortex, many of the same brain areas typically activated in tasks involving actual movement. Other brain areas are typically activated in navigation tasks, and yet others in other tasks, such as perceiving faces or body parts. In groundbreaking work, Adrian Owen and colleagues have developed a neuroimaging paradigm to assess the cognitive status of patients exhibiting no outward signs of consciousness. Owen and colleagues capitalized on known task-dependent regularities in brain activation to test for potential covert cognitive abilities in brain-damaged patients (Owen et al. 2006).

In the original study Owen and colleagues put a PVS patient in the fMRI scanner, and instructed her to perform different imaginative tasks, e.g., to imagine playing tennis or to imagine walking through her house (Owen et al. 2006). Surprisingly, this PVS patient, who had been unresponsive for five months, showed patterns of brain activation indistinguishable from the patterns found in a population of healthy controls doing the same imagery tasks. These results strongly suggest that this patient was aware of her surroundings, able to understand the experimenter's instruction, and, moreover, able to volitionally perform two complex mental tasks of significant duration. Owen et al. concluded that the patient had been misdiagnosed as being in PVS, and that rather than being unaware of her surroundings, she retained substantial cognitive abilities and consciousness. In further studies the group tested populations of normal and PVS patients. Unsurprisingly, the normal subjects showed reliable activation in canonical (and importantly, highly distinguishable) brain regions in these two tasks. While most of the brain damaged subjects lacked these canonical activations, a number of patients (17%) were able to follow the visualization instructions (Monti et al. 2010). In addition, by using these two visualization commands as proxies for answering "yes" or "no," researchers found that upwards of 15% of their tested patients believed to be in PVS were able to correctly answer questions about topics such as their family and their life history (Owen and Coleman 2008; Monti et al. 2010).

These findings suggest that a significant number of patients previously believed to be in PVS may actually occupy robust conscious states and may retain the ability to comprehend language, form intentions, and exercise executive control over their mental states. This realization carries

with it consequential ethical implications. First, it means that a significant number of brain-damaged patients have been misdiagnosed as being in a persistent vegetative state when in fact they enjoy (or perhaps suffer) some significant level of consciousness. This raises directly the question of what the ethical implications are of having the capacity for various types of conscious states (see “The Moral Significance of Consciousness” section). Second, the ability to use these fMRI-discriminable cognitive tasks as proxies for “yes” and “no” answers to questions (and increasingly, with less costly and cumbersome neuroimaging techniques, see e.g., Cruse et al. 2011, 2012) opens up the possibility of using neurotechnologies not only to assess levels of consciousness, but also to communicate with such patients, potentially allowing them to play a role in determining their own futures. This possibility raises further ethical issues, which we explore below.

#### **4 What Can We Conclude from These Studies about Consciousness?**

The original Owen et al. studies strongly suggested that patients were conscious, but did they prove it? Earlier brain imaging studies had revealed stimulus-related increases in metabolism (de Jong et al. 1997) or increased brain activity in brain areas associated with semantic processing when spoken to (Dehaene et al. 1998), which had been argued to be indicative of consciousness. However, we have ample evidence from a variety of studies that significant automatic activation of neural processing occurs even in cases in which subjects are not conscious of a given stimulus. For example, subliminal (unconscious) primes can activate brain areas normally implicated in explicit or conscious processing of those stimuli (Meneguzzo et al. 2014). There is evidence for quite a lot of stimulus-specific neural activity in a variety of cognitive tasks, including some aspects of semantic processing, which can be independent of conscious state (Nigri et al. 2016). What arguably enabled Owen et al.’s original observations to circumvent this worry is that the brain activation he measured was not stimulus-locked in a straightforward way: his instructions had first to be comprehended, and then the patient had to sustain a cognitive task for a significant period of time (~30 seconds) in the absence of further stimulus. In contrast, automatic neural responses tend to be transient, lasting only a few seconds (Owen et al. 2006, 2013; Boly et al. 2007). In addition, the key responses observed in the Owen et al. studies were not in regions known to be automatically activated by semantic processing, but in those associated with the content of the visualization scenarios. Thus far, the best explanation for the observed activation patterns is that patients understood the instructions and deliberately and volitionally complied with them. Given our current understanding, such executive function implicates a significant degree of access consciousness, and is likely to implicate phenomenal consciousness as well.

More recent studies by Owen and colleagues (Sinai et al. 2017) that employ neuroimaging techniques to measure answers to yes/no questions by using cognitive tasks as proxies expand the scope of consciousness in these patients. Their ability to answer questions reliably and veridically suggests not only that they are capable of prolonged attention, but that they can retain old memories, can form new ones, and that they understand the norms of communication. These results are exciting and important, but they also raise important questions about how such neurotechnologies should be used and about the conditions under which severely brain-damaged patients ought to be able to make decisions regarding their lives and treatments (see e.g., Calabró et al. 2016).

Although one cannot definitively rule out all skeptical arguments that permit doubt about the levels of consciousness of these patients, these studies provide good evidence that there are a significant number of patients diagnosed as in PVS who remain conscious at least some of the time (Fernández-Espejo and Owen 2013; for more discussion about these arguments, see Peterson and Bayne, this volume). Suppose we take it as established that some PVS patients are

indeed in some sense conscious. There are further, and perhaps more difficult, questions about the degree, nature of, and limits of their retained conscious and cognitive capacities. Monti et al. (2010) have established that some of these patients can correctly identify their names and current locations, as well as answer questions about their family, their history, etc. (see also Naci and Owen, 2013; Naci et al. 2017; Peterson et al. 2013). Their reliably correct answers indicate that they understand the questions asked. But what is the depth of their understanding, and the scope of it? How are we to assess understanding in cases in which we are unable to verify their answers?

This last question becomes important if the questions we have reason to ask them concern the nature of their phenomenal experience. Perhaps the most ethically pressing question we can ask these patients is whether they are in pain or are suffering, for we have the ability to rectify their suffering by modifying their treatment. However, the nature of phenomenal experience is subjective and in principle unverifiable. How can we assess whether a severely brain-damaged patient adequately understands these questions? What is the possibility that despite her ability to answer objective questions correctly she may not understand the meaning of subjective concepts such as “pain,” and that her answers would thus not accurately portray whether she is experiencing pain? Must we be able to independently ensure that patients understand the meaning of terms for subjective states (such as pain, desire, hope, sadness, happiness) before we ask them questions about their experience? Must we be able to verify their answers to do so?

Is this a real problem? In theory, it is impossible to be certain about the subjective experience of fully conscious and healthy individuals, but in normal cases we have embodied cues and other behavioral information that can inform our understanding of their phenomenal states and the intensity of their emotions. For instance, if a child affirms that he is in excruciating pain, but he is sitting on the floor calmly sucking on his finger rather than writhing and screaming, we can infer that he probably does not fully understand our question. Because PVS patients do not exhibit overt behaviors, we do not have the possibility of this kind of behavioral corroboration.

Complicating the matter further, there is evidence that patients with brain damage who exhibit signs of consciousness fade in and out of consciousness, sometimes over short periods of time. Accordingly, we have no guarantee that when we use fMRI techniques for ascertaining consciousness, patients remain equally conscious from one scanning session to the next, or even from one question to the next. Because fMRI requires significant time to administer, it is possible that patient responses could range from reliable to unreliable, and if the subjective questions (or unverifiable questions) were to be administered during an unreliable phase, we may not be able to detect the change.

## 5 Epistemic Issues

Diagnosis of states of consciousness, whether by bedside examination, or by measurement of brain activity, is made on the basis of objective, physically manifest phenomena. But what it is to be conscious is to have a subjective perspective, for it to be like something to be that entity. We never have access to someone else’s subjective experience, but instead infer it or assume it on the basis of behavior (and similarity to ourselves). As Peterson and Bayne discuss (this volume), assumptions must be made about what evidence is evidence of consciousness in order to infer the presence of consciousness from objective data.

Consciousness is usually assessed by observation of and communication with another agent. Indeed, most of the evidence we use to assess consciousness in humans comes from verbal reports of the subject. But verbal report is just a kind of behavior (though perhaps a privileged kind, since its content can be about subjective experience). The avenues that verbal report provide into subjectivity point to the importance of opening up avenues of communication with

subjects who lack the ability to communicate through overt behavior. And although we may automatically assume that other humans are conscious, the assumption is defeasible. Once the consciousness of another is in doubt, it is a difficult question to determine exactly what evidence would be necessary or sufficient to warrant ascriptions of consciousness (think, for example, about the difficulty we would have in deciding and justifying our ascription of or denial of consciousness to an artificial intelligence that can match the complexity of human behavior, or to an octopus writhing when it is injured—is it in pain or just manifesting an outward behavior?). So one important question concerns whether neural data (in lieu of behavior) poses a different philosophical problem than does behavior itself for assessment of consciousness. To this we respond with the following suggestions: (1) Different behaviors provide different degrees of evidence for ascriptions of consciousness, and for different kinds, levels, or dimensions of consciousness. Which behaviors are diagnostic will depend upon one's theory of consciousness. For example, if intentionalism is right, then the contents of experience are fully specified by the mental representations giving rise to them. If we can identify those representations, whether verbally or via regular correlations with neural activity, we have evidence of consciousness. (2) If neural activations corresponding to a certain behavior were necessary and sufficient for the production of that behavior they should be accorded the same epistemic weight as the behavior in inductions about consciousness; and (3) since neural data rarely are so closely linked with behavior, their epistemic weight should be modulated by the degree to which the behavior can be reliably inferred by the neural signature in question. A Bayesian framework can thus be used to assess the value of the neural evidence.

The problem is perhaps slightly more difficult if the question is not just whether someone is conscious at all or capable of consciousness, but to what degree, in what respect, or on what dimensions they are conscious. In that case, a similar formula may be applied, but relative to the degree of evidence the behavior or neural data provides for ascribing a certain level or kind of consciousness. Because the measures we have are not perfectly correlated with the states or behaviors that we take to be evidence of awareness, we ought to look for agreement among different measures and types of evidence. This corroboration is what Peterson and Bayne term "consilience" (Peterson and Bayne, this volume; Gibson et al. 2014).

Even when we ascertain consciousness to a reasonable degree, and even if we feel sure that the patient understands the meaning of the questions we ask, we still face the problem of competence. It is hard enough to set the bar for competence for serious medical decisions (e.g., a choice for euthanasia, withholding treatment, etc.) with fully conscious patients without brain damage with whom we can communicate easily. A patient's answers obtained with fMRI to objective questions requiring reasoning or memory might be evidence of some level of rational competence, but perhaps the kind of competence we seek evidence of for consequential decisions needs to be broader and more holistic. The tools currently at our disposal may be too blunt to ascertain the kind of competence necessary for autonomy in life-or-death decisions.

A technique that enables us to ask only yes-or-no questions may not be sharp enough to give us the kind of confidence we need for consequential decisions, as they only scratch at the edge of phenomenal consciousness and deep rationality. In addition to yes-or-no answers, we may want to hear *reasons*, to understand *why* it is that a person answers as he does. Because of the limited periods of lucidity that these patients enjoy, they are unlikely to be able to use the kinds of labor-intensive communication techniques that people with locked-in syndrome do, such as eye-movement driven computer interfaces or brain-computer interfaces that enable them to transcribe full thoughts. As neural decoding with fMRI improves, it is possible that this problem can be ameliorated.

One way to increase confidence in results of asking questions by neuroimaging may be the following. While we cannot accurately discriminate, say, 26 different mental acts to correspond



to different letters (nor could we reasonably expect patients to memorize such mappings), we may be able to broaden our options to 3: “Yes,” “no,” and “opt-out.” It has been shown that use of an opt-out option in behavioral experiments with monkeys enables researchers to measure the animal’s confidence in their answers (Fetsch et al. 2014; Kiani and Shadlen 2009; de Lafuente and Romo 2014). Appropriate use of an opt-out option when the patient is unsure or fails to comprehend the question may provide information about their confidence as well as their metacognitive abilities (and thus, at least on many views, a type of higher order consciousness).

Finally, a remaining important question involves what to make of PVS patients that do not present evidence of mental command-following with neuroimaging. Since phenomenal consciousness is subjective, there is no logical way to rule out its presence with objective data, whether behavioral or neural. Few would disagree that it would be tragic to mistake a conscious person who cannot overtly respond for someone who lacks the capacity for consciousness. It is this that leads some to place an extremely high bar on what is necessary to warrant a denial of consciousness, and to refuse to accept absence of evidence as evidence of absence. On the other hand, for pragmatic and social reasons it may be equally as important to determine that someone lacks the capacity for consciousness. What if all we can expect to acquire is evidence of absence?

Some researchers deny that evidence of absence is necessary. For example, Levy and Savulescu claim “we utterly reject the view that we need evidence for the absence of consciousness before we can justifiably conclude that consciousness is lacking. Sometimes absence of evidence is evidence of absence” (Levy and Savulescu 2009: 368). But when? We suggest that a Bayesian approach provides a principled answer to this question, and that it depends on what the hypothesis space is. If you think that the only possible evidence of consciousness is first-personal, then absence of evidence is not evidence of absence, because the relevant evidence is inaccessible. But if you accept that neural states can provide information about states of consciousness, you already reject that proposition. Absence of these is indeed evidence of absence. And depending on how many potential correlations with subjective states there are, and how reliable they are, continued absence then provides strong evidence of absence. Of course, the hypothesis space regarding the constructs of consciousness and their potential correlates is in flux: philosophers and neuroscientists are still in the process of developing and perhaps rethinking theories of consciousness, precluding a straightforward application of Bayesian principles.

## 6 The Moral Significance of Consciousness

The above concerned difficulties in establishing the presence and nature of consciousness. But there is a further question we must ask: What is the moral significance of consciousness? Many people find it intuitive that either (1) exhibiting clear signs of consciousness or (2) exhibiting some capacity for consciousness is a criterion for continuing care in cases of severely brain-damaged patients, and thus that the withdrawal of life-preserving treatment from patients satisfying either criterion would be morally prohibited. However, such a view rests upon an assumption about the moral significance of consciousness which may not be correct. Here we explore how different theories of consciousness may affect views of the moral significance of consciousness.

Kahane and Savulescu (2009) identify the Principle of the Moral Significance of Consciousness (SC) which states that the capacity for consciousness characterizes an important moral boundary that fundamentally separates conscious beings from their non-conscious counterparts. However, as many philosophers and scientists have realized, consciousness is not a single phenomenon, as there are arguably a variety of types or dimensions of consciousness. This raises the question whether all varieties of consciousness have the same moral importance. In order to address these questions, we must first ask what underlies the intuition that consciousness is morally

significant? Rather than being a bedrock principle that requires no justification, perhaps there are underlying intuitions that explain the intuition underlying SC. In understanding these, we may also better come to understand how the presence of different types of consciousness might affect our moral duties to patients.

### ***Pain and Suffering***

Perhaps the most intuitive view is that the ability to feel pain is the criterion that lends an organism moral standing. Although the philosophical literature on pain is itself controversial (see e.g., Aydede 2009), let us accept the reasonably intuitive thesis that pain is bad, or has negative utility. If we further accept that pain is a paradigmatic phenomenal experience, and that phenomenal experience is the hallmark of phenomenal consciousness, then we can understand why consciousness delimits an important moral boundary: creatures that lack phenomenal consciousness will be unable to experience pain, and thus have no moral standing, whereas creatures that have the ability to feel pain require moral consideration. Levy and Savulescu explain it thus: “We are morally required to minimize the amount of pain suffered by any sentient being (to the extent to which this is compatible with our other moral obligations), where sentience is the ability to have phenomenally conscious states” (Levy and Savulescu 2009: 366).

Things may not, however, be even that simple. If it is not pain, but rather suffering (or the capacity to suffer) that is necessary for having moral standing, then the relation to consciousness becomes less clear. On this view, a suffering organism is morally significant because we have a moral duty to diminish suffering (this can be seen as definitionally the case or can be framed in terms of interests: “the sufferer has an interest in ameliorating its suffering”) (for more on interests, see below). Experiencing suffering requires consciousness, but as we shall see, it may require something more than phenomenal consciousness. Let us call this “suffering-enabling consciousness.” Therefore, suffering-enabling consciousness is morally significant insofar as it allows us to fulfill our moral duty to diminish suffering.

What is suffering-enabling consciousness? On the most basic view, suffering is just feeling pain, so the suffering view collapses to the simple pain view above. But what if suffering is something more than just feeling pain? It is reasonable to think that suffering involves something in addition to pain, or even perhaps something altogether different (for example, we speak of mental suffering in the absence of physical ([bodily] pain). However, there is indication from brain imaging studies that similar brain areas are involved in mental suffering and in the experience of physical pain (Eisenberger et al. 2003; Lamm et al. 2011). Just what else may be involved in suffering? Some have argued that suffering requires the conceptualization of oneself as an agent enduring through time, or an agent with life plans that could be realized or frustrated, or an ability to anticipate the future. These views of suffering may involve kinds of consciousness that go beyond pure phenomenal awareness. For example, if suffering requires self-conceptualization, then self-consciousness in addition to (or perhaps instead of) phenomenal consciousness may be required for morally significant consciousness. Or perhaps temporal awareness or high-level cognition and planning may be required in addition to phenomenal consciousness.

Peter Carruthers, in “Brute Experience” (1989), applies his preferred theory of consciousness in order to draw boundaries for morally significant consciousness in a way that is incompatible with those drawn by the simple pain view. His paper illustrates the interesting way in which substantive theories of consciousness can interact with ideas about the moral significance of consciousness in order to yield substantive views about the scope of our moral duties. Carruthers subscribes to the Higher Order Thought (HOT) view of consciousness: that we are only conscious of things that we have (or can have) HOTs about (Rosenthal 1986: 334). He also denies

that animals have the capacity for HOT. In consequence, although he accepts that animals can feel pain, he thinks it is not *like* anything for animals to have these pain experiences: all their experiences are nonconscious. In addition, he holds that for a mental state to be an appropriate object of moral concern there must be *something it is like* for an organism to have it. Since he holds that animals only have non-conscious experiences, their lives and experiences are not appropriate objects of moral concern.

There are clearly many points at which the HOT argument could be contested. There is the viability of the HOT theory itself, the empirical claim about which animals have what kinds of capacities for HOTs (and particularly the great emphasis placed on linguistic competence in this debate), and the notion that only subjects with the kind of experiences enabled by HOTs are appropriate objects of moral consideration (see e.g., Gennaro 1993, 2012). While we think that Carruthers' argument is fundamentally flawed and may have potentially ethically pernicious consequences, it is easy to see how this argument could be applied to patients with extensive brain damage. While one might acknowledge that much of the neural machinery for registering pain remains in such patients, it is also the case that many patients with brain damage do not evidence the ability to think higher order thoughts (this doesn't obviously apply to the miscategorized PVS patients identified by Owen and colleagues). If this is the case, proponents of Carruthers' view would have to conclude that such patients likewise do not merit moral consideration.

### Interests

Pain and suffering are very intuitive potential ways of grounding moral standing, but not the only ones. Kahane and Savulescu (2009) argue that what grounds moral standing are interests because "interests matter morally" (Kahane and Savulescu 2009: 11), and that interests come in many guises. The interest view subsumes the pain and suffering views, because not suffering (or not feeling pain) are only some of the interests an organism might have, and the reach of the interest view is much broader.

Kahane and Savulescu argue that merely identifying the presence or absence of consciousness is insufficient to settle the ethical issues surrounding end of life issues, because facts about our interests do not neatly line up with facts about consciousness. They argue against the assumption that consciousness is the basis for moral significance both by arguing that our interests don't necessarily have a phenomenal or experiential character and by arguing that the moral imperatives they ground do not necessarily point in the direction of extension of life. Indeed, they contend that the enjoyment of consciousness might actually give stronger moral reasons *not* to preserve a patient's life.

Kahane and Savulescu identify experiential or hedonic interests, desiderative interests, and objective interests. Experiential or hedonic interests refer to states of suffering or enjoyment, and thus are linked to experiences or phenomenal consciousness and perhaps to other cognitive abilities as well. Desiderative interests refer to the interests organisms have in satisfying their desires, and objective interests are interests that an organism may have in things that are objectively good for a life (for example, deep relationships, health etc.). Kahane and Savulescu argue that both desiderative and objective interests presuppose a variety of cognitive and motivational states and capacities that they term "sapience," and that sapience requires not phenomenal but access consciousness.

Kahane and Savulescu question whether phenomenal consciousness is sufficient for having interests, though they recognize that it may be necessary. They write,

Indeed, it is doubtful that a mental life consisting only of a bare stream of consciousness — a sequence of random and hedonically neutral sensations — could be said to

involve interests of any kind. A being cannot have desires, and thus desiderative interests, without a sufficient degree of cognitive capacity. Nor can one possess objective interests such as the interest in friendship or knowledge in the absence of such capacities (indeed many objective goods seem to require self-consciousness, not phenomenal consciousness). What about experiential interests? One cannot enjoy or suffer without being phenomenally conscious, but it is far from obvious that mere possession of phenomenal consciousness implies that one has the capacity to experience pain or pleasure. A being that lacked both cognitive capacities and the capacity to feel pleasure and pain might be a being without interests despite possessing phenomenal consciousness.

*(Kahane and Savulescu 2009: 14)*

But even when the requisites for having interests are fulfilled, the moral imperatives do not always point in the way many people take for granted: the interests involved may actually not militate for preservation of life. For example, perhaps a person prior to brain injury valued her autonomy and desired not to live a life in which her survival was predicated upon being kept alive by a machine. Provided she had sufficient access consciousness and other capacities to preserve sapience and thus some desiderative and objective interests, satisfaction of her desiderative interests may require terminating life support. Or on the objective view, if we deem it objectively bad to continue to exist without the possibility of cultivating friendships, being creative, etc., or that burdening one's loved ones is objectively bad, then a person's objective interests may also not point in the direction of continued life. Kahane and Savulescu also consider the interesting possibility that a person could have interests that persist beyond the limits of their consciousness, just as the law acknowledges that persons can have legal interests that extend beyond their lifetimes. They argue that these interests often would tend not to favor life-preservation. On the interest view, then, the relationship between kinds of consciousness and our moral duties is complex, and may rest more upon access consciousness and other kinds of capacities than on phenomenal consciousness.

### ***Personhood***

The personhood view contests the standard assumption that evidence of consciousness provides a reason to grant a being full moral status. On this view what confers (full) moral status is personhood, and personhood requires self-consciousness. As Levy and Savulescu (2009) argue, only full moral status entails a right to life; merely being a moral patient (that is, having the capacity to possess mental states that matter morally) implies certain minimal duties, such as the duty to minimize aversive mental states via analgesics or other drugs, for example, but does not provide reason to value or preserve the life of the moral patient. Levy and Savulescu argue that beings that can experience aversive mental states are morally equivalent to animals, and they take for granted that we have no duties to preserve animal lives because of their intrinsic worth, unless they exhibit hallmarks of self-consciousness. Thus, while Levy and Savulescu disagree with Carruthers about the scope of suffering, allowing that phenomenal consciousness does matter morally and entails some minimal moral duties, they agree that higher-order or self-referential thoughts are necessary for full moral consideration. Such thoughts at a minimum require a type of sophisticated access consciousness. Thus they take the kind of evidence for consciousness found by Owen and colleagues in a subpopulation of PVS patients to be insufficient moral ground for life-preserving measures:

But whether they are conscious or not, it can be argued that we have little reason to maintain them in existence (and perhaps even some reason to bring about the cessation

of their lives), unless their mental states are at least as sophisticated as those exhibited by children, and, importantly, as connected across time. It is not merely consciousness that is required for what we shall call full moral status; it is self-consciousness, and we do not believe that we can (yet) attribute self-consciousness to any PVS patients.

(Levy and Savulescu 2009: 362)

Finally, it bears mentioning that any theory we have about the moral significance of consciousness should be applicable across the board. If self-consciousness is what we deem necessary for moral consideration, it should apply to humans as well as nonhumans, if there are any that are self-conscious. But if we decide that phenomenal consciousness is what ultimately matters, then far more beings than humans should be accorded moral consideration in matters of life and death. Thus, the theories that govern the way we treat patients with varying kinds of disorders of consciousness will, if we are consistent, inform and guide our treatment of nonhuman animals.

## 7 Future Directions

Neuroimaging has opened up exciting possibilities for the diagnosis and care of patients with disorders of consciousness. Future work will involve improving the relevant technologies for cost-effective use at the bedside and developing more incisive diagnostic test paradigms. Theoretical work will involve refining and perhaps reconstructing theories of consciousness to reflect the novel scientific insights from continuing work on the neuroscience of consciousness, and developing more sophisticated views about the moral significance of consciousness and its relationship to what we value. Disorders of consciousness continue to provide a proving ground for neuroethics.

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