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# The Moral Status and Welfare of Patients Diagnosed as Vegetative With Covert Awareness

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## **Abstract**

Several neuroimaging studies have demonstrated that a minority of patients diagnosed as being in the vegetative state are able to modulate their brain activity in response to the commands of researchers, thus demonstrating that they are ‘covertly aware.’ I examine the moral significance of this discovery, with a specific focus on the implications for patient welfare. I argue that the presence of awareness in these patients is important because it allows for the presence of sentience—the capacity for suffering and enjoyment—which I argue is a sufficient condition for moral status. Insofar as these patients have moral status, their interests matter morally; we have an obligation to give them proper consideration in our decision making. I present empirical evidence which supports the assumption that patients diagnosed as vegetative with covert awareness are sentient, and thus have moral status. I then consider an account of the welfare of these patients, which incorporates three traditional conceptions of welfare—hedonism, desire-satisfaction, and objective theories—and concludes that these patients are faring poorly, such that we may have a moral obligation to end their lives. I analyse and ultimately reject this conclusion. I argue that the application of traditional theories of welfare to these populations is impeded by a lack of knowledge of their subjective experiences, as well as challenges to the conceptions of welfare themselves. I then propose a novel approach for assessing the welfare of these patients, based on their subjective experiences. This approach involves extrapolating from the reported welfare interests of similar patient populations, as well as making plausible inferences about the residual cognitive capacities of these patients, based on the results of novel neuroimaging studies. Using these two sources of information, we can begin to construct a clearer picture of the welfare of these patients, and work to ensure that they have a decent quality of life.

## **Keywords**

Welfare, neuroimaging, vegetative state, sentience, moral status, quality of life.

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## **Chapter 1: The Vegetative State, With Covert Awareness: A Unique Patient Population**

### **1.1 Introduction**

“Welfare matters.”

-L.W. Sumner, *Welfare, Happiness, and Ethics*.

It is uncontroversial to say that, generally speaking, people care about their own welfare. Naturally, we want our lives to go as well as possible, even if we might occasionally fail in our efforts. Even without a robust philosophical understanding of the concept of welfare, most people can say when their own lives are going well, or poorly, or when something makes their lives go better, or worse. For many people, one of the most extreme ways in which one’s welfare might be compromised would be to exist in a vegetative state. In 2005, during the height of the Terry Schiavo saga, a *Washington Post* poll reported that 87% of respondents would not want to be kept alive in a permanent vegetative state (Constable, 2012). Similarly, a 2011 study by Demertzi and colleagues of nearly 2500 medical and paramedical professionals found that 82% would not want to be kept alive in a vegetative state (Demertzi et al., 2011). While these respondents may have a number of reasons for not wanting to be kept alive in a vegetative state, it seems reasonable to assume that one such reason is that most people think that those in a vegetative state are faring poorly. Of course, in the paradigm case, a patient in the vegetative state is wholly unaware of his- or herself, or environment; they are wholly unaware of how their lives are going.



Unfortunately, the very nature of the vegetative state makes it extremely difficult to tell when a patient is *truly* vegetative. In fact, recent studies have shown that a considerable minority of patients diagnosed as vegetative are nevertheless aware (Owen et al., 2006; Monti et al., 2010; Bardin, Schiff, & Voss, 2012; Naci, Cusack, Jia, & Owen, 2013). These patients, who repeatedly satisfy behavioural criteria for the vegetative state, are capable of modulating their brain activity in response to the commands of researchers. Because command-following is well-established in the clinical and neuroscientific community as an operational definition for awareness, this provides conclusive evidence that these patients are aware.

The discovery of awareness in these patients is highly significant, not only because it is of great scientific interest, but because of the range of clinical, legal, and ethical implications it raises for the patients themselves and their families. In what follows, I will argue that the discovery of ‘covert awareness’ in these patients is important because of its implications for their welfare. Specifically, I will argue that we may need to re-evaluate our assumptions about the welfare of these patients; we cannot simply assume that they are faring poorly in virtue of their condition. Rather, as I will argue, we need to undertake careful and deliberate analysis of their subjective experience, in order to gain a clearer sense of what life is actually like for these patients. Does it make sense to talk about these patients as welfare subjects, that is, as individuals capable of faring better or worse in a morally significant way? And, if so, what does it mean for these patients to fare well or poorly, and how might we begin to assess their welfare? This sort of investigation is critical for ensuring that these patients are able to live lives of decent quality. Moreover, focussing on the welfare of these patients in particular allows

for a critical analysis of our intuitions regarding individual welfare in general, and more specifically, how traditional theories of welfare are applied to what we might call ‘non-standard cases,’ such as individuals with severe physical or cognitive disabilities or impairments.

## **1.2 The Vegetative State**

### ***1.2.1 The Vegetative State: Prevalence***

Each year, an estimated 500 out of every 100,000 Canadians sustain some sort of brain injury (Brain Injury Association of Canada, 2015). In the United States, the number of brain injuries requiring an emergency room visit each year occurs at a rate of more than 800 per 100,000 (over 2.5 million in 2014) (Center for Disease Control, 2015). While the majority of these brain injuries are not serious, approximately 100 per 100,000 people require hospitalization, as a result of a severe traumatic brain injury (Center for Disease Control, 2015). Non-fatal severe traumatic brain injury may result in a period of extended unconsciousness (i.e. coma) for days, or even weeks, after which patient outcome is highly variable (Laureys, Owen, & Schiff, 2004). Availability of data related to the incidence of disability post-traumatic brain injury in the United States is limited, though extrapolations from state-level data suggest that between 3.2 million and 5.3 million people were living with a post-traumatic brain injury disability between 2003 and 2005 (Selassie et al., 2008; Zaloshnja, Miller, Langlois, & Selassie, 2008). Traumatic brain injury can result in a spectrum of impairments, ranging from issues with cognitive function (e.g., attention, memory), motor function (e.g., weakness, impaired coordination), sensation (e.g., sensitivity to heat or light, changes in vision or hearing),

and emotion or behaviour (e.g., delusions, severe mood disturbance, agitation, confusion) (Centers for Disease Control, 2015). Approximately 2% of patients who are brought to the emergency department with a traumatic brain injury do not survive their injury (Center for Disease Control, 2015).

After a severe traumatic brain injury, some patients may awaken from coma, but remain in a vegetative state. The term ‘vegetative state’ was first coined in 1972 by physicians Bryan Jennett and Fred Plum, to refer to patients who have awoken from coma (they open their eyes occasionally for extended periods, and demonstrate irregular but cyclic circadian sleeping and waking), but who are wholly lacking in awareness of the self or the environment (Jennett & Plum, 1972). In the United States and Canada, ‘persistent vegetative state’ is standardly used to describe patients who, after undergoing behavioural examination by neurologists, are thought to be ‘highly unlikely’ to ever regain awareness. This designation is typically made after approximately four weeks in the vegetative state, while a diagnosis of ‘permanent vegetative state’ is generally made after three months in the case of non-traumatic brain injury, and after 12 months in the case of traumatic brain injury (Multi-Society Task Force on PVS, 1994). Conversely, in the UK, the Royal College of Physicians recommends referring to patients who have been in the vegetative state for longer than four weeks as being in a ‘continuous vegetative state.’ Patients who remain in this state for over 12 months are referred to as being in a ‘permanently vegetative state’ (Royal College of Physicians, 1996). Precise epidemiological data is lacking regarding the prevalence of the vegetative state in adults, due in part to the absence of a universally accepted diagnostic criteria for the vegetative state, as well as inadequate systems for collecting epidemiological data on these patients

(Beaumont & Kenealy, 2007). However, estimates of the prevalence of the vegetative state in the United States are between 40 and 168 per million in the United States (Hirsch, 2005), and between 2 and 34 per million in Europe (Pisa, Biasutti, Drigo, & Barbone, 2014).

### ***1.2.2 The Vegetative State: Causes and Recovery***

In addition to severe traumatic brain injury, the vegetative state can also be caused by non-traumatic brain injury (e.g., anoxic brain injury caused by infection, tumor, or stroke), degenerative and metabolic brain disorders, and severe congenital malformations of the nervous system (Multi-Society Task Force on PVS, 1994). Recovery of consciousness is unlikely after 12 months if the vegetative state is caused by brain trauma, and exceedingly rare after three months if it is caused by non-traumatic brain injury or other brain disorders; however, some exceptional patients may show limited recovery outside of this time frame, though this is most likely in patients with non-traumatic coma without cardiac arrest (Tresch, Sims, Duthie, Goldstein, & Lane, 1991; Laureys et al., 2004). In general, though, adults in a coma immediately following a non-traumatic brain injury have a poorer prognosis than those in a coma after traumatic brain injury. The life expectancy for patients in the vegetative state is between two and five years, (approximately 82% of patients will have died after 3 years, and 95% after 5 years) though some statistics have shown that survival beyond 15 years can occur (Multi-Society Task Force on PVS, 1994).

Recovery from the vegetative state is understood to occur along two dimensions: recovery of awareness, and recovery of function (Multi-Society Task Force on PVS, 1994). Recovery of awareness entails that the patient has regained a sense of themselves

and their environment; this is verified by the patient demonstrating consistent voluntary behavioural responses to visual or auditory stimuli (e.g., command-following). Recovery of function is characterized by the ability to communicate with others, learn and perform new tasks, and in cases of good recovery, mobility and self-care (Multi-Society Task Force on PVS, 1994). For most patients in the vegetative state, recovery of function is unlikely. For those suffering a traumatic brain injury, approximately 24% of patients in the vegetative state for one month will have made either a good or moderate recovery 12 months after injury, though this number drops to 0.5% after 6 months. Patients in the vegetative state as a result of non-traumatic brain injury recover consciousness within 12 months of injury in approximately 15% of cases, with very few having good functional recovery. (Multi-Society Task Force on PVS, 1994).

### ***1.2.3 The Vegetative State: Symptoms and Assessment***

Patients in the vegetative state show no evidence of sustained, reproducible, purposeful, or voluntary behavioural responses to visual, auditory, tactile, or noxious stimuli, and no evidence of attention, intention, or learned responses (Wade & Johnston, 1999). They are unable to track moving objects with the eyes, or fixate on a moving stimulus. In fact, the appearance of visual pursuit is one of the signs that a patient has emerged from the vegetative state and regained awareness (Laureys et al., 2004). These patients are usually not completely immobile, though movements of the limbs are non-purposeful, or merely reflexive (Wade & Johnston, 1999). However, they may exhibit inconsistent primitive auditory or visual orienting reflexes, characterized by turning the head and eyes toward peripheral sounds or movements. They may sometimes appear to smile or cry, and occasionally utter grunts or moans, but they show no evidence of

language comprehension or capacity for expression (Wade & Johnston, 1999). Moreover, positron-emission tomographic (PET) studies of regional cerebral glucose metabolism show levels far lower than those in patients who are aware (approximately 40-50% of the normal range of values), and are comparable to those reported during deep general anesthesia in normal subjects (Laureys et al., 2004). In patients who have been in a vegetative state longer than 12 months, brain metabolism drops to 30-40% of the normal range. (Laureys et al., 2004)

Typically, clinical tools like the Glasgow Coma Scale are used for initial assessment of cognitive function after brain injury, and assess patients along three sub-scales: visual response, verbal response, and motor response (Teasdale & Jennett, 1974). Conversely, tests like the Coma Recovery Scale are predominantly used in chronic disorders of consciousness. The Coma Recovery Scale uses six sub-scales (auditory function, visual function, motor function, verbal function, communication, and arousal), with the lowest item on each subscale representing reflexive activity, and the highest items representing cognitively-mediated behaviours. Scoring is standardized, and is determined by the presence or absence of operationally-defined behavioural responses to specific sensory stimuli (Giacino, Kalmar, & Whyte, 2004).

#### ***1.2.4 The Vegetative State: Comparison to Coma, and Minimally Conscious State***

Importantly, the vegetative state is distinct from both coma and brain death. While patients with brain death or in a coma are neither awake nor aware, patients in the vegetative state go through cycles of wakefulness and sleep. Contrary to brain death, these patients can also breathe spontaneously without assistance and have preserved

brainstem reflexes and hypothalamic functioning (Laureys et al., 2004). Additionally, while both coma and vegetative state are potentially transitory states, brain death is irreversible.

The vegetative state is distinct from the minimally conscious state (MCS). Prior to 2002, a lack of diagnostic categories for patients with disorders of consciousness forced clinicians to group relatively heterogeneous patients into broad categories, typically based on the severity of their injuries. This lack of specificity resulted in important behavioural and cognitive differences often being overlooked. By 2002, a new diagnostic category, the minimally conscious state, had been described by the Aspen Neurobehavioural Work Group, amalgamating into a consensus statement previously published definitions and diagnostic criteria (Giacino et al., 2002). MCS patients, while possessing severely altered consciousness, are capable of demonstrating—albeit inconsistently—behavioural evidence of awareness of self or environment. For example, they may be capable of purposeful (i.e., non-reflexive) behaviour such as reaching for objects, vocalizations, intelligible verbalization, or following simple commands. Because of the inconsistency with which they demonstrate these behaviours, it is often very difficult to distinguish between a patient who is VS, and a patient who is MCS. However, correctly diagnosing a patient as MCS (rather than VS) is critical, as MCS is typically associated with much greater improvement and better health outcomes than VS, and may impact the treatment they receive.

### **1.3 Operationalizing Consciousness in a Neurological Context**

By definition, patients in the vegetative state are unconscious; they wholly lack awareness of the self, or the environment. Accordingly, diagnosing the vegetative state requires making an evaluation of the patient's level of consciousness. However, evaluating consciousness in others requires an agreed upon understanding of what this concept actually entails. In the philosophy of mind, for example, no such agreement exists (Van Gulick, 2014). Even amongst clinical neuroscientists, one's definition of consciousness may depend on one's clinical, neuroscientific, or philosophical approach. While providing a precise definition of consciousness as a concept is an interesting (and extremely challenging) philosophical problem, it is not one that I will attempt to address here. With respect to patients in the vegetative state, I argue, the salient question is whether we are justified in ascribing awareness to them, on the basis of some agreed upon operationalization of awareness. In other words, are there some criteria which an individual might exhibit, on the basis of which a reasonable person would feel confident in ascribing consciousness to them, and do patients in the vegetative state meet this criteria? I am not arguing that meeting this condition is all there is to being conscious. Rather, I am making the more measured claim that we might adopt a certain condition, or conditions, the satisfaction of which should make us confident in ascribing consciousness to these patients. Accordingly, for the purposes of this project, I will adopt an operational definition of consciousness that is well-established in the clinical and neuroscientific literature: the ability to command-follow.

In the domain of clinical neurology, consciousness is traditionally understood as consisting of two distinct elements: wakefulness, and awareness. (Plum & Posner, 1983). We might think of wakefulness as referring to one's level of consciousness; it



encompasses an individual's level of arousal. At its highest level, one is fully awake. When an individual is asleep, or under general anaesthetic, that individual lacks wakefulness, and thus, consciousness. Conversely, awareness is understood as the contents of one's consciousness; it encompasses one's sense of oneself, where one is, and the phenomenological character of one's situation. Accordingly, consciousness in this sense is not 'all-or-none', but rather a continuum of varying degrees of wakefulness and awareness.

Wakefulness is typically verified behaviourally (when one's eyes are open, one is awake), but can also be verified using techniques such as electroencephalography (EEG), which identifies the pattern of electrical signals that characterize an individual's normal waking state. Thus, we can operationally define wakefulness as 'the presence of prolonged periods of spontaneous or induced opening of the eyes' (Laureys, Perrin, & Bredart, 2007). Awareness is more difficult to assess. In the absence of specific neural markers, the only way in which an individual can demonstrate awareness is by producing some sort of volitional behaviour (e.g., responding to commands); this is true of both healthy individuals and those with disorders of consciousness. We know that someone else is aware because they tell us that they are, either verbally, (e.g. 'I am aware') or by exhibiting some agreed upon response to a physical stimulus (e.g., squeezing someone's hand after being told 'squeeze my hand if you are aware'). For patients who are unable to communicate verbally, the method of ascertaining a patient's self-report of awareness generally takes the form of 'command-following.' If a patient is able to reliably perform a certain action, such as the moving of a finger or squeezing of a hand, when requested to do so, the patient is understood to have followed the command, and thus demonstrated

her awareness. Thus, we can operationally define awareness as the capacity to formulate reproducible, voluntary, purposeful and sustained behavioural responses to auditory, tactile, visual, or noxious stimuli (Laureys et al., 2007).

The notion of volition is important here. Command-following is indicative of awareness, because the response to command (whether verbal or behavioural) is voluntary; it is possible for the individual to either confirm, or fail to confirm her awareness, based on her response to the command. Conversely, machines that ‘reliably perform a certain action when requested to do so’ are not thereby taken to be aware, because the performing of the action is automatic, and thus non-voluntary. Equivalently, if I request a patient to smile if they are aware, and coincidentally, they smile as a reflex at the time I asked them to do so, they have not exhibited behaviour indicative of awareness. Ensuring that an exhibited behaviour was a voluntary response to command is thus critical for establishing awareness.

Accurately diagnosing the preserved consciousness of a patient after injury is of great importance to their appropriate management (Bernat, 2006). However, diagnosis of the vegetative state is highly difficult, because the presence of awareness can only be inferred on the basis of a patient’s behaviours. This creates two different potential sources of false negatives (i.e. falsely concluding that awareness is absent). First, a patient may retain the capacity to demonstrate their awareness behaviourally, yet simply be unable to perform these behaviours at the time the assessment takes place. Or, if they do perform the behaviours, they may have them misinterpreted. While the assessments mentioned above are standardized, some degree of subjectivity with respect to judging particular behaviours on the part of the physician administering the evaluation is inevitable (Wade

& Johnston, 1999; Monti et al., 2012). The motor skills of these patients are severely limited as a result of their condition, and are often highly inconsistent. Moreover, as mentioned above, vegetative patients may exhibit behaviours such as smiling and crying which are presumed to be merely reflexive; however, it remains possible that these are volitional behaviours in certain contexts. A patient's level of awareness may also fluctuate over time, which may confound a physician's assessment. In fact, it is estimated that as many as 43% of patients diagnosed as vegetative actually retain some level of awareness (Childs, Mercer, & Childs, 1993; Andrews, Murphy, Munday, & Littlewood, 1996; Schnakers et al., 2009).

While we might think that rigorous and careful assessment is sufficient to account for this first potential source of error, the second potential source of false negatives is much more pervasive, and cannot be accounted for even with the utmost care in assessment. This second potential source of error arises from the fact that diagnosing a patient as being in the vegetative state depends on the absence of any evidence of sustained, reproducible, purposeful, or voluntary behavioural response to visual, auditory, tactile, or noxious stimuli. In other words, the lack of evidence of awareness is taken to be positive evidence for the vegetative state. However, a patient may be unable to exhibit behavioural evidence of awareness, yet nevertheless remain aware. We can imagine a patient who suffers a brain injury and remains entirely conscious, while losing the ability to make any sort of behavioural response. No matter how careful our assessment of this patient, it would be impossible to determine if they were aware through behavioural assessment.

In response to this problem, researchers have begun devising new methods of assessing awareness, which do not rely on overt behaviours. Instead, these researchers have developed ways to measure specific brain responses, and use these as a proxy for traditional behavioural responses to commands. If a patient can modulate their brain activity in response to the commands of researchers, for example, by imagining performing a specific activity, researchers can use these responses as a proxy for a behavioural response, and on this basis infer that the patient is aware. In the next few sections, I will provide a brief overview of the research using functional neuroimaging in patients diagnosed as vegetative, which laid the groundwork for the mental imagery task originally used by Owen and colleagues (Owen et al., 2006) to detect covert awareness in a patient diagnosed as vegetative. I will then describe in greater detail the mental imagery task itself, as well as some initial objections levelled against its conclusions, and responses to those objections. Finally, I will conclude this chapter by providing an overview of the ethical issues associated with the discovery of covert awareness in these patients, and introduce the particular ethical issue which will be the focus of this thesis: the welfare of patients diagnosed as vegetative, with covert awareness.

#### **1.4 Functional Neuroimaging in Vegetative Patients**

Initial research using functional neuroimaging on vegetative patients focussed primarily on the capacity of patients to experience pain. These studies found significant activations in the midbrain, contralateral thalamus, and S1 of vegetative patients presented with high-intensity noxious stimuli. (Laureys et al., 2002; Boly, 2008). However, unlike control participants, the vegetative patients did not show the activation

in secondary somatosensory, insular, posterior parietal, or anterior cingulate cortices that would be consistent with higher-level cognitive processing.

Other studies have attempted to discern whether vegetative patients remain capable of language comprehension. Di and colleagues (2007) used fMRI to measure the brain activity of seven vegetative patients, in response to their name being spoken by a familiar voice. While two of these patients exhibited no significant activity, three patients showed activation in primary auditory areas, and two vegetative patients exhibited activity in higher-order associative temporal lobe areas. Staffen, Kronbichler, Aichhorn, Mair, and Ladurner, (2006) used fMRI to compare the response of a vegetative patient to a variety of sentences spoken by unfamiliar voices, some containing the patient's name, and some containing a different first name. Activation to the patient's own name in a region of the medial prefrontal cortex was similar to that observed in healthy volunteers. However, although selective cortical processing of one's name requires the ability to perceive and access the meaning of words, and may imply some level of comprehension on the part of this patient, a response to one's own name is elicited automatically, and may not depend on the higher-level linguistic processes required for comprehension (Staffen et al., 2006). A later study by Coleman and colleagues (2009) demonstrated that nearly 50% of patients diagnosed as either vegetative or MCS (19 out of 41), showed normal or near-normal temporal-lobe activation in response to auditory stimuli, as well as in response to speech in particular. Four patients, including two who had been diagnosed as vegetative, also exhibited normal fMRI activity when presented with semantically ambiguous speech, suggesting that some patients who meet all of the behavioural criteria

for the vegetative state may nevertheless retain the capacity for understanding speech (Coleman et al., 2009).

Of course, the presence of normal brain activation in these patients does not entail awareness. Indeed, a great deal of research has shown that stimuli such as faces, speech, and pain can elicit automatic responses in the brain, and so it is entirely possible for the sort of neural activation observed in the studies mentioned above to occur in patients who lack awareness (Owen, 2013). For example, Davis, Coleman, & Absalom (2007) have shown that while the semantic processing of speech in healthy volunteers is highly degraded at low levels of sedation with propofol, the perceptual processing of speech remains resilient even at high levels of sedation. Healthy volunteers who have been heavily sedated (i.e., they do not respond to conversation, and are understood to lack awareness) will demonstrate a characteristic pattern of activation in response to semantically ambiguous speech. This suggests that because individuals known to lack awareness (i.e., heavily sedated healthy volunteers), show evidence of perceptual processing of speech, evidence of the same perceptual processing in vegetative patients is not evidence that they are aware (Davis, Coleman, & Absalom, 2007).

One common thread between the above studies on language processing and pain experience in vegetative patients is that ‘normal’ activation can occur in the absence of awareness. To verify awareness using neuroimaging, researchers must therefore determine a pattern of activation that could not occur without awareness. Operationalizing awareness as command-following meets this requirement. An individual cannot produce a purposeful, volitional response to command unless they are aware. The simplest way to demonstrate command-following ability is by producing a particular

agreed-upon motor or verbal response. However, as researchers have sought to demonstrate, this is not the only way that command-following might occur. One potential alternative to verbal or motor response is the volitional activation of certain areas of the brain. In fact, as Boly and colleagues (2007) have demonstrated, healthy participants are capable of generating a robust and reliable pattern of brain activity, which can be measured by fMRI, by imagining performing certain tasks. Interestingly, imagining these tasks activates the same brain areas as actually undertaking the task itself (Jeannerod & Frak, 1999; Aguirre, Detre, Alsop, & D'Esposito, 1996; Owen, 2013). For example, in the study by Boly and colleagues (2007) healthy participants were asked to imagine hitting a tennis ball back and forth with a coach when they heard the word 'tennis', (eliciting imaginary arm movements) and to imagine walking from room to room in their house, when they heard the word 'house' (eliciting spatial navigation). All of the patients showed clear activation of the supplementary motor area while imagining playing tennis. Moreover, clear activation of the parahippocampal cortices, the posterior parietal lobe, and the lateral premotor cortices—all regions which have been shown to contribute to spatial navigation—was observed when the patient imagined walking through their house.

The reliability of these results across individuals means that researchers can use these responses as a proxy for volitional behaviour, in the same way that motor and verbal responses are used, in the context of command-following. Just as in more traditional cases of command-following, these participants must understand the instructions of the researcher and select an appropriate response from a range of alternatives, at the right time. Producing the proper volitional response demonstrates that

the participant understands the relationship between the instructions and what their own behaviour signifies. Of course, this verdict presupposes that imagining certain tasks in response to commands implies awareness, in the same way that volitional motor or verbal response to commands is presumed to imply awareness.

### **1.5 Functional Neuroimaging in Vegetative Patients: The Mental Imagery Task**

Provided that modulating brain activity in response to commands is a reliable indicator of awareness, the mental imagery task described above provides a way to assess the awareness of patients who cannot produce motor or verbal responses to command. This is precisely the insight of Owen and colleagues (2006), who used the mental imagery task to demonstrate that a patient who satisfied all of the behavioural criteria for the vegetative state, and thus was presumed to lack awareness, was capable of command-following, and was in fact aware (Owen et al., 2006; Owen & Coleman, 2007). This patient repeatedly demonstrated statistically significant levels of activity in the supplementary motor area when instructed to imagine playing tennis—activity which was indistinguishable from the activity measured in healthy controls—and in the parahippocampal gyrus, the posterior parietal cortex, and the lateral premotor cortex, when instructed to imagine walking through her house. Again, this activity was indistinguishable from that seen in healthy controls. On this basis, researchers concluded that this patient was capable of understanding commands and voluntarily producing behaviour in response to those commands, and was thus aware. A subsequent study by Monti and colleagues, (Monti et al., 2010), demonstrated that of 23 patients diagnosed as vegetative that were scanned, 4 (17%) were able to produce neural activation of the same sort in response to command, and were thus aware.



Is activating an area of one's brain really functionally equivalent to moving one's arm, blinking one's eyes, or saying a word, as evidence of command-following ability, and thus awareness? Critics might argue that brain activation is somehow less immediate, and so less reliable, as an indicator of awareness than motor or verbal response. However, issues of reliability can be resolved with thorough replication. It is true that, were a patient to demonstrate neural activation in response to command in a single trial, it would be mistaken to simply conclude that the patient is aware, given so little evidence. However, this same skepticism would apply to patients who raise a hand in response to command a single time. Repeated neural activation in response to command reduces the possibility that the original activation was a mere chance occurrence, just as a patient repeatedly raising her hand over the course of many trials increases our confidence that such behaviour is voluntary. The fact that the patients to whom awareness was ascribed in both the Owen and Monti studies above were able to repeatedly activate the appropriate brain areas over the course of several trials makes it highly unlikely that the patients were doing anything other than imagining the task in response to command, and thus exhibiting volitional behaviour.

Another concern with this sort of command-following approach is that the observed neural activation might be the result of unconscious or automatic neural responses to the cue words (Nachev & Husain, 2007). While it is well documented that some words can produce an automatic neural response, these responses tend to be transient (Owen, 2013). Conversely, in both the Owen and Monti studies, the observed activation persisted for the full 30 second interval of each task; far longer than the fleeting activation which would be expected from an automatic response to a cue word.

Moreover, the observed activation only ceased at 30 seconds because participants were cued that they should switch tasks. Additionally, the activation patterns observed by Owen et al. and Monti et al. were, as predicted by the researchers, concentrated in regions known to be involved in motor movement (in the case of the ‘tennis’ task), and spatial navigation (in the case of the ‘house’ task). They were not in brain regions that are known to be involved in word processing, as would be expected from a non-conscious neural response to language. In fact, research has shown that healthy volunteers show no activation when presented with non-instructive sentences using the key words ‘tennis’ or ‘house’ (Owen et al., 2013).

This mental imagery paradigm has even been extended to allow functional communication in a subset of patients diagnosed as vegetative with covert awareness. By instructing participants to imagine playing tennis as a proxy for ‘yes’, and imagine moving through their house as a proxy for ‘no,’ multiple patients have been able provide biographical information unknown at the time to researchers, but later externally verified. For example, one patient was able to correctly identify his father’s name, his current location, the date, and the name of his personal care worker, through a series of yes or no questions (Fernandez-Espejo & Owen, 2013).

### **1.6 The Discovery of Covert Awareness in Vegetative Patients: Ethical Issues**

Perhaps not surprisingly, one of the most hotly contested issues arising from this research is the role this technique should play in decisions concerning the removal of life-sustaining treatment. A number of high profile cases in recent years, in which family members disagreed about whether a patient should continue with life-sustaining

treatment, have brought to the forefront the ethical and legal complexity of these issues. Many of these cases center on the lack of possibility of recovery, the determination of which depends, at least in part, on our understanding of the condition of the patients in question. If, for example, a patient is determined to have the ‘right to die’ because they are believed to lack awareness, and recovery is impossible, the discovery of awareness through neuroimaging might influence these sorts of decisions (Wilkenson, Kahane, Horne, & Savulescu, 2009; Skene, Wilkenson, Kahane, & Savulescu, 2009; Fisher & Appelbaum, 2010).

As provocative and complex as these issues are, I do not believe that they are particularly relevant to the specific patient population that forms the core of the research under discussion here, or their families. For patients who survive severe traumatic brain injury long enough to be admitted to hospital, mortality rates are between 30 and 40%, with the majority of deaths—between 70 and 80%, depending on the particular study—being the result of withdrawal of life-sustaining treatment (Turgeon et al., 2011; Verkade, Epker, Nieuwenhoff, Bakker, & Kompanje, 2012; Cote et al., 2013). Moreover, the decision to withdraw life-sustaining treatment from a patient with a severe traumatic brain often occurs within the first few days of the injury. (Turgeon et al., 2011; Kitzinger & Kitzinger, 2013).

Conversely, the patient population which I am focussed on are typically several years removed from their initial injury, which suggests that for many of these patients, withdrawing life-sustaining treatment is no longer an option under consideration. While a few patient’s families may seek the withdrawal of artificial nutrition and hydration (or some other means of allowing the patient to die), several months or years after the patient

is diagnosed as vegetative, this is uncommon. Indeed, in many cases, the families of these patients believe that the patient retains some form of awareness, and are seeking confirmation of this belief through functional neuroimaging. Research by Tresch et al. (1991) suggests that 90% of family members of patients in a vegetative state believe the patient retains some awareness of pain, environment, taste, conversation, or the presence of others, although 32 of the 33 family members did not expect the patient to improve.

What I intend to focus on here is an issue which I believe to be important to both the patients themselves, and their families, but which has received only cursory attention in the neuroethics literature: how are these individuals faring, and what can others do to help them fare better? Answering this question involves an investigation into the welfare of these patients, and adopting an ethical perspective that focuses on patient welfare. It has been argued that because vegetative patients lack awareness, they do not have interests; accordingly, it is incoherent to talk about their welfare (Wade, 2001; Fenwick, 1998). However, it is clear that some patients diagnosed as vegetative *are* aware, and so may be capable of having interests, in which case it is possible for them to fare better or worse. Of course, what it means for these patients to have interests, what sort of interests they might have, and most importantly, why these interests are morally relevant, are all questions which need to be answered, and will occupy the majority of the next chapter.

### **1.7 Patient Welfare and Patient Autonomy**

A number of ethical principles bear on our treatment of vegetative patients. In their seminal work on medical ethics, Beauchamp and Childress (2009) propose a framework of four basic ethical principles; respect for autonomy, beneficence, non-

maleficence, and justice, which should guide decision-making in medical practice. The majority of the neuroethics literature concerning patients diagnosed as vegetative can be divided into two broad categories: that which advocates for an autonomy-centered approach to the treatment of patients, what Fins refers to as “an ethic grounded in self-determination” (Fins, 2005), and that which adopt an approach focussing on beneficence, where the welfare of the patient is of primary concern. Why should one adopt a perspective which focuses on patient welfare?

The principle of autonomy recognizes the right of the individual to make his or her own medical decisions, and is in large part a reflection of a larger societal value; the right to self-determination. The requirement that patients provide informed consent prior to receiving certain kinds of treatment is meant to ensure that the decision to receive (or not receive) treatment is made autonomously. An autonomy-centered approach typically focusses on whether patients diagnosed as vegetative with covert awareness are sufficiently aware and autonomous to participate in decision-making regarding their own care. Accordingly, much of the debate concerning patients diagnosed as vegetative with covert awareness has centered on whether these patients have decision-making capacity (Wilkenson et al., 2009, Fins & Schiff, 2010).

Traditionally, decision-making capacity in a clinical context has been understood as consisting of four independently necessary, but jointly sufficient, criteria (Buchanan & Brock, 1989; Appelbaum et al., 1995). First, a patient must be able to communicate a medical preference; this will typically take the form of verbal expression, though in patients for whom communication is restricted, this criterion may be satisfied in other ways (i.e. non-verbal communication). Second, a patient must understand the treatment

options presented; they must encode and comprehend the information they have been given. Third, a patient must appreciate the consequences of their decision. They must demonstrate that they can relate different treatment options to themselves, thereby acknowledging that a particular decision has consequences *for them*. Finally, a patient must show that the decision they have made was based on some rational deliberation on their part.

Assessing autonomous decision-making capacity thus requires a great deal of interaction between those being assessed, and those performing the assessment. Evaluations such as the MacArthur Competence Assessment Tool, typically take the form of a semi-structured interview, where the individual giving the assessment can analyze the respondent's answers to questions, including pauses, inflexions, and non-verbal cues, in order to determine whether the four criteria above are met (Appelbaum & Grisso, 1995).

### ***1.7.1 Challenges of an Autonomy-Centered Approach***

Obviously, the sort of communication required for an assessment like the MacArthur Competence Assessment Tool is not possible in vegetative patients with covert awareness, even those who can communicate using fMRI. Fins and Schiff have argued that communication via functional neuroimaging might eventually “reach the clinical standard of decision-making capacity”, and thus allow patients to make their own medical decisions, but that this is not yet the case (Fins et al., 2010). Accordingly, they argue, because patients cannot initiate questions, give nuanced responses, or demonstrate appreciation of the gravity of a decision, responses from patients cannot currently indicate informed consent or refusal.

However, strategies are being developed to accommodate these limitations, and assess decision-making capacity in behaviourally non-responsive patients with covert awareness (Coughlan et al., 2005; Peterson et al., 2013). Peterson and colleagues (2013) have argued that it is possible, at least in principle, to further deconstruct the higher-order capacities on which the four criteria for decision-making capacity are based, into their underlying cognitive components. These simpler cognitive faculties, in turn, may be more amendable to assessment through ‘yes’ or ‘no’ questions, or through direct evaluation using different tasks. For example, ‘consequential reasoning,’ might be reduced to the ability to retain new information; the ability to distinguish oneself from others; the ability to situate oneself in space and time; and the ability to appreciate temporal sequencing. They also argue that decision-making capacity might be understood as a threshold concept, with high-stakes decisions requiring a high degree of decision-making capacity, and lower stakes decisions requiring a comparatively lower degree of decision-making capacity. As these authors acknowledge, however, even if a satisfactory deconstruction of higher-order cognitive capacities into more basic components is possible, there are considerable practical limitations to implementing such an assessment (e.g. limitations on the type and quantity of questions which can be answered in a single imaging session due to patient fatigue) (Peterson et al., 2013). Thus, while promising, assessing decision-making capacity in this way is not yet possible.

An autonomy-based approach faces other challenges. Mackenzie (2013) argues that decision-making involves the integration of subjective values and emotions, and that these factors may change as recovery proceeds. For example, the presence of underlying psychiatric conditions secondary to brain injury may influence a patient’s choices, and

thereby compromise their decision-making capacity. Similarly, a central criterion of decision-making capacity is the consistent application of a stable value set throughout the clinical reasoning process. During neurorehabilitation and recovery, these patients' states of awareness are likely to alter and fluctuate, which may in turn influence their decision-making capacity at any given time.

Because decision-making capacity is difficult to assess, and thus, autonomy difficult to establish in these patients, adopting an autonomy-based approach often requires an appeal to a patient's previously expressed autonomous decisions. In cases where a patient lacks an advanced directive, for example, or has never explicitly discussed what they would want to have happen to them were they in a vegetative state, an autonomy-based approach has little guidance to offer. Yet even when a patient has an advanced directive, it is unclear to what extent this previously expressed autonomous decision should be followed. Because advanced directives are expressions of an individual's expected desires at some future time (i.e., I anticipate now that I will want X at some later time), they require the assumption that the person now continues to hold the values and desires which informed their prior decision. We typically respect an individual's autonomy because we assume that they have privileged access to their interests and values, and are reasonably good at predicting what outcomes they want when presented with a particular decision. This is why, at least in a medical or legal context, autonomous decision-making must be reasonably informed. However, it is, at best, difficult to imagine what it would be like to be in a vegetative state, and we should exercise caution in simply assuming that an individual would continue to identify with



their pre-injury autonomous desires. I will re-examine this issue in greater detail in chapter four.

### *1.7.2 Objections to a Focus on Patient Welfare*

On the other hand, the principle of beneficence refers to actions which promote the welfare of others, and holds that medical practitioners ought to act according to the best interests of the patient. In the context of patients diagnosed as vegetative, those commentators who emphasize the importance of patient welfare, typically do so in the context of end-of-life decision making. Gillon (1998) argues that whether or not life-sustaining treatment is withdrawn ought to depend on whether withdrawal is consistent with the best interests of the patient. Where an intervention is highly unlikely to benefit a patient, there is no medico-moral obligation to provide it, and, where the continued provision of a non-beneficial intervention actually deprives the patient, or others, of some benefit, there may be a positive reason to forego such treatment. Thus, if life-sustaining treatment is no longer benefitting a patient in a vegetative state, and thus is no longer in their interests, it may be consistent with beneficence to cease such treatment.

Conversely, Fenwick claims that patients in the vegetative state have no interests, and thus, attempts to make end-of-life decisions based on the best interests of the patient are incoherent, and serve only to impede ethical decision-making (Fenwick, 1998). According to this argument, justifying the withdrawal or withholding of life-sustaining treatment from patients, on the grounds that continuing treatment is ‘not in the patient’s best interests,’ is illogical. If a patient has no interests, then the set of interests from which to draw a ‘best interest’ is empty; nothing can be in her interest, or not in her interest. Fenwick seems to imply that in order for something *not* to be in a patient’s best

interests, there must be some alternative that *is* in a patient's best interests, as it seems reasonable to argue that if a patient has no interests, then he or she has no best interests, and thus continuing treatment cannot be a 'best interest.'

A similar argument has been made by Chan and Tipoe (2013), who claim that "one would not dispute that a patient in a PVS [persistent vegetative state] no longer has any quality of life," and so there is "no room for the court to hold that denial of life-sustaining treatment is in the best interests of a patient in a PVS." They argue further that only under the guidance of an advance directive can withdrawal of life-sustaining treatment ever be consistent with a patient's best interests. They also argue that, while patients in the vegetative state have "no cognitive function," and we should be "indifferent to whether he or she lives or dies," to decide on behalf of a patient "that death is in a patient's best interests is a grave violation of a patient's autonomy." In the absence of any cognitive function, a patient is obviously not autonomous. Thus, any violation of their autonomy must refer to a past autonomous decision, for which there exists a current obligation, on the part of proxy decision makers, to respect. Indeed, this is precisely the problem raised earlier, regarding the application of advance directives, namely, that a patient's past autonomous desires may conflict with their present 'best interests'. In such a case, how should a proxy decision maker proceed? Moreover, if acting in a patient's 'best interests' is only possible in the presence of an advance directive, it is unclear what justification physicians or proxy decision makers can give for any action, in the absence of an advanced directive.

Suchy-Dicey criticises the welfare-centered approach on the grounds that it can result in a patient's wishes being disregarded (Suchy-Dicey, 2009). She argues that, on a

welfarist perspective, decisions about how to treat a particular patient are made “solely on the basis of how much pain or pleasure would result from each treatment,” and thus may not reflect decisions the patient would have made. Certainly, there is the possibility for a patient’s autonomous decisions to conflict with their best interests. However, as stated above, the absence of autonomy in patients diagnosed as vegetative, as well as the uncertainty surrounding ‘what a patient would have wanted’ often requires that physician’s and proxy decision-makers appeal to something other than a patient’s autonomous decisions. Surely, appealing to the best interests of the patient is a reasonable alternative. Moreover, Suchy-Dacey offers an unnecessarily narrow view of welfare, as consisting merely of the balance of pleasure over pain. Indeed, making treatment decisions solely on this basis may violate a patient’s autonomy, but it may also violate what is in their best interests. While some accounts (e.g. hedonism) hold that pleasure and pain are the only components of welfare, one might argue that pleasure and pain are two of many factors which might influence an individual’s welfare, and furthermore, that their relative importance in determining welfare depends on the patient’s own appraisal.

Similarly, Rich cautions against privileging a patient’s ‘best interests’ over their previously expressed autonomous decisions, and argues strongly against using information gained through functional neuroimaging to help inform decisions when this new information appears to conflict with previously stated patient values (Rich, 2013). In highlighting the difficulty of balancing a patient’s prior wishes (expressed with varying degrees of information, but made with full autonomy), and their current best interests (about which we may be uncertain), Rich makes an important point. However, if researchers are able to ascertain reliable information about a patient’s interests, desires, or

values through neuroimaging, it seems that this information would be tremendously valuable in informing our understanding of patient experience, and what course of action might improve their well-being.

### ***1.7.3 The Need for a Welfare-Centered Approach***

Perhaps because it has only been recently discovered that patients diagnosed as vegetative may retain covert awareness, and thus have some sort of experience of the world, very little has been written about the welfare interests of these patients, outside the sphere of end-of-life decision making. (On the other hand, little has been written about the potential welfare interests of MCS patients, even though it is clear that they retain intermittent awareness). The sorts of patients I am interested in here, namely, those patients who have been diagnosed as vegetative and demonstrated awareness, but who are several years removed from their injury, are not the sorts of patients for whom the removal of life-sustaining treatment is particularly relevant. This does not mean, however, that the ethical issues involving these patients are unimportant, or unworthy of critical investigation. These are individuals who were presumed to be unaware, and thus have no interests, desires or experiences, but who in fact are aware. What is life actually like for these patients? Given the severity of the injuries which resulted in their being in the vegetative state, it is likely that these patients are severely cognitively deficient; they probably do not experience the world in the same way that a healthy adult human does. Yet this gives us very little insight into what they *can* experience, what they *do* think or feel, if anything. Are these patients suffering? Are they more or less content in their limited state, perhaps capable of only mild sensory pleasures and pains? Do they experience emotions like happiness, sadness, fear, loneliness, or excitement? How do

they feel about their lives moment to moment, or can they imagine themselves in the future? Given that behaviourally non-responsive patients with covert awareness are capable of experience, and thus can have their lives go better or worse depending on the experiences they have, it is important to determine the actions others can take to ensure that their lives go as well as possible.

At its core, a focus on patient welfare requires only that these patients be capable of possessing interests, something that can be assessed using current technology. In this way, it avoids many of the problems endemic to an autonomy-based approach; specifically, the difficulty with assessing decision-making capacity in this patient population. I am not arguing that one ought to adopt an ethics of welfare view, at the exclusion of an autonomy-centered framework, in all cases. In fact, it seems reasonable to suppose that we have *prima facie* obligations of both beneficence and autonomy to patients who demonstrate covert awareness. However, when the information required for ascribing autonomy to a patient is absent, (specifically, when it is unclear whether a patient has decision-making capacity), a focus on patient welfare provides valuable moral guidance about how a patient ought to be treated. Accordingly, this is the approach I will adopt in this project. In the next chapter, I turn to the question of why the ability to have certain interests is morally significant, and how sentience—the ability to experience suffering or enjoyment—is sufficient to ground the moral status of an individual, and generates an obligation on the part of others to take the interests of those individuals with moral status into account.

## Chapter 2: Sentience and Moral Status

In the previous chapter, we saw that some patients who satisfied the behavioural criteria for the vegetative state may nevertheless retain covert awareness. By demonstrating the ability to command-follow, these patients satisfy a widely accepted clinical and neuroscientific criterion for awareness. Moreover, they have shown that they are capable of at least some degree of language processing, working memory, selective attention, and executive function. Given that prior to completing the mental imagery task, these patients were believed to be completely unaware, these results are important—both scientifically, and for their ethical implications. The discovery that some patients diagnosed as vegetative are aware may call into question many of our assumptions about what their lives are like, which in turn may force us to re-examine our treatment of them. Specifically, it may mean that these patients have moral status. As I will discuss in greater detail below, an entity has moral status if and only if its interests matter morally, for the entity's own sake, such that it can be harmed or wronged. Indeed, there is a lack of consensus amongst philosophers about the moral status of patients diagnosed as vegetative; it is not obvious what our moral obligations are to these patients. For example, philosophers who subscribe to the view that human death is the irreversible cessation of the capacity for consciousness dispute whether patients who are permanently vegetative—who have irreversibly lost the capacity for consciousness—are even alive in a morally significant sense of the term. (For an overview of this discussion, see DeGrazia, 2011).

I will not attempt to defend a particular conception of death here. Whether one adopts a whole brain death account, or an irreversible loss of consciousness account as

being sufficient for the death of a person, patients diagnosed as vegetative with covert awareness are clearly not dead, in either a biological sense, or in the sense of irreversibly lacking the capacity for consciousness. Does this give them moral status? On most traditional accounts of moral status, being alive in a biological sense, in and of itself, is not sufficient for moral status. But patients diagnosed as vegetative with covert awareness are more than merely alive in a biological sense; they are also aware. Is the presence of awareness in these patients sufficient to grant them moral status? To answer this question, we must address several issues. What sort of entities have moral status, and more importantly, on what grounds, is far from a settled issue. Accordingly, to determine if patients diagnosed as vegetative with covert awareness have moral status, we must first determine criteria sufficient for the ascription of moral status. Second, we need to show that patients diagnosed as vegetative with covert awareness are capable of satisfying these criteria. Of course, it is a further question how the possession of moral status ought to influence our treatment of these patients, if indeed they do have moral status.

Answering this further question, I claim, will depend in large part on how we understand the welfare of these patients; this will be the focus of chapters four and five of this thesis.

Investigating the putative moral status of these patients in particular also provides an opportunity to critically examine the moral relevance of those criteria that are generally taken to be sufficient for moral status. Most, if not all, accounts of moral status take it as given that healthy adult humans have moral status, and attempt to justify their moral status by appealing to certain characteristics that they possess. However, if a significant portion of human beings turn out to lack these moral status-conferring attributes (e.g. self-consciousness, rationality), this suggests that these attributes may not

be suitable candidates for conferring moral status, and moreover, cannot be used to justify the partial treatment accorded to human beings over other living beings, such as non-human animals or fetuses. On the other hand, if the justification for treating living beings in certain ways *does* rest to some extent on their possession or lack of certain intellectual attributes, this may in turn justify treating cognitively disabled human beings in ways that it would be unacceptable to treat cognitively intact adult humans. Depending on one's account of moral status, the fact that the patients under discussion are aware may not be sufficient to justify assigning them moral status. Furthermore, assigning moral status to these patients may also necessitate revising our intuitions regarding the moral status of other entities, like non-human animals.

Most accounts of moral status can be divided into two categories: Individually-based accounts and group-based accounts. Roughly speaking, individually-based accounts attempt to pick out one or more characteristics of a particular individual which grants them moral status. These characteristics may be things like autonomy or rationality, (often referred to collectively in this context as 'sophisticated cognitive capacities'), the potential for such capacities, or more rudimentary cognitive capacities like sentience. Group-based accounts, on the other hand, typically argue that membership in a particular group grants each member of the group moral status, whether or not there exists some characteristic (beyond group membership) that each member shares (Feinberg, 1980; McMahan, 2002).

Furthermore, accounts of moral status, whether individually-based or group-based accounts, may differ in the ways they take their selected criteria to actually justify the conferring of moral status on a particular individual. On some accounts, cognitive



capacities may ground the capacity for certain kinds of interests (DeGrazia, 1996; Singer, 2006), while on other accounts, the presence of particular cognitive capacities may generate certain duties in others (Korsgaard, 2004; Regan, 2004) or be necessary for participation in a community of moral agents (Scanlon, 1998).

In this chapter, I argue that sentience, the capacity for suffering or enjoyment, is a *sufficient condition* for moral status, and thus, insofar as they are sentient, patients diagnosed as vegetative with covert awareness have moral status. Sentient beings have at least one kind of morally significant interest, specifically, an interest in avoiding suffering or experiencing enjoyment, and it is through the promotion or violation of this interest, as well as others that they might have, that others are capable of affecting the welfare of these beings. In short, sentient beings have a capacity for certain experiences, which generates an interest in having or avoiding those experiences, an interest that others have a moral obligation to respect. This obligation is captured by the idea of moral status.

I defend a sentience-based account of moral status for a few reasons. First, although the question of moral status and its grounds arises in a number of philosophical contexts, I am here concerned with providing a sufficient condition for the moral status of one particular group of patients, namely, those diagnosed as vegetative with covert awareness. Given the limits of our knowledge of the cognitive capacities of these patients, any effort to justify their moral status must not only be philosophically robust, but also practically verifiable. Thus, while one could argue that the presence of some other cognitive capacity, such as rationality or autonomy, would generate interests or

rights which would also be sufficient to ground moral status, verifying the presence of such a capacity in these patients is beyond our current capabilities.

Second, the experience of suffering or enjoyment is a fundamental constituent of individual welfare. And, it is plausible to suppose that it is an especially important aspect of the welfare of the patients under discussion, given the potential limits to the ways in which we can affect their welfare, in light of their cognitive and behavioural deficits. As DeGrazia points out, “ethics is centrally concerned with interests,” and that most ethical theories protect or promote individual interests, at least to some degree (DeGrazia, 1996, p.39). Because moral status is fundamentally concerned with the protection and promotion of the interests of its bearers, it makes sense that a sufficient condition for having moral status would be the possession of some sort of interests. And, because I am concerned with the welfare of patients diagnosed as vegetative with covert awareness, I adopt an account of moral status which focuses on the kinds of interests—sentient interests—that likely form a central part of their welfare.

My argument will proceed as follows: I will begin by offering a general account of the concept of moral status, as well as the notion of interests, and defend the adoption of sentience as a sufficient condition for moral status. I will then consider alternative theories of moral status, which are inconsistent with a sentience-based criterion, and show how these alternative theories are inadequate.

Because I am only attempting to defend sentience as a sufficient condition for moral status, I leave open the possibility that some non-human animals may turn out to have moral status. For example, Paul Taylor has argued for a view called ‘biocentrism’, according to which each living thing—animal, plant, or micro-organism—has a good of

its own, and that all such things have equal intrinsic worth which entitles them to moral respect (Taylor, 1986). Indeed, some environmental philosophers (Crisp, 1998; Varner, 2000) reject the individualism of biocentrism, and favor group-based accounts which argue that ecological wholes like species, populations, biotic communities, and ecosystems, have intrinsic value as well. (For an overview of this debate, see Brennan, 2015). The claim that sentience is a sufficient condition for moral status does not contradict these sorts of claims, and so engaging further with this debate is beyond the scope of this project.

Similarly, I leave open the possibility that there may be other sufficient conditions for moral status. (Mary Anne Warren, for example, offers a multi-attribute account of moral status, wherein more than one condition may be sufficient for moral status) (Warren, 1997). Insofar as group-based accounts hold that all human beings have moral status, these accounts will only differ from sentience-based accounts—with respect to who is granted moral status—when considering the moral status of non-human animals. Arguing that sentience is a sufficient condition for moral status does not rule out the moral status of any human being (even a non-sentient human being), and so is consistent with group-based accounts. My focus will be primarily on other individually-based accounts of moral status, which directly conflict with a sentience-based account, though I will remark briefly on the limitations of group-based accounts.

## **2.1 What is Moral Status?**

Is it morally wrong to hit a baseball as hard as one can with a bat? Barring certain special circumstances, it is not. This is because baseballs are inanimate objects; they do

not have needs, interests, well-being, or a good of their own which we might violate by acting in a certain way. It makes no difference to a baseball how it is treated. Conversely, it *is* morally wrong to hit a child as hard as one can with a bat. This is because children are not inanimate objects; they do have needs, interests, well-being, and a good of their own which we might violate by acting in a certain way. It *does* make a difference *to them* how they are treated.

The concept of moral status captures the difference between how we may treat things like baseballs, and how we must treat things like children. In essence, the ascription of moral status divides individuals into two different groups; those whose interests matter, for their own sake, and those whose interests do not matter. To have moral status is to be an entity toward which moral agents have, or can have, moral obligations. Moral status entails that we may not treat those who have it in any way we please; we are morally obliged to give weight in our deliberations to their needs, interests, or well-being (DeGrazia, 1996; Warren, 1997). Moreover, an entity with moral status matters for its own sake, and has interests such that the entity can be wronged through the violation of these interests. For example, person A has moral status if and only if his suffering is morally bad, not because of its effect on others, but because of its negative effect on person A. Entities with moral status thus have a moral claim against others not to have their interests violated, and to have their interests given proper consideration. Importantly, violating the interests of a being with moral status is wrong insofar as it is bad for the entity itself, and not because of the consequences which might result for others. The obligations one has to some other person, in virtue of that person's moral

status, is independent of any special relationships or contracts that might also exist between the two parties (DeGrazia, 1996; McMahan, 2002).

Accordingly, moral status imposes limits on how I may act towards those who possess it; I cannot simply disregard the interests of an individual with moral status. Because moral status creates an obligation not to violate the interests of an entity, it is often characterized as a negative obligation, specifically, as a presumption against interference. Interfering in the life of another person by causing them suffering, by killing them, or otherwise disrupting the realization of their interests, is morally wrong, precisely because they have an interest in those sorts of violations not occurring (Warren, 1997). Thus, to give ‘proper consideration’ to an entity’s interests in my moral decision-making requires that I avoid committing those actions which I can reasonable expect will violate their interests. However, others have understood an entity’s moral status as generating a positive obligation of others (e.g., Jaworska, 2007). If my failure to act results in the violation of an individual’s interests, when I may have acted to prevent this violation at minor cost to myself, we might think that I have wronged that individual. We can certainly imagine a case in which an individual with moral status lacks the capacity to promote her own interests, and relies on others not simply to abstain from actively violating their interests through unwanted interference, but also to promote her interests.

## **2.2 Who has Moral Status?**

One of the most challenging aspects of the concept of moral status is determining who possesses it, and on what grounds they possess it. I argue that the possession of sentience is a sufficient condition for the ascription of moral status. On this account, all

entities that are sentient have moral status, although it is possible that entities which lack sentience may nevertheless possess moral status as well.

In its most general sense, the capacity for sentience is the capacity to have subjective experiences; the capacity to feel and to perceive the world around oneself. One of the reasons that sentience is important, then, is because it grounds the ability to have experiences of a morally significant kind. In order to have interests of the sort we are concerned with when talking about moral status, such as an interest in not experiencing suffering, or in experiencing enjoyment or pleasure, one must be capable of having such experiences in general, in the first place. Conversely, some philosophers, such as Mary Anne Warren understand sentience as implying the capacity for pleasure and pain. She writes: “to be sentient is to be capable of at least some of the many forms of suffering and enjoyment—from simple feelings of pain and pleasure, to more complex emotions, moods, and passions’ (Warren, 1997 pg. 55).

Because I am interested in using sentience as a sufficient condition for moral status, I will understand the concept ‘sentience’ as referring to the capacity to experience suffering or enjoyment. This definition goes slightly beyond the general use of the term as outlined above, because the capacity for subjective experiences does not entail that these experiences are positive or negative. However, using sentience in this more nuanced way nicely captures its moral significance. Causing an individual to suffer is one of the most basic ways of violating its interests—of causing it harm. The experience of suffering is intrinsically bad for the sufferer, just as the experience of enjoyment is intrinsically good, because the experience of suffering, by its very nature, is negatively valenced. Suffering necessarily involves a negative attitude on the part of the sufferer,

towards the suffering. For precisely this reason, individuals who are capable of these sorts of experiences (i.e., who are sentient), have an interest in experiencing enjoyment and avoiding suffering, because suffering is harmful to them, and experiencing enjoyment is beneficial. Moreover, we have an obligation to take into account the interests of those individuals who we may harm or benefit through our actions, because their interests matter, just as ours do.

For example, the experience of suffering is often caused by the experience of physical pain. Typically—although as I shall discuss below, not necessarily—we find the experience of physical pain aversive, disagreeable, or otherwise negatively valenced; it is this fact that makes physical pain a source of suffering, and harmful to the sufferer. Of course, there are other ways in which an individual can suffer, without having to experience physical pain. One might be incapable of experiencing physical pain, but nevertheless suffer from emotional or mental distress. On my understanding of sentience, such a person would nevertheless be considered sentient, because they are capable of suffering. Accordingly, even if it turned out that patients diagnosed as vegetative with covert awareness were incapable of experiencing physical pain, it may nevertheless be the case that they are sentient, if it turns out that they are capable of suffering in other ways.

### **2.3 Sentience and Moral Status: Historical Background**

The idea that the capacity for suffering (or enjoyment) is a sufficient condition for moral status has a long history in western moral philosophy. In his *Introduction to the Principles of Morals and Legislation*, Jeremy Bentham argued that the capacity for

suffering is what grounds an individual's moral status, and the accompanying obligation of others not to violate their interests (Bentham, 1789/2007). The distinguishing quality, Bentham asserts, which obliges us to avoid causing unnecessary suffering, is not whether the individual in question can reason, or has the capacity for language, but whether it can suffer. Any entity with the capacity for suffering thus has morally significant interests, and the accompanying moral status which protects those interests. Accordingly, we have an obligation as moral agents to not simply disregard their interests, but to account for them in our moral decision-making.

Subsequent philosophers, most famously Peter Singer, have refined and expanded on Bentham's call to acknowledge the interests of all sentient beings. According to Singer, equality is a basic ethical principle. When we make moral judgments, we must not do so from a partial or personal perspective, but rather a universal point of view which takes into account not only our own interests, but the interests of all those affected, unless we have a sound reason for doing otherwise (Singer, 2011). Singer points out that each of us has a natural inclination to look after our own interests, which suggests that we would want others to take our interests into account, and not simply disregard them because they are ours and not theirs. Accordingly, if I expect others to universalize their judgments of value (i.e. to give the same weight to my interest in X that they give to their interest in X), then I too must universalize my judgements of value, and take account of the interests of others as important to them, and give them equal weight with my own. Singer claims that this provides us with a basic principle of equality, which he refers to as 'the principle of equal consideration of interests.' This principle requires that the comparable interests of all sentient beings be given equal weight in moral deliberations. It



does not mean that all sentient beings must be treated exactly alike, since different sentient beings may have different needs and interests which must be taken into consideration. It does mean that the moral significance of a being's pains and pleasures does not depend on arbitrary characteristics, such as sex, race, or species: "an interest is an interest, whosever interest it may be." (Singer, 2011 pg. 20)

For Singer, all and only sentient beings have moral status, because all and only sentient beings have interests. The capacity to experience suffering and enjoyment is a prerequisite for having interests at all: "if a being suffers, there can be no moral justification for refusing to take that suffering into consideration...if a being is not capable of suffering, or of experiencing enjoyment or happiness, there is nothing to be taken into account" (Singer, 2011 p. 50). A stone does not have interests because it cannot suffer; there is nothing that we could do to it to affect its welfare in any way. Conversely, a child, or a dog, or a whale, *can* suffer (or experience enjoyment), and so there *is* a way for us to affect its welfare. What Singer is arguing is that the capacity for suffering or enjoyment is a necessary condition for a being's welfare; for a being to have moral status, something must be capable of being good or bad for it—it must be capable of being harmed or benefitted—and something cannot be good or bad for one, unless one is sentient. He does not deny that a being's higher-order interests (e.g. those which require the capacity for self-consciousness) may affect their welfare; indeed, this helps to explain why it is more wrong to kill certain entities than others. However, the violation of higher-order interests is morally wrong for the same reason that the violation of sentient interests is morally wrong; it causes suffering in the individual whose interests are violated.

It is worth mentioning that Singer's consideration of sentient interests is made in the context of a broader utilitarian argument, specifically, preference utilitarianism. Roughly, those with moral status deserve equal consideration of their interests, because the satisfaction of interests is what has utility, and the satisfaction of one individual's interests generates equal utility as the satisfaction of the like interests of any other individual. Thus, from a utility standpoint, all like interests count equally, and so deserve equal consideration. However, subscribing to the notion that moral status requires equal consideration does not also require that one adopt a utilitarian moral theory. As DeGrazia argues, contract theory, libertarianism, and rights-based theories all assume equal consideration, at least to some degree, as well (DeGrazia, 1996). My discussion of Singer's view should not be taken as an endorsement of the view in its entirety. For example, I leave open the possibility that certain special relationships (e.g., between a parent and child) may warrant an unequal consideration of like interests. (Or, a special relationship may simply create an additional interest which would need to be weighed). Similarly, I will not provide an argument that this experience is bad because it fails to maximize overall utility, or because it is a violation of the individual's rights, or because it violates some tenant of a social contract. All that I am arguing for here is that the capacity for suffering or enjoyment (i.e. sentience), is sufficient for moral status, because the experience of suffering is inherently bad—and the experience of enjoyment inherently good—for the person who experiences it. And, the possession of moral status entails that those who possess it cannot have their interests disregarded by others.

## **2.4 Sentience and the Capacity for Interests**

Is it the case that all and only sentient beings are capable of having interests? We sometimes say that someone *has* an interest in something, such as completing a degree, or eating a good meal, insofar as that person wants, desires or cares about that thing. We might also say that something is *in* someone's interest, for example, clean water, friendship, or having a successful career, insofar as that thing has, or may have, a positive impact on the individual's good. Following Tom Regan, we might refer to the first kind of interests as 'preference interests,' and the second as 'welfare interests' (Regan, 2004). As we see from the examples, certain things may be both preference interests and welfare interests (sometimes simultaneously). In fact, depending on one's account of welfare, (e.g. if one thinks that welfare simply consists in the satisfaction of one's desires) one's preference interests and one's welfare interests may overlap considerably. However, it is not necessarily the case that something which is a preference interest is also a welfare interest, or vice versa. For example, I may know that excessive alcohol consumption is not consistent with my welfare, but I may nevertheless desire to do it. Similarly, I may detest visiting my dentist, even though it is in the interest of my welfare to do so.

It seems plausible to suppose that sentient beings have the capacity for both preference and welfare interests, at least on some basic level. Insofar as enjoyment and the absence of suffering are at least partly constitutive of an individual's welfare, sentient beings have welfare interests which can be satisfied or dissatisfied. Similarly, insofar as pleasure and the absence of pain are taken to be desirable, or are typically desired (i.e., something that a being has an interest in), sentient beings have preference interests which can be satisfied or dissatisfied. Of course, avoiding suffering and experiencing enjoyment are only two of a host of possible preference or welfare interests. Indeed, one might be

harmed (i.e., one might have one's preference or welfare interests violated or frustrated), without thereby experiencing suffering, just as one might experience suffering without having been harmed. Accordingly, if a patient diagnosed as vegetative with covert awareness is sentient, it follows from this that they are capable of being harmed or benefitted in one particular way, namely, through the experience of suffering or enjoyment. It *may* be the case that they are also capable of being harmed or benefitted in other ways, depending on what other capacities they retain.

On the other hand, inanimate objects like tables or pots clearly do not have preference or welfare interests, because they both lack desires, and lack a 'good of their own.' But what about non-sentient beings like plants, or ecosystems? While these sorts of entities surely lack preference interests, philosophers like Taylor (Taylor, 1986) and DeVall (DeVall & Sessions, 1985) have argued that entities like plants are teleological systems, and as such do have a 'good of their own.' Accordingly, it would be possible to cause harm to these entities. Similarly, as mentioned above, it has been argued that ecosystems, populations, and species have 'welfare interests', and thus, would be capable of being harmed.

I will not attempt to argue that non-sentient, living things such as plants cannot have a 'good of their own,' and thus cannot have welfare interests, or cannot be harmed. However, when we talk about interests and their connection to moral status, what we seem to have in mind is that violating an individual's interests is morally wrong because the individual whose interests are violated actually experiences the violation as a bad thing. In other words, sentient beings 'mind' when their interests are violated. Non-sentient beings may have needs, and thus a good of their own, but they do not experience

anything positively valenced when these needs are met, or anything unpleasant or aversive when they are not met. While some plants may appear to exhibit patterned behaviours (e.g. a sunflower turning to face the sun, or a Venus Fly-trap closing on an insect), these are entirely unconscious, automatic behaviours. And so, because there is no subject which experiences the various interests which apparently contribute to its overall good, it seems mistaken to speak of a plant as ‘faring better or worse,’ in a way which is morally significant. Because plants and ecosystems do not experience the harms which result from the violation of their putative welfare interests, they do not suffer as a result. While we may sometimes, as a figure of speech, speak as if a plant is ‘yearning for sunlight,’ we know that this is not actually the case, any more than my car could be ‘hoping for an oil change.’ Neither the plant, nor the car, is, was, or ever could be, the subject of experience of any kind. Therefore, nothing can be in its interests, nothing can be ‘good *for it*,’ because there simply is no ‘it’ in the relevant sense that is capable of experiencing the putatively good or bad thing. Arguing whether or not ‘harms’ of the sort which are argued to apply to ecosystems, populations or species are morally wrong is beyond the scope of this paper. For this reason, I will focus on the capacity for suffering and enjoyment as a sufficient condition for moral status, and set aside issues about the potential moral status of non-sentient beings.

## **2.5 Group-Based and Individually-Based Accounts of Moral Status**

The view that sentience is a sufficient condition for moral status can be categorized as an ‘individually-based’ account of moral status. Individually-based accounts hold that moral status depends on the possession of one (or more) intrinsic characteristics. Conversely, group-based accounts hold that moral status does not depend

on the possession of a particular characteristic, but is derived from one's membership in a particular group. Thus, on an individually-based account, possession of the relevant characteristic C is sufficient for moral status (though C may or may not be necessary for moral status), while on a group-based account, all members of the group may have moral status, even though there is no non-relational characteristic which all of them possess.

The majority of group-based accounts of moral status take membership in the human species as sufficient for moral status, although they may ground moral status in different ways. For example, the 'species-based' account of John Finnis holds that membership in the human species is sufficient for moral status because all members of the human species group belong to a kind whose nature it is to possess self-consciousness and rationality (Finnis, 1995; Liao, 2010). Whether a particular individual actually possesses self-consciousness or rationality is irrelevant to whether they have moral status; because these traits are the norm for human beings, every member of the group has moral status simply in virtue of belonging to the group.

Other species-based accounts hold that what makes species membership morally significant is that it is an important relational property. As Thomas Scanlon argues, "the mere fact that a being is 'of human born' provides a strong reason for according it the same status as other humans...it is not a prejudice to hold that our relation to these beings gives us reason to accept the requirement that our actions should be justifiable to them". (Scanlon, 1998 pg. 185) On Scanlon's contractualist account, wrong actions are those which are not justifiable to others; accordingly, the scope of morality is limited to beings with the capacity to hold judgement sensitive attitudes. However, Scanlon asserts, even if a particular human being is severely cognitively disabled, and will never develop even

the limited capacities required for judgement sensitive attitudes, the “tie of birth gives us good reason to want to treat them ‘as human’ despite their limited capacities.” (Scanlon, 1998 pg. 185). Thus, moral status comes from the relation in which any given member of a species stands to all other members; it is this relationship which generates the obligation to treat members in a certain way.

Similarly, Bernard Williams has argued in favor of a view which he refers to as ‘humanism’, according to which membership in the human species is sufficient to ground moral status. However, in contrast to Finnis’ or Scanlon’s view, membership in the human species is significant not because of some property or capacity which human beings typically possess, but because we have a loyalty to, or identity with, members of our own species; we are simply partial to members of our own species, in a way that we are not to members of other species (Williams, 2006). Moreover, this ‘human prejudice’ is justified by the fact that as human beings, we cannot adopt the perspective of what Williams calls an ‘Impartial Observer.’ Rather, we are bound by the very fact that we are human beings to view the world through our own uniquely human perspective (Williams, 2006).

Group-based accounts of moral status are not without their problems. For example, with respect to species-norms accounts, it is not clear why the moral status that comes from having morally significant properties (e.g. self-consciousness, rationality) should also be granted to certain individuals who lack those properties, simply because they are members of the same group (DeGrazia, 1996; McMahan, 2002). Conversely, it is unclear why individuals who do possess these erstwhile morally significant properties should be denied moral status, simply because they are a different species (McMahan,

2002). Additionally, it is not clear from the fact that certain special relations tend to elicit partiality that they also justify partiality, or that species membership even *is* a ‘special relationship’ of a kind that generates moral status (McMahan, 2002). While one’s relationship to others can ground special obligations or justify special treatment in a range of cases (e.g., the relationship between parent and child is often taken to justify partial treatment from the parent to the child), it is not clear that the species relationship grounds such partiality, and if it does, to what extent (McMahan, 2002).

I will not pursue these issues any further here. Insofar as they take membership in the human species to be a sufficient condition for moral status, and not a necessary condition, these species-based accounts of moral status do not conflict with the claim that all sentient beings have moral status. While a sentience-based account of moral status does not grant moral status to non-sentient human beings, it does not rule out that they may have moral status, for other reasons. Similarly, a species-based account does not grant moral status to non-human animals, though it may not necessarily rule out granting them moral status on different grounds. My aim in this chapter is only to show that sentience is a sufficient condition for moral status; accordingly, I will now move on to consider views which are inconsistent with sentience as a sufficient condition for moral status.

## **2.6 Indirect Duty Views**

I argued previously that because sentient beings have interests, they are capable of being wronged by others. Accordingly, we have an obligation to treat sentient beings in certain ways, and avoid treating them in certain ways, because of how our treatment



affects their interests. In other words, we have ‘direct duties’ to sentient beings. Contrary to this view, philosophers such as Immanuel Kant (1980; 1993) have argued that we have only ‘indirect duties’ to merely sentient beings. Indirect duty views with respect to sentient beings hold that we have no obligations to such beings themselves. Rather, our actions with respect to these beings are constrained only by how this may impact the performance of our obligations to those with moral status.

Because Kant believed that we have moral duties only to rational agents, any moral constraints on our treatment of sentient (but non-rational) beings must be in virtue of our duties to those with moral status (Kant, 1980; Kant, 1993). For example, it may be wrong to inflict physical abuse on a child with severe cognitive disability, not because it is morally wrong to cause harm to the child, but because this may cause psychological harm to the parent of the child, who does have moral status. Causing harm to the parents (e.g., by failing to show them adequate respect) is what is morally wrong in this case. Thus, it is only in virtue of our obligations to the child’s parents that we have a duty to avoid harming the child. Similarly, one might argue that cruel actions against those without moral status may foster character traits which make us more likely to act with cruelty towards those who do have moral status. This provides a sufficient reason to treat those without moral status well, not for their own sake, but to decrease the likelihood that we might mistreat those who do count morally (Kant, 1980).

This view is implausible for several reasons. First, it depends for its force on the assumption that one causing harm to those without moral status will make one more likely to cause harm to those with moral status. As Robert Nozick argues, there is no good reason to believe that this sort of ‘undesirable moral spillover’ will actually occur

(Nozick, 1974). Moreover, it seems that inflicting unnecessary harm on those without moral status would be wrong even if spillover were impossible. For example, it seems absurd to suggest that there would be nothing wrong with brutally beating an animal, provided one was the last person on Earth, or was sufficiently isolated from others (Nozick, 1974).

Similarly, the argument that cruelty to those without moral status is wrong because it manifests a bad character, does not seem to fully account for the wrongness of such actions. It seems plausible to suppose that the act of brutally beating a non-human animal, or a person with a severe cognitive disability, manifests a bad character. Yet, as Regan points out, these actions are wrong at least in part because of the suffering experienced by the abused (Regan, 2004). If one argues that the ultimate ground of our duty not to harm those without moral status is the development of virtue, it is unclear why cruelty to those without moral status is a vice—and conversely, why compassion for them is a virtue. If an entity lacks moral status, and so cannot be wronged, there seems to be no difference between an animal and a rock; why should beating an animal reveal or promote a defect in character, any more than smashing a rock with a hammer? The only plausible way to account for the presumed wrongness of causing suffering in another individual is to hold that we have some direct obligation to the suffering being itself, and not simply an indirect obligation to others who may be affected by their suffering. Granting moral status to all sentient beings coheres with our intuition that at least part of what is wrong with causing suffering to another being is that it wrongs them directly.

## **2.7 Alternatives to the Sentience Criterion**

We have seen that adopting a sentience-based criterion for moral status has several advantages. First, it is consistent with our intuitions about the moral status of healthy, adult humans, as well as children and those with severe cognitive disability. Second, it admits of a reasonable justification. Sentient beings have moral status because sentient beings can experience suffering and enjoyment, and thus they can be benefited or harmed by others. Insofar as we agree that it is, *ceterus paribus*, bad to cause unnecessary suffering in others and good to promote others' enjoyment, we ought to take into consideration the interests of all sentient beings.

A sentience-based criterion for moral status is not the only possible condition for moral status. Why shouldn't we accept one (or more) of the other available theories? I have argued to this point that sentience is a sufficient condition for moral status; I leave open the possibility that there are other ways an entity might merit moral status. However, some theories of moral status are inconsistent with the view that sentience is sufficient for moral status, in that they consider other capacities to be *necessary* for moral status. In the next section, I will examine the most prominent of these views, and argue that there are serious difficulties with holding that the capacities implicated are necessary conditions for moral status.

### ***2.7.1 Sophisticated Cognitive Capacities***

One of the most popularly cited conditions for moral status is the possession of sophisticated cognitive capacities. These capacities may include autonomy, practical rationality, self-awareness, awareness of oneself as a continuing subject of mental states, being future-oriented in one's plans and desires, and having the capacity to care for others (Tooley 1972; Quinn, 1984; Feinberg, 1980; McMahan, 2002). While each of

these conditions may pick out different subsets of the human population, they share the idea that the feature which grounds moral status is non-relational and does not require the active participation of another person. An individual has moral status because they can engage in certain cognitively sophisticated acts or responses on their own.

There are a few ways that the possession of sophisticated cognitive capacities is argued to ground moral status. First, these capacities may confer moral status insofar as they make it possible for individuals to have interests and desires, which should *prima facie* be respected by others. It is because people are conscious, are future-oriented in their plans, experience emotions, and so forth that they have values and interests (Tooley, 1972; Quinn, 1984; McMahan, 2002). On this conception, it is only because of their sense of self, their life-plans, and their stakes in their own futures that people can be ascribed the fundamental rights which accompany moral status. This justification for moral status is quite similar in form to the sentience-based criterion. Because an individual has a certain capacity, this gives rise to morally significant interests. Sentience is a capacity which allows entities to have certain kind of interests, (e.g. experiencing pleasure and avoiding pain). Conversely, sophisticated cognitive capacities allow individuals to have more cognitively demanding kinds of interests, such as satisfying certain goals or life-plans. According to these views, it is not the capacity for sentience that makes us ‘persons’; it is the capacity for consciousness, personal identity, rationality, autonomy, and other sophisticated cognitive capacities which make us persons, and allows us to have the kinds of values and interests which it is morally wrong to violate.

Second, one might adopt a broadly Kantian account, where the possession of sophisticated cognitive capacities, specifically, an autonomous will, may be understood

as conferring on their bearers a certain dignity (Kant, 1993). For Kant, there is something inherently valuable about being the sort of being who can determine her own will in accordance with the moral law; all and only beings with this capacity are moral agents, and all and only these beings are entitled to consideration of their interests. The possession of these sophisticated cognitive capacities requires that others demonstrate proper respect for the individual's autonomy, by treating them always as an end and never as a mere means.

Third, the possession of sophisticated cognitive capacities may be viewed as requirements for participation in a community of moral equals. On this sort of account, associated with contractualism, the possession of sophisticated cognitive capacities is not in and of itself worthy of respect and consideration. Rather, the possession of sophisticated cognitive capacities allows their possessors to enter into relationships with others that are characterized by mutual recognition and respect. Roughly speaking, contractualism derives moral actions from what members of a moral community would agree to; a wrong action is one which could not be justified to other members of the moral community, provided they are reasoning in the appropriate way. The possession of sophisticated cognitive capacities is necessary for membership in a moral community, because these capacities allow us to act according to reasons that others could not reasonably reject, and to see others as worthy of recognition and respect.

A similar, though not necessarily contractualist, justification for grounding moral status in the possession of sophisticated cognitive capacities is based on what DeGrazia calls the 'principle of reciprocity.' (DeGrazia, 1996) According to this principle, A cannot have moral obligations to B, unless B also has moral obligations to A. Having

moral obligations to others is often burdensome; it may restrict one's freedom, or require one to forego certain benefits. Accordingly, it would be unfair for some to bear this burden for the benefit of others, unless those others bore a similar burden for their benefit. Insofar as the possession of sophisticated cognitive capacities is necessary in order to carry out moral obligations to others, only entities with such capacities can have moral status.

### ***2.7.2 Objections to Sophisticated Cognitive Capacity Views***

Do these attempts at justifying the sophisticated cognitive capacity criterion pass muster? It is not clear that they do. First, it is not obvious how moral agency is relevant to moral status. On the one hand, the Kantian argument given above suggests that all and only moral agents have dignity, which in turn gives them moral status, such that their interests carry more weight than the relevantly similar interests of those without moral status. But as DeGrazia points out, to have 'dignity' just seems to mean that one is the kind of being that has moral status; it is not a fact about an agent that merits moral status, but is rather simply an announcement of one's moral status (DeGrazia, 1996). Thus, if dignity is merely a reflection of one's moral agency (and is not a separate, morally relevant fact), the claim that all and *only* those with sophisticated cognitive capacities have moral status, because all and only those with sophisticated cognitive capacities have 'dignity', simply begs the question.

On the other hand, those who support a sophisticated cognitive capacity view might argue that it is the capacity for consciousness, personal identity, rationality, autonomy, and other sophisticated cognitive capacities which give rise to the kinds of interests it is morally wrong to violate. I am not arguing that moral agency is irrelevant to

moral status. Indeed, it seems quite reasonable to suppose that a capacity such as rationality might give rise to certain kinds of interests or obligations, such as the obligation of others to respect my rationality and treat me always as an end and never a mere means. Moreover, if moral agency can affect what sort of interests a being has, the fact that one being is a moral agent and the other is not may justify treating moral agents differently than non-agents, in certain circumstances.

What is at issue is whether to accord the same moral weight to the relevantly similar interests of both moral agents and non-agents (i.e. whether moral agency is a necessary condition for moral status). If A is a moral agent, and B is not, and both undergo a relevantly similar pain experience, why should the fact that A is a moral agent give greater moral weight to A's pain experience than B's? While moral agency does seem relevant to what kind of interests a being might have, it seems irrelevant to how those interests which are equal between A and B ought to be weighed. The fact that sophisticated cognitive capacities are morally relevant gives us no reason to think that sentient interests, whether accompanied by moral agency or not, are morally *irrelevant*. Indeed, if it is only the interests which emerge from sophisticated cognitive capacities that are morally significant, then violating an individual's merely sentient interests would only be wrong insofar as it also violated an individual's rationality, or autonomy, for example. This seems implausible. Surely, at least part of what is bad about causing someone to suffer is that it violates their interest in not suffering.

Similarly, the argument from reciprocity also fails to demonstrate the necessity of sophisticated cognitive capacities to moral status. On the one hand, this argument is highly unintuitive. Infants and young children seem to be the recipients of some duties,

while being unable to reciprocate them, yet we nevertheless feel as though infants and young children deserve moral status. On the other hand, it is unclear that the principle of reciprocity can be grounded in a sense of fairness. As DeGrazia argues, it begs the question to argue that moral agents cannot have duties to beings that cannot reciprocate, in advance of working out our moral relationships with these entities (DeGrazia, 1996). For example, a sense of fairness does not seem to prevent us from having certain duties to human infants, even those who lack the potential to ever reciprocate.

Nevertheless, the sophisticated cognitive capacity criterion faces a much more difficult problem. If moral status is determined by possession of sophisticated cognitive capacities, it is likely that many humans, including the severely cognitively disabled, infants and perhaps even very young children, lacking in sophisticated cognitive capacities as they are, will thus lack moral status. This problem is often referred to as ‘the problem of marginal cases.’

### ***2.7.3 The Problem of Marginal Cases***

The idea that some human beings, including infants, young children, and those with severe cognitive disability, lack moral status, and thus, are not entitled to the same consideration of their interests as others, is highly problematic. If these individuals lack moral status, virtually any kind of treatment of them would be morally acceptable. For example, it would seem to imply the permissibility of subjecting severely cognitively disabled individuals to any research for which the use of animals is currently viewed as appropriate. According to sophisticated-cognitive capacities views, (most) non-human animals lack moral status, and thus subjecting them to experimentation which may cause them a great deal of pain, or result in their death, is a permissible violation of their



interests, in a way that experimenting on a human being would not be. However, if certain humans lack moral status, we would not be wronging them by violating their interests through painful medical experimentation. Moreover, if sophisticated cognitive capacities are necessary for moral status, there would seem to be no moral difference between a child, a dog, and a baseball; we would not wrong any of them by striking them with a bat. This is clearly an unacceptable consequence.

Proponents of a sophisticated cognitive capacities criterion for moral status need not be forced to accept that harming or killing infants or young children is morally permissible, however. Even if the killing of infants or young children is not a violation of their moral status, it may nevertheless be wrong and justifiably prohibited on other grounds. One might argue that there are strong utilitarian reasons for adopting moral rules condemning infanticide; it would be disrespectful and harmful to the child's parents, it might cause psychological harm to the killer or the community, etc. Nevertheless, these are not reasons for the child's own sake; the wrong being committed in harming or killing an infant or young child is not one done directly to the child on this account. Indeed, this is essentially to argue that we have indirect duties to infants and small children, and deny that they themselves have moral status.

A further challenge for the sophisticated cognitive capacity criterion of moral status is to provide a morally significant attribute or capacity that is consistent with moral status as a threshold and range concept. Most psychological or cognitive capacities viewed as grounding moral status come in degrees, and undergo continuous development, at least early in life. Indeed, the cognitive capacities which make up moral agency (or rationality, or autonomy), are often found, to some degree, in non-human mammals.

Cognitive capacities like autonomy and rationality are not ‘all-or-nothing.’ Conversely, the possession of moral status is taken to be categorical. Thus, it is unclear at what stage of the development of a morally significant attribute or capacity this capacity grants moral status. Similarly, some explanation is required for why possession of a particular capacity, above a certain threshold, grants moral status, while the degrees to which an individual is able to exercise that capacity beyond the threshold are irrelevant to moral status. For example, if the capacity to exercise one’s rationality is taken to grant moral status above a certain threshold (i.e., one must possess a certain level of rationality in order to have moral status), advocates of the sophisticated cognitive capacity view would need to explain why those who are able to exercise their rationality better than others do not thereby have greater moral status.

One might argue that even if certain individuals lack the moral-status conferring attribute, we nevertheless ought to treat them as if they have moral status. For example, certain accounts of moral status claim that an individual’s moral status can also be derived from their relationships with others who do have full moral status. Thus, an individual with a severe cognitive disability would have moral status not because they possess a moral status-conferring attribute, but because of their relationship to other individuals who do possess such an attribute—specifically, family and close friends—a relationship which generates a duty of partiality. (For an overview, see McMahan, 2002). On some versions of this account, the individual has moral status only for those with whom they have the relationship; others do not need to treat them as if they have moral status (though they must respect the obligation of the individual’s family to do so.) On other versions of this account, the individual with the severe cognitive disability does not

have moral status even for close relations, although these relations must treat them *as if* they have moral status (McMahan, 2002).

The justification for treating these individuals as having ‘derivative moral status’ is that the nature of the familial relationship is such that it creates certain moral obligations. However, there are several difficulties with this sort of view. First, it may imply that individuals with severe cognitive disabilities do not have moral status for all other human beings. On the one hand, if derived moral status can only arise from close familial relationships, an individual with a severe cognitive disability will only have moral status for a limited number of people. Conversely, if moral status can be derived from a much more ubiquitous relationship, such as being a fellow human being (akin to the sort of group-based accounts discussed earlier), it is less plausible that such a relationship should be considered morally significant, such that an individual’s moral status can be derived from it.

Second, derivative moral status makes the moral status of individuals with severe cognitive disabilities dependant on certain contingencies, namely, the existence of the relationship in question. Suppose that an individual’s family passed away, or disowned them, such that they no longer had a familial relationship with anyone. It would seem to follow that this individual would no longer have moral status, a consequence which seems highly problematic. Insofar as the moral status of a healthy, adult human is based on some moral-status conferring attribute that they themselves possess, their moral status is not contingent on the existence of any other individual or relationship. Conversely, the ‘derivative’ moral status of individuals with severe cognitive disability would be so

contingent. Any theory of moral status which can avoid this problem has a strong advantage over theories which entail it.

#### ***2.7.4 Potential for Sophisticated Cognitive Capacities***

Might we resolve these difficulties, and salvage the sophisticated cognitive capacity criterion? One possible strategy is to identify a less restrictive criterion for moral status, one which includes a wider range of humanity. For example, we might amend the sophisticated cognitive capacity criterion to include those entities with the *potential* to develop sophisticated cognitive capacities. On this sort of account, all those who actually possess sophisticated cognitive capacities (or some other moral status conferring attribute), or have the potential to develop them, will have equal moral status. For example, the fact that a zygote or a developing fetus is a potential human being is often argued to grant it the moral status of an actual human being (Stone, 1987; Marquis, 1989). Expanding the criterion for moral status to include those who potentially possess sophisticated cognitive capacities would allow for the inclusion of entities like infants and young children, and so at least partially resolve the problem of marginal cases.

#### ***2.7.5 Objections to Potentiality Views***

Unfortunately, introducing the notion of potentiality creates a new set of issues. First, it is not clear that the potential possession of a moral status conferring attribute should result in the possession of moral status. Joel Feinberg has famously argued that it is a 'logical error' to deduce actual rights from merely potential qualification of those rights. For example, the fact that a small child has the potential to one day have a driver's license does not give them the right to operate a motor vehicle now (Feinberg, 1986).

John Pogue has argued that ‘the potentialist’ (his term for one who supports a potentiality criterion for moral status) does not commit the logical error Feinberg claims (Pogue, 1998). The potentialist is committed to the following claim: all individuals with sophisticated cognitive capacities, or with the potential for sophisticated cognitive capacities, have actual moral status. Feinberg’s objection is that “what follows from potential qualification, is potential, not actual, rights; what entails actual rights is actual, not potential, qualification.” (Feinberg, 1980, p. 266) Thus, if the potentialist is claiming that the possession of sophisticated cognitive capacities is what gives an individual moral status, then Feinberg is correct that the mere potential for sophisticated cognitive capacities (i.e. the mere potential for satisfying the criterion) does not entail moral status. However, as Pogue points out, this is not what the potentialist is arguing. Rather, the potentialist is claiming that the potential for sophisticated cognitive capacities is itself the criterion for moral status; thus, the claim that an individual who potentially has sophisticated cognitive capacities is an actual moral person is not a logical error (Pogue, 1998).

Perhaps what Feinberg is arguing is simply that the *potential* for sophisticated cognitive capacities cannot be a criterion for *actual* moral personhood (although if this is what Feinberg is arguing, it is unclear that this is a ‘logical error’). In other words, the justification for according special treatment to those with certain kinds of potential does not simply follow from the moral significance of the actualized potential. Some argument must be given to explain the moral significance of the potential for sophisticated cognitive capacities.

One attempt at such an argument is given by Stone. Stone (1987) argues that moral status is grounded in an individual's biological nature. Insofar as it is in an individual's nature to develop sophisticated cognitive capacities—that this being now is the same being as the one which will have sophisticated cognitive capacities in the future, if its biological nature is actualized—then this individual currently has moral status, because its future self does (Stone, 1987). Because actualizing its nature (i.e., realizing its sophisticated cognitive capacities) is good for the individual when it occurs, we have a *prima facie* obligation to protect the interests of the individual prior to this point (i.e., to grant it moral status), so that it can actualize its nature (Stone, 1987).

The concept of an individual's nature is critical to a potentiality argument like that made by Stone. It is because the development of sophisticated cognitive capacities is argued to be in an individual's nature that they have moral status, even though they do not possess those cognitive capacities currently. However, as John Fischer argues, an individual's 'biological nature' is much broader than Stone seems to think (Fischer, 1994). Specifically, it might be in an individual's biological nature to develop sophisticated cognitive capacities, while simultaneously be in an individual's biological nature not to develop sophisticated cognitive capacities. Because of the broad range of potentialities which exist in an individual's nature, Fischer argues, we cannot assign moral status to an individual simply because they may actualize one of those potentialities, when any of the other potentialities would be identical with them as well (Fischer, 1994).

Alternatively, Elizabeth Harman has argued that an individual's potential for sophisticated cognitive capacities may not itself grant moral status, but nevertheless, may

enhance the moral status of the individual, such that causing that individual harm is morally worse than harming an individual without enhanced moral status. Causing harm to an infant is morally worse than causing harm to a cat, the argument goes, not because the infant has greater moral status *per se*, but because the infant has greater potential for sophisticated cognitive capacities, and so, can be harmed in ways that the cat cannot. Again, however, the potential for sophisticated cognitive capacities is not what grants the individual moral status; Harman's view still requires some appeal to the intrinsic properties of the individual to ground their moral status (which for her, is the fact that an individual is conscious) (Harman, 2003).

Even if these difficulties can be resolved, the potentiality criterion for moral status may still be regarded as underinclusive. Many individuals with severe cognitive disabilities not only lack sophisticated cognitive capacities, but also the potential to ever possess them. Conversely, a sentience-based criterion avoids many of the problems associated with marginal cases, while also providing a criterion consistent with the threshold and range concept of moral status.

### ***2.7.6 Ethical Egoism***

Narveson (1977; 1986) has also argued that sentience is not sufficient for moral status. Although primarily an objection to arguments in favor of ascribing rights to non-human animals, Narveson's claims have distinct consequences about the moral status of humans as well, specifically, the moral status of those with severe cognitive disability, infants and young children, or, especially relevant to my argument, patients with disorders of consciousness. Importantly, Narveson does not claim that entities like non-human animals are incapable of suffering (i.e., that they are not sentient). He argues

instead that their suffering does not matter. In other words, the fact that they are sentient is not sufficient to justify concern for their interests, which is equivalent to the denial that sentience is sufficient for moral status.

Narveson adopts a broadly egoist account of morality, and argues that this view provides a reasonable explanation for our common-sense morality (specifically, our moral obligations to other humans, but not to non-human animals). Ethical egoism holds that we ought to act exclusively in our own self-interest. While it does not forbid acting in ways which satisfy the interests of others, the theory insists that what makes an act right is that it is to our own advantage. Narveson points out that it is in our self-interest that others refrain from causing harm to us, and that it is in others' self-interest for us to refrain from harming them. How best to pursue our self-interest in this case? If we make a habit of causing harm to others (or otherwise acting in ways contrary to their interests), people will likely be less inclined to avoid causing harm to us. Thus, it is to our advantage to avoid causing harm to others; by the same token, it is to others' advantage to avoid causing harm to us. For Narveson, our moral obligations to others are simply agreements which we have a self-interested reason to respect; we treat others as having moral status because it is in our self-interest to do so.

Of course, it follows from the ethical egoist's position that if an individual is incapable of entering into agreements of mutual advantage, they cannot be part of the moral community, and thus, we cannot have any direct moral duties to them. This means that even if an individual has an interest in not being harmed by us, if we cannot be harmed by that individual, it is not in our self-interest to restrict our behaviour towards them, because we simply have nothing to gain by it. Indeed, Narveson argues that non-



agents, “may not have enough to offer us to make it a good deal from our point of view to modify our antecedent line of behaviour with respect to them—which is, roughly, to do whatever seems to serve our advantage best, regardless of its effect on them” (Narveson, 1986 p. 201). It would fail to maximize my utility, as a rational egoist, to circumscribe my behaviour with respect to non-agents, because doing so would not provide me a concurrent benefit, which would offset this sacrifice. While we have strong self-interested reasons to circumscribe our behaviour with respect to other rational beings, we do not have any such reasons to do so with respect to non-agents.

A consequence of Narveson’s account is that non-agents like infants, young children, or those with severe cognitive disabilities, are, like animals, outside the boundaries of moral concern; they cannot have moral status, because they lack the rational capacities necessary to form agreements of mutual advantage with rational agents. However, Narveson argues that we still have ‘indirect duties’ to these kinds of individuals. First, he claims that we want to extend the scope of morality to encompass infants and children because most of us have an interest in our own children being protected, and stand to lose very little by extending this protection to the children of others. Moreover, we have an interest in the children of others being properly cared for, because these children will eventually become adults, who are able to affect our interests (e.g., they may be our future caretakers, or they may become criminals). Second, we want the interests of those with severe cognitive impairments to be protected, because we may one day find ourselves in a similar position, and would want our interests protected. Further, Narveson claims, we might have a sentimental interest in these individuals, such that it would be in our interest that they are taken care of. And, because in the vast

majority of cases these individuals will have someone who has a sentimental interest in their welfare, and because we would likely have very little to gain by treating these individuals badly, we ought to treat them as though they have moral status. In the case of patients diagnosed as vegetative with covert awareness, for example, some individuals may have sentimental reasons for ensuring that the interests of these patients are protected (though they just as easily may lack these reasons). However, we have no direct obligations to these patients; insofar as these patients lack rationality, they are outside the moral community, and we have no reason for taking their interests into account, other than because doing so best serves *our* interests.

### ***2.7.7 Objections to Ethical Egoism***

Is Narveson's position adequate? There are several reasons for thinking that it is not. To begin with, it seems false that protecting the interests of marginal cases such as the severely cognitively disabled or infants can always be justified by an appeal to self-interest. For example, Narveson argues that one of the reasons why the interests of those with severe cognitive disabilities should be protected is because we (as rational agents) might one day develop severe cognitive disabilities, and it would not be in our self-interest to enter into agreements in which the interests of these patients are not protected. Yet it does not follow from this that the rational egoist has a reason for ensuring that the interests of *all* individuals with severe cognitive disabilities are protected. Specifically, if an individual is born with a severe cognitive disability, or develops this disability prior to the time they become a rational agent, it would not be in the self-interest of a rational egoist to protect *their* interests, because the rational egoist could never find themselves in

*that* sort of situation. Because all the rational egoist is trying to do is maximize his own interest, he has no reason to protect against outcomes which are no longer possible.

Similarly, the fact that we may have sentimental interests with respect to various non-agents is not sufficient to ensure that the interests of these individuals are protected. Indeed, the protection of their interests is contingent on the fact that we do, in fact, have these sentimental interests towards them. And it is certainly possible, albeit highly regrettable, that some infants, children, or those with severe cognitive disability, may lack the sentimental interests of others. In this sort of case, no appeal to self-interest can be made to protect the interests of the infant, child, or individual with a severe cognitive disability. Thus, it seems that the rational egoist would have no reason to protect the interests of that individual; this seems to be a defect with this sort of view.

As these examples show, protecting the interests of so-called ‘marginal cases’ cannot always be justified by appeal to individual self-interest. Conversely, if we adopt sentience as a sufficient condition for moral status, it follows that we have a direct duty to these marginal cases, as well as normal, healthy individuals, to respect their interests. Their interests in avoiding suffering/experiencing enjoyment matter for their own sake, just as our interests do.

Finally, in an argument most famously proffered by James Rachels, ethical egoism is susceptible to the criticism that it is essentially an arbitrary moral doctrine (Rachels, 1986). Insofar as it advocates that the individual act always to maximize their own self-interest, it requires that we place our own interests above the interests of all other individuals. But, as Rachels incisively asks, why should we think that it is morally required that we do this? What is the morally significant difference between me, and any

other individual, that can justify me placing my interests before theirs? I care very greatly about my own interests, because of how their satisfaction or frustration affects my welfare. Yet the satisfaction or frustration of the interests of others affects their welfare in (more or less) the same way. My interests are no more important to me than someone else's interests are to them; if my needs should be met, so too should theirs. In the absence of some relevant difference between myself and others which can justify the difference in treatment required by ethical egoism, it seems we must reject the theory, on the grounds of its being arbitrary (Rachels, 1986).

Indeed, this is essentially the justification used at the beginning of the chapter in support of sentience as a sufficient condition for moral status. I recognize that I have certain interests (e.g., an interest in not suffering) which affect my welfare, and this justifies others' taking my interests into account. It follows then, that if my interests should be taken into consideration by others, so too should I take into consideration the interests of others. Sentience provides one example of an interest which others have an obligation to respect, and this is why sentience is a sufficient condition for moral status. The ethical egoist claims that I only have an obligation to respect the interests of others if doing so is in my own interest; it holds that *my* interests are more important than others'. And it is on these grounds that Narveson argues we have no direct obligations to so-called 'marginal cases'; taking their interests into account is not required by my self-interest. However, we have seen that ethical egoism is susceptible to a serious objection, namely, that it is arbitrary. Insofar as an individual is capable of suffering or enjoyment, it has interests which must be given proper consideration. Whether or not this maximizes our self-interest is irrelevant, at least from a moral point of view. Correspondingly,

Narveson's argument against adopting sentience as a sufficient condition for moral status fails.

## 2.8 Summary

In this chapter, I have argued that sentience—the capacity to experience suffering and enjoyment—is a sufficient condition for moral status. Because sentient individuals have at least *one* kind of morally significant interest (i.e., an interest in experiencing enjoyment, or in avoiding suffering), they are capable of being harmed or benefitted by others through the violation or promotion of these interests. This capacity to be harmed or benefitted by others is what entitles sentient beings to moral status, which in turn requires others to take their interests seriously. I have argued that because all sentient beings have interests, sentience is a sufficient condition for moral status; I have left open whether or not there are other sufficient conditions for moral status. I have also argued that it is *prima facie* reasonable to claim that it is morally wrong to cause an individual to suffer: since my suffering is bad for me, I feel that others should not cause me to suffer; the fact that someone else's suffering is bad for them means that I should avoid causing them to suffer. The sentience criterion for moral status captures this idea. Finally, I have considered alternative accounts of moral status, which are inconsistent with the sentience criterion, and shown that these views are problematic. Having argued that sentience is a sufficient condition for moral status, I now turn to the question of whether patients diagnosed as vegetative with covert awareness satisfy this criterion, and are thus deserving of moral status.

### **Chapter 3: Sentience in Patients Diagnosed as Vegetative With Covert Awareness**

In the previous chapter, I argued that sentience—the capacity for enjoyment and/or suffering—is a sufficient condition for moral status. Because sentient beings have at least one kind of interest (namely, an interest in avoiding suffering, or experiencing enjoyment), it is possible for others to morally wrong them by violating this interest. Because they are the kinds of beings that can be wronged, others have an obligation to give appropriate consideration to their interests when acting. I concluded the chapter by suggesting that if a patient diagnosed as vegetative with covert awareness is sentient, or if we have good reason for believing that they are sentient, then he or she has moral status. In this chapter, I will demonstrate that we do in fact have good reason to believe that patients diagnosed as vegetative with covert awareness are sentient, or at least should be treated as such. Accordingly, we have an obligation to respect their interests.

How can we determine if patients diagnosed as vegetative with covert awareness are capable of suffering? The nature of suffering makes this somewhat challenging. As Eric Cassell points out, “the only way to learn what damage is sufficient to cause suffering, or whether suffering is present, is to ask the sufferer” (Cassell, 1982). This means that, for patients who are incapable of communication, we cannot assess their capacity for suffering directly; it must be inferred by other means. I propose that we might draw this inference by appealing to a distinct phenomenon, which nevertheless is often closely linked to the experience of suffering, namely, the experience of physical pain. I argue that if it can be shown that these patients are capable of experiencing physical pain, this constitutes good evidence that they are capable of suffering as well, and thus, should be treated as having moral status. My argument will proceed as follows.

First, I will give an account of the physiological nature of physical pain, and illustrate how the presence of physical pain is a good *prima facie* indicator of the presence of suffering. I will then provide evidence to support the claim that patients diagnosed as vegetative with covert awareness are capable of experiencing physical pain—specifically, the aspect of physical pain which typically implies the presence of suffering—and therefore, that they are very likely capable of suffering. Given this evidence of the capacity for suffering in these patients, I will argue that we ought to treat these patients as sentient, and thus, as having moral status.

### **3.1 The Physiological Nature of Pain**

In spite of its familiarity, providing a definition of pain is a rather difficult task. There are many seemingly disparate experiences one might describe as painful: the sharp, stinging, pain of a cut finger; the dull, throbbing pain of a headache; the mild ache of a strained muscle; or the agony of a broken bone. While we may sometimes refer to emotional or mental ‘pains’ as well, such as the pain of depression, loneliness, or anxiety, I understand ‘emotional pain’ or ‘mental pain’ to be referring to something other than ‘pain’ in the literal sense. Generally speaking, most instances of pain have an organic basis, usually (though not exclusively) some threat or damage to bodily tissue. In what follows, I will restrict my talk of pain to physical pain, that is, pain which is felt as the result of bodily injury or disease. This is not to diminish the potential importance of emotional or mental distress as a factor in patient welfare. Indeed, as I will discuss in chapters four and five, if patients diagnosed as vegetative with covert awareness are capable of experiencing emotional or mental distress, this may severely impact their overall welfare. Moreover, given my definition of sentience from the previous chapter, if

it is the case that patients diagnosed as vegetative with covert awareness are incapable of experiencing suffering as a result of physical pain, they may nevertheless be sentient if they experience suffering as a result of mental or emotional ‘pain’. Sentience is simply the capacity for the experience of suffering or enjoyment, and suffering as a result of physical pain is merely one of many kinds of possible suffering. For present purposes, however, I need only to show that these patients are capable of suffering as a result of physical pain, because the capacity for suffering as a result of physical pain is sufficient to show that these patients are capable of suffering in general, and thus, that they have moral status.

How are we to understand the nature of something as familiar as physical pain? There seem to be two important components to our common-sense understanding. On the one hand, a pain is typically understood as being a bodily sensation, of a particular character. As in the examples given above, we can describe various sensory aspects of our painful experience, such as its intensity, its duration, its (general) location, and other features which we might use to classify it as pain of a particular kind (e.g., an ache rather than a twinge.) Additionally, these physical sensations may be external (e.g., pressure, temperature) or internal (e.g., aching, throbbing). Thus, pains are particular conditions of body parts, and have certain spatiotemporal characteristics (e.g., ‘there is a pain *in* my right hand’). When we say that we are in pain, we are reporting on this perceptual experience, just as we report on a visual perceptual experience when we report that we see an apple on the table (Aydede, 2005).

It is important to draw a distinction between the sensory experience of pain, and an entirely different, though often concomitant, phenomenon known as nociception.



Nociception is the encoding and processing of potentially tissue-damaging stimuli by afferent (sensory) neurons in the peripheral and central nervous system. When specialized free nerve endings, called ‘nociceptors’, reach a certain threshold of stimulation, they send a signal along a chain of nerve fibers via the spinal cord to the brain, signalling the presence of noxious stimuli (such as chemical, mechanical, or thermal stimulation). The detection of noxious stimuli generates a series of automatic responses, and is often, though not necessarily, accompanied by a particular sensation (Schmidt, 2007). Thus, nociception is necessary for pain perception, but will not always lead to a conscious experience of pain, while pain, by definition, must be consciously experienced. I will return to this point, as it pertains to patients in the vegetative state.

On the other hand, pain also seems to have an affective aspect as well. A painful experience feels unpleasant, or aversive. However, apparently unlike other sensory experiences, our experience of pain is logically private, subjective, and about which we cannot be mistaken. It is logically private insofar as no one can access my pain in the way that I can (i.e., by feeling it), which differentiates pains from other objects of perception, such as apples on tables. It is subjective in that it depends for its existence on my actually feeling it. Finally, if I feel that I am in pain, or believe that I am in pain, then I am in pain. Understood in this way, rather than being *objects* of perceptual experience, pains just are experiences *themselves*. And, unlike other perceptual experiences, which are liable to error (i.e., because my perception of an object is different from the way the object is in reality), the ‘true’ nature of pain just is the experience of it. When I say that I have a pain in my hand, the fact that there is, say, no physical damage to my hand does not render my statement about the pain in my hand false, because the ‘pain’ just is the unpleasant

feeling that I experience. While I might be wrong about the organic cause of my pain (I may think the bone is broken when it is not), this does not affect the reality of my pain experience, or its potential effect on my welfare (Aydede, 2005).

Furthermore, our experience of physical pain can be significantly affected by contextual factors, including the meaning we ascribe to it. Physical pain typically becomes worse when it is perceived as inevitable or intractable; on the other hand, we often experience physical pain as less intense when we have some degree of control over it, or perceive it as a means to some desired end (Pellino & Ward, 1998; Price & Bushnell, 2004).

### **3.2 Dimensions of Pain Experience**

How then should we characterize pain? First, we might think that ‘pain’ is simply the characteristic sensation itself. Is it then possible to enjoy pain, or at least not be averse to it? If so, then it seems possible that even the most intense pains might be liked just for the way they feel. Yet this seems at odds with our common-sense notion of pain; there seems to be some essential connection between the experience of pain, and a disposition to avoid it, or find it aversive. Moreover, if pain is simply a kind of sensation, with no intrinsic affective component, what kind of sensation is pain? What particular characteristic makes one sensory experience, and not another, a ‘pain’? And, if pain is merely a characteristic sensation, we will have to abandon the intuition that pain is intrinsically aversive, and that the aversiveness of pain is a function of the internal qualities of the sensation (i.e., that more intense pain is more detrimental to our welfare), because a ‘painful’ sensation is not *necessarily* aversive.

Second, we might think that the essence of ‘pain’ is its affective quality, what makes something painful is just that we tend to have a feeling of aversion to it, desire that it cease, or find it unpleasant. However, if this is the case, it is unclear how we are to distinguish between genuine ‘pains’, (i.e., paradigmatically painful sensations, such as the sensation which arises from burning or cutting one’s skin, breaking a bone, or having a migraine), and other physical sensations that also have a negative affective quality, such as itches, nausea, dizziness, fatigue, and the like, which seem to be something other than pain. Moreover, some explanation must be given for cases in which individuals claim to be in pain, but do not mind it. For example, Rainville, Carrier, Hofbauer, Bushnell, and Duncan (1999) describe patients under hypnosis, who reported increases in pain intensity, without concurrent increases in pain unpleasantness. Similarly, historical accounts of the use of lobotomy for patients suffering from intense pain often describe the purpose of the procedure as addressing the ‘emotional substrate of continued pain’, rather than the perception of pain itself (Raz, 2009). Are these individuals, then, not actually in pain?

One attempt at responding to this conflict has been to argue that pain consists of both a sensory component *and* an affective component: one senses a particular stimulus and finds the sensation unpleasant. Neither of these components, taken on its own, provides an exhaustive model of pain. Rather, each is a dimension of the experience of pain. For example, Clark (2005) has argued that typical bodily pain engages our motivations by arousing an aversion in one or another of our desires, drives, interests, preferences—which may or may not manifest itself in behaviour—while also having a distinct sensory character. He asserts that while the qualities sensed and the accompanying painfulness experienced are not always distinguished, they are logically

distinct. Thus, there is a strong, but nevertheless contingent, connection between the sensory dimension of pain, and the affective-motivational dimension of pain (Clark, 2005). Our ordinary concept of pain refers to a combination of both; usually, this doesn't present any problems in our understanding, because both dimensions occur together most of the time. Yet, there are instances in which these dimensions seem to come apart, such as when a patient on opiates states that she can still feel a burning pain in her leg, but it no longer bothers her. Is this patient 'in pain?' In this case, we should say that the patient is experiencing one aspect of pain, (the sensory) but not the other (the affective-motivational). We can see this understanding of pain as consisting of a sensory and affective component in the definition of pain provided by the IASP: "[Pain is] an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (IASP, 2011). If this understanding of pain is correct, however, the 'badness' of pain (i.e. the aspect of pain which causes us to *suffer*) is the affective-motivational aspect.

This conception of pain as a multi-dimensional experience seems to be supported by neurophysiological evidence. The classic view of our basic pain system comprises two largely segregated subsystems, referred to as the 'pain matrix': the lateral neuronal network and the medial neuronal network (Iannetti & Mouraux, 2010). These networks correspond to the sensory-discriminative and affective-motivational dimensions of pain and thus provide the likely neural correlates for the different elements thereof. Each subsystem has a set of neurons in the dorsal root ganglion of the spinal column, which take information from the periphery, and then synapse with a second set of neurons in the dorsal horn. This second set of neurons runs out of the spinal column, some terminating

in the reticular formation of the brain stem, and some in the thalamus. Finally, a third set of neurons projects from the thalamus to the postcentral gyrus in the cerebral cortex.

The lateral neuronal network encodes sensory-discriminative information, and generates an individual's sense of the location, intensity, duration, and nature of painful stimuli. This network is composed of nociceptors called A-delta fibres, myelinated neurons which transmit information rapidly along the network from the spinal column, to the midbrain (i.e., periaqueductal matter) and ventroposterior lateral nucleus of the thalamus (Mutschler, Wankerl, Seifritz, & Ball, 2011). From there, nociceptive information is transmitted to the primary (S1) and the secondary somatosensory (S2) cortex, as well as the posterior insula (Mutschler, Wankerl, Seifritz, & Ball, 2011). These nociceptors transmit what is known as 'fast pain', and remain active only as long as nerve endings are stimulated.

The medial network encodes the affective-motivational dimension; this corresponds to the feeling of aversion that typically accompanies the physical sensation, and the urge to avoid or withdraw from the stimuli perceived as responsible for the disliked feeling. This network is composed of nociceptors called C-fibers, unmyelinated neurons which transmit information more slowly than A-delta fibers, and thus are responsible for what is referred to as 'slow pain.' These nociceptors will continue to fire for a period of time after noxious stimulation has ceased, and transmit information to the anterior insula, the anterior cingulate cortex (ACC) and the prefrontal cortex, as well as the posterior cingulate cortex (Wiech, Preissl, & Birbaumer, 2001).

The above description of the pain matrix is meant to illustrate that the experience of physical pain involves the activation of two distinct neural networks; the lateral

neuronal network, which encodes and transmits information about the sensory aspects of physical pain, and the medial network, which encodes and transmits information which causes our aversive response. While these networks typically are activated together (i.e., a pain experience usually has both a sensory and affective-motivational dimension), this is not always the case. Indeed, a great deal of empirical research supports the notion that the sensory-discriminative and affective-motivational dimensions of pain can be dissociated (Hardcastle, 1997; Rainville, Carrier, Hofbauer, Bushnell, & Duncan, 1999). The fact that the sensory and affective-motivational aspects of pain experience are only contingently related allows us to explain the aforementioned sorts of cases in which individuals report that they feel ‘pain’ but do not mind it; they are experiencing the sensory aspect of pain, but not the affective-motivational aspect. Similarly, individuals who seem to enjoy pain (e.g., masochists) may be having the same sensory experience as non-masochists when subject to a certain stimulus, but whereas these sensations arouse in non-masochists feelings of aversion, they arouse in masochists a different collection of motivations or affect.

The tension between the various accounts of the nature of pain have generated an enormous philosophical literature, attempting to determine the precise nature of pain. Indeed, as Valerie Hardcastle (1997) writes, “just about every conceivable position is currently held today by some leading thinker or another”. One might adopt the view that pain is completely objective, and intrinsic to the injured body part, a functional state, a set of behaviours, or a kind of perception. One might also adopt the view that pain is completely subjective, and even that it does not correlate with any biological markers, and is completely mysterious. For present purposes, however, these issues can be largely

set aside. Whether we take the essence of pain to be its sensory quality, our affective-motivational response to the painful stimuli, or some combination of the two, it seems clear that it is our affective-motivational response to painful stimuli that is responsible for our feelings of *suffering* as a result of physical pain. Whatever ‘pain’ turns out to be, the experience of physical pain causes us to suffer only insofar as we have the appropriate aversive response to it; this is the role of the affective-motivational dimension of pain. Therefore, if patients diagnosed as vegetative with covert awareness experience the affective-motivational dimension of pain (i.e., they experience the feeling of aversion characteristic of a physically painful experience), it follows that they are capable of suffering, and are sentient. While we cannot assess this directly in the absence of direct communication, we can use activity in the medial neuronal network as a proxy for a patient’s experience of the affective-motivational dimension of pain. Thus, while activity in the medial network does not prove that these patients are experiencing the affective-motivational dimension of pain, it nevertheless provides good evidence that they are (Price, 2000; Vogt & Sikes, 2000; Sowards & Sowards, 2002).

Importantly, having an aversive response to physical pain is not the only way in which an individual might suffer. There may be many ways in which patients diagnosed as vegetative with covert awareness suffer, including depression, loneliness, or a loss of self. Moreover, there are some cases, as mentioned above, where a patient may be sentient and experience physical pain, but not mind it. If this were the only kind of ‘pain’ experienced by vegetative patients with covert awareness, perhaps this would be unproblematic, from a moral point of view. (Setting aside the fact that the pain may be signalling tissue damage, which could cause other kinds of harm in the future, for

example). What I am arguing here is that the affective-motivational dimension of pain (which usually, although not necessarily, accompanies a particular sensation of pain) is what is responsible for the experience of suffering which often results from the experience of physical pain. One might experience the sensory aspect of pain without the affective-motivational aspect, and thus, not suffer as a result. Alternatively, one might suffer as a result of something other than the affective-motivational dimension of physical pain. I am arguing that insofar as they experience the affective-motivational dimension of physical pain, patients diagnosed as vegetative with covert awareness are capable of experiencing one kind of suffering, and this is sufficient for considering them sentient. In the next section, I will argue that there is good evidence to support the notion that patients diagnosed as vegetative with covert awareness are capable of experiencing the affective-motivational dimension of pain.

### **3.3 Evidence for Sentience in Patients Diagnosed as Vegetative**

In the previous section, I briefly described the neural networks responsible for pain experience in normal, undamaged brains. Noxious stimuli are detected, processed and encoded through the lateral and medial neural networks, which produces both the particular sensation of pain, as well as the unpleasant feeling that characterizes the experience of pain. If these networks are not functioning properly (e.g., patients with congenital analgesia), or have been damaged in some way, pain experience becomes impaired, or impossible. Moreover, in the absence of awareness, a necessary condition for pain experience, an individual cannot experience pain.



In spite of this, some patients in the vegetative state may nevertheless appear to respond to the presentation of noxious stimuli. Researchers typically recognize four levels of neurologic response to nociceptive stimuli, ranging from unconscious responses to the experience of pain and suffering (Multi-Society Task Force on PVS, 1994). At the first level, monosynaptic reflex responses occur at the level of the spinal cord. At the second level, simple nociception occurs at the level of the thalamus. At the third level, subcortical nociceptive responses produce patterned behaviours (e.g., grimacing or crying), which appear similar to those that accompany conscious emotional responses. These responses are commonly seen in patients in a vegetative state, and are likely mediated at subcortical levels through synaptic connections between the thalamus and limbic system. Nociceptive stimulation is also known to elicit generalized autonomic responses (e.g., increased heart rate or blood pressure, sweating), which may be observed in patients in a persistent vegetative state. At the fourth level, conscious awareness of pain (usually including the experience of suffering) occurs at a cortical level through synapses connecting parietal cortical neurons with other areas of the cerebral cortex. Moreover, the sorts of responses characteristic of the conscious experience of pain tend to differ from decorticate or decerebrate posturing displayed by vegetative patients (Multi-Society Task Force on PVS, 1994). Patients diagnosed as vegetative are thought to be incapable of neurologic response at the fourth level.

However, because these motor and autonomic responses can occur in the absence of conscious awareness, they cannot be used to infer that the patient is experiencing pain. For example, studies have shown that individuals will display motor or autonomic signs of pain perception (e.g., changes in respiratory frequency, increased heart rate and blood

pressure, changes in pupillary diameter, and increased skin conductance), even under general anesthetic (Demertzi et al., 2009). Similarly, presentation of a noxious stimulus may elicit involuntary decerebrate (abnormal extension of the arms by the side), or decorticate (flexion of the arms, elbows, wrists and fingers, inward towards the chest) posturing in coma patients, as well as patients in the vegetative state. In other words, the observed behaviours may be a reflex response (i.e., nociception) rather than a genuine pain experience, with the affective component that entails.

Several studies have attempted to investigate the possibility that patients in the vegetative state are capable of experiencing pain. Laureys and colleagues (2002) used positron emission tomography (PET) imaging to measure cerebral metabolism in 15 VS patients when presented with high-intensity electrical stimulation of the median nerve, and compared this to the cerebral metabolism of 15 healthy controls. While they found that overall cerebral metabolism was 40% of normal values in VS patients, they detected activation in the midbrain, contralateral thalamus, and primary somatosensory cortex in each of the VS patients. However, they found that noxious stimulation elicited no downstream activation beyond the primary somatosensory cortex. Moreover, functional connectivity assessment showed that the observed cortical activity was functionally disconnected from higher order associative cortices (i.e., secondary somatosensory, bilateral posterior parietal, premotor, polysensory superior temporal, and prefrontal cortices) that are currently thought to be necessary for conscious awareness. Similarly, Kassubeck and colleagues (2003) used positron emission tomography to analyze central processing of pain using electrical stimulation in 7 anoxic VS patients. Like Laureys and colleagues, they found activation in the primary somatosensory cortex—as well as in the

secondary somatosensory cortex, insular, and anterior cingulate cortices—but found these areas to be dissociated, with no functional connectivity between higher order associative cortices (Kassubeck, et al., 2003). A 2005 study by Boly and colleagues (2005) also found that while many brain regions of the pain network are activated in VS patients, they are disconnected from each other. Thus, in spite of the fact that VS patients may retain islands of cortical functioning within areas of the brain involved in pain experience, the functional disconnection between these areas makes it unlikely that patients are consciously aware of the noxious stimuli, and thus, unlikely that they are experienced as aversive (Lutkenhoff, 2013).

These results are supported by recent findings which suggest that patients in the vegetative state present a severe impairment of backward connectivity in higher-order associative cortices, which is crucial for the sort of integrated brain processing necessary for consciousness. Boly and colleagues (2011) measured effective connectivity in backward and forward connections at two hierarchical cortical levels (i.e., temporal and frontal cortices) in VS and MCS patients, as well as healthy controls, during auditory processing; they found that VS patients exhibited significantly impaired backward connection from frontal to temporal cortices compared to both MCS and controls. They conclude that recursive processing in high-order cortical areas is necessary for the generation of conscious perception. Thus, because primary cortical activation is isolated from higher-order associative cortical activity in patients in the vegetative state, these patients are highly unlikely to be capable of conscious experience, including the conscious experience of pain (Boly et al., 2011). Similarly, Laureys and colleagues (2004b) point out that in rare cases where VS patients recover awareness, PET shows a

functional recovery of metabolism in the associative cortices—bilateral prefrontal regions, parieto-temporal, and posterior parietal areas—as well as functional connectivity within these areas, and between these areas and intralaminar thalamic nuclei.

### **3.4 The Relationship Between Awareness and Sentience**

Because awareness is a necessary condition for sentience, we could rule out the possibility of sentience in those patients in whom awareness is absent. Unfortunately, determining whether awareness is absent is notoriously difficult; there simply is no diagnostic tool which can quantify the extent of consciousness. Thus, determining that a patient is vegetative relies on an inference from a lack of evidence of awareness, to a lack of awareness. Currently, this inference is based on two main sources: a detailed clinical history, and careful observation of the patient's spontaneous and elicited behaviour. Several protocols exist for conducting behavioural assessments; however, they differ in their ability to detect evidence of awareness. In fact, research indicates that as many as 40% of patients initially diagnosed as vegetative are in fact misdiagnosed (Andrews et al., 1996). A number of factors might contribute to this number, including the replicable, but nevertheless inconsistent nature in which MCS patients display evidence of awareness (making it easy to confuse VS and MCS), the limited amount of time which physicians have to conduct a behavioural exam, as well as the subtlety of certain behaviours which might demonstrate awareness, or a lack of experience in assessing the condition. Similarly, certain assessment scales, such as the Coma Recovery Scale-Revised, and Full Outline of Unresponsiveness (as opposed to the Glasgow Coma Scale), test for a greater variety of certain behaviours, making it more likely that these assessments will generate a diagnosis of MCS, rather than VS. Finally, patients with

physical disability may be unable to respond to stimulation even if they retain some level of awareness.

Thus, there is an inherent lack of certainty in diagnosing a lack of awareness (i.e., in diagnosing someone as ‘truly vegetative’). Nevertheless, there are a number of factors which provide an indication of the likelihood that a patient retains, or may recover, awareness after brain injury. The first such factor is the amount of time spent in the vegetative state. In a study of 603 patients, 42% of patients in the vegetative state at one month went on to regain awareness by one year post-injury, whereas only 27% of patients after three months, and 12% after six months went on to regain consciousness by one year post-injury (Multi-Society Task Force on PVS, 1994). Second, a patient’s age is also negatively correlated with their chances of recovery of awareness. Third, traumatic brain injury tends to be associated with recovery of consciousness after one year more closely than non-traumatic injuries (52%, compared to 13%) (Multi-Society Task Force on PVS, 1994).

Neurologists may also look to a patient’s functional neuroanatomy for indications about the prospects of recovery of awareness. One such approach is to assess the structure and function of the cerebral cortex, thalamus, and connecting fiber tracts. In VS, the brainstem is relatively spared (which allows for the preserved autonomic functions observed in these patients), whereas the grey or white matter of both cerebral hemispheres is widely and severely damaged. Overall cortical metabolism of vegetative patients is 40-50% of normal values, while 12 months after traumatic injury, or three months following non-traumatic injury, cerebral metabolism drops to 30-40% of normal values (Laureys et al. 2004). Diffusion-weighted imaging with MRI can be used to

provide robust evidence of a lack of awareness in patients with this condition. For patients with traumatic brain injury, extensive abnormalities on diffusion tensor imaging, indicating extensive damage to white matter, is also highly suggestive of a lack of awareness (Newcombe et al., 2010; Fernandez-Espejo et al., 2011). In the case of anoxic ischemic encephalopathy, the presence of decerebrate or decorticate posturing, as well as impairment of brainstem reflex responses is highly suggestive of the absence of awareness. Moreover, somatosensory evoked potentials can be used to assess whether a stimulus activates the primary somatosensory cortex, which has been found to be an extremely reliable indicator of a lack of awareness in patients with anoxic or traumatic brain injuries. (Cruse, Norton, Gofton, Young, & Owen, 2014)

It is important to stress that while the above assessment tools certainly provide insight into the potential awareness of brain injured patients, none are capable of saying with certainty that a patient diagnosed as vegetative has irretrievably lost awareness. At best, then, we can say that sentience is unlikely in a considerable number of patients; awareness is improbable given the extensive damage to (and consequent lack of interconnectivity between) various brain structures. Accordingly, we can focus our investigation of sentience on those patients where positive evidence of awareness is present, or borderline cases where there is some reason to believe that awareness may be present, while bearing in mind the possibility that some patients in which there is no evidence of awareness may nevertheless be aware, and thus, may be sentient. We might organize these patients into three groups. The first group consists of those patients who are capable of functionally communicating with researchers via the mental imagery task. The second group is comprised of patients who are capable of command following using

the mental imagery task, but are not able to communicate. The third group consists of those patients who have not demonstrated awareness, but in whom we are uncertain about whether awareness is absent. Some of the patients in this group will have undergone the mental imagery task, and failed to demonstrate evidence of awareness. However, the majority of patients in this group will simply never have been tested for awareness using functional neuroimaging. In what follows, I will focus primarily on establishing the sentience of the members of the first two groups, though I will revisit the third group at the conclusion of the chapter.

### **3.5 Sentience in Patients Diagnosed as Vegetative with Covert Awareness**

#### ***3.5.1 Evidence for Sentience in Functional Communicators***

Let us begin with the first group of patients, those who are capable of communicating using the mental imagery task. Why should we think that they are sentient? The most straightforward way to verify that an individual is in pain is to appeal to their self-report. If I give someone an electric shock, and ask them if the resulting sensation is painful, to which they respond affirmatively, this is strong evidence that they are experiencing pain (i.e., both the sensory and affective-motivational dimensions of pain) and, *a fortiori*, that they are sentient. When someone claims to be in pain (and we have no reason to suspect the presence of a factitious disorder, or patient malingering), and moreover, behaves as though they are in pain, this is the best evidence we have for believing that they are in pain. Appeal to patient self-report is treated as the ‘gold-standard’ for identifying and assessing pain in virtually all communicative patients; vegetative patients with covert awareness should be no different. If a patient diagnosed as

vegetative with covert awareness can report to researchers that they are in pain, or that the presentation of a noxious stimulus is painful, this is convincing evidence of their sentience.

### *3.5.2 Evidence for Sentience in Covertly Aware, Non-Communicators*

Identifying the presence of sentience in patients capable of functional communication, at least conceptually, is rather straightforward. Conversely, determining whether or not patients in the second of the three groups given above—patients who are covertly aware, but who cannot communicate through mental imagery—is much more challenging. What reason do we have for thinking that patients like this are sentient? First and foremost is the fact that they satisfy a necessary condition for experiencing pain: they are aware. While awareness does not entail sentience, the absence of awareness eliminates the possibility of sentience. Thus, the discovery of awareness in patients diagnosed as vegetative with covert awareness removes a significant barrier to sentience, and creates the possibility that they may be sentient, a possibility that does not exist in those patients who lack awareness.

Second, there is evidence to suggest that some patients diagnosed as vegetative may nevertheless retain activity within the neural structures typically involved in the conscious experience of pain. As mentioned above, Kassubeck et al. (Kassubeck, 2003) found pain-induced activation in a broad pain-related cerebral network, including areas associated with the affective dimension of pain (i.e., secondary somatosensory cortex, insular, and anterior cingulate cortices) in seven anoxic VS patients. Moreover, in a 2013 study, Markl and colleagues used fMRI to investigate brain activation in response to noxious electrical stimulation of the right index finger in 30 patients diagnosed as



vegetative. (Markl, 2013) While no pain-related activation was found in 14 patients, 15 patients diagnosed as vegetative showed activation in the sensory-discriminative part of the pain matrix (S1, S2, posterior insula, thalamus), and nine patients showed activation in the affective part (anterior cingulate cortex, anterior insula). Moreover, about one-third of the patients had pain-related responses in both the sensory and affective-motivational parts of the pain matrix. While neither of these studies demonstrates definitively that patients diagnosed as vegetative actually experience pain (insofar as activation within a certain brain area cannot prove the presence of a certain subjective experience), they do suggest that brain activation in response to noxious stimuli may be more extensive in these patients than initially thought, leading some to speculate that patients with activation of the affective pain network may experience pain (Chatelle, 2014a).

Third, the functional neuroimaging studies cited above (Laureys, 2002; Boly, 2005) strongly suggest that the reason VS patients are incapable of experiencing pain is because the neural structures involved in the conscious processing of pain (i.e., the pain matrix) are either inactive, or functionally dissociated from one another in these patients. There is behavioural evidence, as well as evidence from functional neuroimaging, to suggest that these patients remain capable of nociception, as evidenced by activation in lower-level brain areas, as well reflexive behaviours in response to noxious stimulation (Schnakers & Zasler, 2015). However, the widespread activation of, as well as the functional connectivity between, the relevant brain regions within the pain matrix—the anterior cingulate cortex, the anterior insula, and prefrontal cortices—which is necessary for the conscious experience of pain is absent. In short, these patients may experience something like painful sensations, but due to a lack of connectivity with the pain matrix,

lack the affective component of pain which makes it unpleasant, and thus, concerning for their welfare. Accordingly, if the connectivity between these brain areas were present in patients diagnosed as vegetative with covert awareness, this might give us further reason to believe that these patients are capable of experiencing pain.

There is good reason for thinking that patients diagnosed as vegetative with covert awareness may retain functional integrity of the pain matrix. As was mentioned above, intact functional connectivity between primary and associative cortices appears to be a critical component of conscious awareness. Thus, it seems reasonable to suppose that patients diagnosed as vegetative, who have demonstrated covert awareness—and have thereby demonstrated that they retain a degree of functional connectivity sufficient to allow for conscious awareness—may also retain functional connectivity of the pain matrix. Moreover, the patients under consideration here have demonstrated significant cognitive ability in performing the mental imagery task, including attention, working memory, and language comprehension. (Fernandez-Espejo & Owen, 2013) Sentience, on the other hand, is thought to be a much more basic element of consciousness, (Panksepp, 2005) which supports the view that if patients diagnosed as vegetative with covert awareness can perform the complex cognitive tasks necessary to complete the mental imagery task, they likely retain the capacity to consciously experience pain.

Consider another group of patients with disorders of consciousness, in whose sentience researchers are confident: patients in the minimally conscious state. Studies involving these patients have produced a great deal of evidence, both behavioural and through functional neuroimaging, to support the idea that these patients are capable of experiencing pain (Schnakers, 2010a). For example, Boly and colleagues (2008) studied

brain activation induced by bilateral electrical stimulation of the median nerve in five MCS patients, and found activation in the thalamus, primary somatosensory cortex, the secondary somatosensory, as well as the frontoparietal and anterior cingulate cortices (i.e., the 'pain matrix'). No area was less activated in MCS patients than healthy controls, and in contrast to VS patients, MCS patients displayed preserved functional connectivity between the thalamus, primary somatosensory cortex, and a wide cortical network, including the secondary somatosensory cortex, the posterior cingulate cortex, and the anterior cingulate cortex. Moreover, patients in MCS have been shown to retain larger cortical activation than VS patients using other modes of stimulation, and demonstrate a better connectivity between the primary and associative cortices. (Boly, 2004; Boly, 2008; Kotchoubey B, 2013.)

The results of these functional neuroimaging studies are confirmed by the use of behavioural scales in MCS patients. The Nociception Coma Scale, and subsequent Nociception Coma Scale-Revised, have been developed to assess nociception in non-communicative patients recovering from coma (i.e., VS and MCS patients), by measuring behaviours believed to be indicative of nociception. Like any behavioural scale, the Nociception Coma Scale Revised cannot verify the experience of pain directly. However, it has been shown to have a strong correlation with other validated pain scales, as well as sensitivity to the difference between VS and MCS patients, which suggests that it is assessing pain. For example, a study by Schnakers and colleagues (2010b) using the Nociception Coma Scale measured the responses of 28 VS patients and 20 MCS to the application of pressure to the fingernail bed. Both VS and MCS patients displayed responses to the noxious stimulation; however, the scores obtained were higher in MCS

patients than VS patients. While VS patients exhibited stereotypical responses linked to brainstem activation, (e.g., startle response, abnormal flexion like decerberate or ecorcitate posturing), MCS patients exhibited responses linked to subcortical and cortical activation (e.g., flexion withdrawal from painful stimulus, purposeful movements directed at the site of the noxious stimulation, and visual fixation). Furthermore, a study by Chatelle and colleagues (2014b) has demonstrated a significant positive correlation between scores on the Nociception Coma Scale Revised and activity in the anterior cingulate cortex, the cerebral area which most consistently displays activation during the experience of pain.

While this evidence is not sufficient to draw an entailment relation between conscious awareness and sentience, the fact that MCS patients retain functional connectivity of the pain matrix is highly suggestive of a connection between the presence of awareness, and the ability to consciously experience pain. Because the functional integrity of the pain matrix (i.e., primary somatosensory and associative cortices) is good evidence of the experience of pain, and because conscious awareness appears to require a high degree of cortical integration (i.e., functional connectivity between thalamocortical areas and cortico-cortical areas), (Laureys, 2004; Boly, 2011) it is likely that patients diagnosed as vegetative with covert awareness retain functional integrity of the pain matrix, and thus, the capacity to consciously experience pain (Schnakers, 2015).

Because this analysis of sentience is restricted to the clinical context, in which patient welfare is of primary concern, I argue that the satisfaction of the above conditions is sufficient to warrant the belief that patients diagnosed as vegetative with covert awareness are indeed sentient. On the one hand, the potential harm of ignoring a patient's

sentience, is considerable. Allowing them to experience suffering, when remedial treatment is readily available, is a serious moral harm, and inconsistent with their moral status. On the other hand, the cost of handling the patient so as to minimize the risk of causing suffering, and administering analgesics, is negligible. One complicating factor, however, is the patient's inability to communicate the cause of their potential suffering. While it may be safe to assume that intense physical pain causes a patient to suffer, it may be the case that eliminating this source of suffering causes the patient to suffer in other ways, and actually makes them worse off. For example, while administering a strong sedative may reduce the patient's suffering caused by physical pain, it may cause greater suffering to the patient by reducing their level of awareness. Further research is needed to develop evidence-based guidelines for the prevention and treatment of suffering in these patients, especially how the experience of physical pain may result in patient suffering (e.g., potential differences between patients' experience of nociceptive versus neuropathic pain). However, it seems reasonable that when subjecting these patients to procedures known to cause physical pain, certain treatment measures (e.g., the provision of a mild analgesic such as acetaminophen) should be taken, because they are unlikely to cause additional suffering in the patient (Schnakers & Zasler, 2007).

### **3.6 Sentience in Patients Diagnosed as Vegetative With Uncertain Awareness**

What about the third group of patients mentioned above; patients in whom awareness has not been detected (either because they did not complete the mental imagery task, or have not been tested), but in whom we cannot be certain that awareness is absent? Do we have reason for thinking that these patients are sentient? This is perhaps an even more difficult question than the question of sentience in patients who are capable

of command-following, because there is very little information on which to base a claim of sentience. A lack of response to command-following tasks may result from a lack of awareness but may also result from the patient failing to understand instructions, falling asleep, or being unable to remain sufficiently still during scanning. Moreover, patients diagnosed as vegetative are highly heterogeneous and vary considerably in their ability to produce robust brain activity that can be detected with neuroimaging. Producing brain responses in compliance with the mental imagery task may be too demanding a requirement for some patients who are aware, but are nevertheless unable to comply with structured instructions, due to deficits in executive function, or working memory (Naci, 2014). Thus, it may be the case that a subset of patients who do not complete the mental imagery task are nevertheless aware, and thus, may retain functional connectivity of the pain matrix. Moreover, given the high rate of misdiagnosis of patients in the vegetative state (Schankers, 2009), it is not unreasonable to suppose that some patients behaviourally diagnosed as vegetative may nevertheless be aware, and perhaps sentient as well. Indeed, the studies mentioned above by Kassubeck and Markl (Kassubeck, 2003; Markl, 2013) show that some patients believed to be vegetative show activation within both the sensory and affective dimensions of the pain matrix; it might be the case that these are patients in whom awareness is present, but remains undetected.

### **3.7 Assessing Sentience in Non-Communicative Patients: Future Directions**

Further research is needed to gain a better understanding of the minimal anatomical and functional requirements for sentience and its relationship to awareness, especially because different structures may mediate pain experience when the structures that normally perform this function are damaged or destroyed (McCullagh, 2004). Just as

it is unclear why patients who are capable of performing command-following tasks using functional neuroimaging are incapable of providing behavioural evidence of awareness, it is unclear why such patients, if they are sentient, do not provide behavioural evidence of sentience. While it remains an open question whether all vegetative patients should be treated as if they were sentient, this is an important issue in need of greater consideration. Indeed, vegetative patients with ‘covert sentience’ who fail to demonstrate awareness may in fact be *more* vulnerable and receive *less* careful attention than those who are shown to be aware.

A further technique, still in its early stages, has been developed by Wager and colleagues (2013), and may be useful in shedding further light on the potential sentience of non-communicative patients. They have developed a “brain-based neurologic signature for experimental thermal pain”, in order to ascertain a direct measure of pain intensity (Wager et al., 2013). These researchers identified a pattern of fMRI activity across brain regions—including the thalamus, posterior and anterior insulae, secondary somatosensory cortex, anterior cingulate cortex, and periaqueductal gray matter—associated with heat-induced pain in healthy participants. Using this ‘neurologic signature,’ Wager and colleagues were able to discriminate between pleasant warmth and painful heat in a new sample of healthy participants, with 88% sensitivity and 85% specificity in the test of pain versus no pain, and with 100% sensitivity and specificity in a ‘forced choice’ test (Wager et al., 2013).

While this assessment technique might prove useful in assessing the presence of sentience in non-communicative patients, there are limitations to using functional neuroimaging to predict or diagnose pain. While a neurologic signature for pain could be

useful in confirming pain in patients who are unable to communicate, the neurologic signature Wager and colleagues have identified has yet to be validated in a large population of healthy volunteers, or applied to patients. A further necessary step will be moving from developing and validating a test in a large group of healthy participants, to showing robustness and sensitivity and specificity in single healthy individuals. This will be critical for the application of this technique in individual patients. The psychophysical response to painful stimulation can vary across individuals, and as such, the response to pain detected by neuroimaging may also vary across individuals. As Wager and colleagues readily point out, “pain associated fMRI patterns may differ according to body site, type of pain (visceral vs. cutaneous), and clinical cause”, which may require the development of several different kinds of pain signatures (Wager et al., 2013). This potential issue is magnified by the fact that many patients diagnosed as vegetative have suffered traumatic brain injury, which may have altered the structure of their brains, and would make the application of a neural signature developed in healthy brains especially difficult. Also, while researchers have identified areas of the brain activated by noxious stimuli, most of these brain regions also contain non-nociceptive neurons, and so may be activated by a variety of stimuli, in addition to painful stimulation.

### **3.8 Summary**

In this chapter, I have argued that we have good reason to believe that patients diagnosed as vegetative with covert awareness are capable of experiencing pain. Pain, by definition, is both a sensory and affective experience, and involves the integrated functioning of a number of brain areas collectively referred to as the ‘pain matrix.’ Accordingly, a necessary condition for the experience of pain is awareness; an individual



who lacks awareness cannot experience pain. It is for this reason that patients diagnosed as vegetative are believed to be incapable of experiencing pain, in spite of the fact that they may demonstrate behaviours characteristic of pain.

I argue, however, that we have good reason for believing that patients diagnosed as vegetative with covert awareness *can* experience pain, and thus are sentient. In the case of patients capable of communication, we can verify sentience on the basis of self-report. In the case of patients who have demonstrated awareness using fMRI-based command-following tasks, the functional connectivity between thalamocortical and cortico-cortical areas which seems necessary for awareness is highly suggestive of the preserved functional connectivity of the pain matrix. Studies of VS patients show widespread functional disconnection between various brain areas which are thought to underlie awareness, including awareness of pain. Conversely, patients in MCS retain sufficient cortical integration to allow for awareness, including awareness of painful experience, as well as demonstrating behavioural evidence of pain experience. Thus, because patients diagnosed as vegetative with covert awareness also have sufficient cortical integration to allow for awareness, it is reasonable to believe that they have sufficient integration of the pain matrix to allow for the conscious experience of pain. For those patients in whom awareness has not been established, the ascription of sentience is less well-grounded. Nevertheless, we may have reason for treating these patients as if they are sentient as well.

I began this chapter by arguing that if vegetative patients with covert awareness are sentient, then they have moral status. In light of their moral status, others have an obligation to respect the interests of these patients in their treatment of them. Sentience is

critical, because it provides one such interest—an interest in avoiding pain—that can be violated by others, and thus provides content to the requirements of moral status.

However, it may be the case that patients diagnosed as vegetative with covert awareness have interests beyond avoiding painful experiences. What interests might these be? And more importantly, how does the moral status of these patients shape our obligations with respect to these interests? Answering these questions will be the focus of the next chapter.

## **Chapter 4: Assessing the Welfare of Patients Diagnosed as Vegetative With Covert Awareness**

Before moving on to the arguments of the fourth chapter, let us briefly take stock of what has been argued to this point. In chapter 2, I presented sentience—the capacity to experience pleasure or pain—as a sufficient condition for the possession of moral status. The capacity to experience pleasure and/or pain, entails that sentient beings have certain interests; namely, interests in experiencing enjoyment and avoiding suffering. This in turn gives these beings moral status, and creates in others an obligation to respect these interests. We cannot treat beings with moral status in any way we please; these beings have an interest in what happens to them, and thus, through the violation of these interests, can be morally wronged by others.

In chapter 3, I argued that patients diagnosed as vegetative with covert awareness were likely sentient, and thus should be accorded moral status. In other words, they are among the class of beings whose interests count morally. While some studies have shown that patients diagnosed as vegetative may demonstrate activation of certain brain areas typically implicated in the experience of pain when presented with noxious stimuli, the functional disconnection between these areas makes it unlikely that vegetative patients experience pain (Boly, 2005; Lutkenhoff, 2013). Conversely, minimally conscious patients have been shown to retain these connections, as well as demonstrate behavioural responses to painful stimuli (Boly, 2008; Schnakers 2010). I argued that because minimally conscious patients retain the functional connectivity between cortical areas required for awareness generally, and the experience of pain specifically, the fact that patients diagnosed as vegetative with covert awareness also retained the capacity for

awareness makes it reasonable to assume that they also retain the functional connectivity between cortical areas required for the affective-motivational dimension of pain. This means that patients diagnosed as vegetative with covert awareness have moral status.

What are our obligations to these patients? In this chapter and the next, I will attempt to provide at least the outline of an answer to this question. As I argued previously, having moral status creates an obligation in others to give consideration to the interests of beings who possess it, when we are making decisions which affect their interests. Specifically, I claimed, we have a *prima facie* obligation to avoid violating these interests through our actions. In the case of patients diagnosed as vegetative with covert awareness, one of our most important obligations is the protection and promotion of their welfare. Thus, in order to determine how we can best promote the welfare of these patients, we need to know what it means for them to be faring well or poorly. Once we have this conception of welfare in mind, we may then be able to better determine whether they are, in fact, faring well or poorly, and how we might protect or promote their welfare interests.

#### **4.1 The Concept of Welfare**

According to most accounts, the concept of welfare measures how well a life is going for the individual whose life it is, either at a particular time, or across an extended period of time (Griffin, 1986; Sumner, 1996; Feldman, 2004). When philosophers talk about welfare, they are typically referring to what makes someone non-instrumentally, fundamentally better or worse off. As Campbell articulates, things that promote an individual's welfare are "things that are *good for you*, *benefit you*, have *prudential value* for you, and make you *better off*" (Campbell, 2016). On this concept of welfare, theories

of welfare measure prudential value. Something has prudential value insofar as it makes one's life (or a part of one's life) go better from the point of view of the individual whose life it is. Importantly, prudential value is only one potential contributor to the overall value of a life; in addition to prudential value, a life may have moral value, aesthetic value, spiritual value, etc., all of which may contribute to the overall 'goodness' of a life, but without necessarily contributing to the welfare of the individual (Campbell, 2016).

While it is generally accepted that welfare is concerned with how an individual's life is going for them, (as opposed to its moral or aesthetic goodness), there is nevertheless some discrepancy about the proper understanding of the concept of welfare, including what it means for something to be 'good for,' as well as other features of the concept. (For an overview of various analyses of the concept of welfare, see Campbell, 2016). For example, philosophers like Sumner argue that one of the key features of our ordinary concept of welfare is that it is *subject-relative*, and that a substantive theory of welfare must be able to explain why a potential contributor to an individual's welfare is *good for* that individual (Sumner, 1996).

In an oft-cited passage, Peter Railton gives voice to this intuition about the subject-relativity of welfare: "what is intrinsically valuable for a person must have a connection with what he would find in some degree compelling or attractive, at least if he were rational and aware...it would be an intolerably alienated concept of someone's good to imagine that it might fail in any way to engage him." (Railton, 1986). For many, this is a powerful intuition. What makes something a good for me should depend on what *I* as an individual am like, and not what some other individual or group is like; the things that make my life go better should not be alien to me.

However, this concept of welfare is not universally shared. One might also argue that welfare is concerned not with facts or aspects of the individual welfare subject, but on things like species-level traits or objectively valuable goods. For example, Richard Kraut appears to reject the subject-relativity of welfare when he argues that welfare consists in human flourishing, and that humans (and all living things), flourish when they develop and utilize their naturally-developing faculties and capacities (Kraut, 2007). (For an overview of this debate, see Hall & Tiberius, 2016). I will not enter into this debate here, however, and instead simply adopt the widely-held view that the concept of welfare refers to what makes an individual non-instrumentally better or worse off, and that it is in some sense subject-relative.

Assessing the welfare of patients diagnosed as vegetative with covert awareness is challenging, because it is unclear what kinds of prudentially valuable states of affairs these patients are capable of realizing, and to what extent. Indeed, while we may be reasonably confident that these patients are capable of the kind of suffering that typically results from physical pain, we have very little idea about the other kinds of experiences they may be capable of, or what prudential interests they may have, and consequently, how they are faring, given the satisfaction or frustration of these prudential interests. The important question with respect to the welfare of these patients is twofold: what is the nature of these patients' welfare, and given this conception of welfare, are these patients faring well?

#### **4.2 Faring Poorly: An Argument from Kahane and Savulescu**

One attempt at answering this question has been given by Kahane and Savulescu, who argue that the presence of covert awareness in patients diagnosed as vegetative may

actually detract from their overall welfare, by frustrating their interests (Kahane & Savulescu, 2009). These authors adopt a pluralistic conception of welfare, which draws on traditional subjective and objective theories, and attempt to defend our common-sense intuitions that these patients are faring poorly. They go on to conclude that patients diagnosed as vegetative with covert awareness are likely faring so poorly that we may have a moral obligation to withdraw life-sustaining treatment. I believe that this strong conclusion is ultimately unjustified. As I will argue, the picture of patient welfare that the application of these traditional theories provides is much less clear than Kahane and Savulescu seem to acknowledge. It is not obvious, given the arguments which Kahane and Savulescu present, that these patients are faring poorly, and because of this, I suggest, we should exercise caution in our determination of what will best promote their welfare, including the withdrawal of life-sustaining treatment.

#### ***4.2.1 Kahane and Savulescu's Argument***

Kahane and Savulescu motivate their discussion by questioning the assumption that the presence of consciousness, in and of itself, is morally significant (Kahane & Savulescu, 2009). They argue that it is because consciousness is necessary for the presence of interests, which themselves are morally significant, that the presence of consciousness in and of itself is often thought to make a moral difference. Thus, in spite of the fact that some patients diagnosed as vegetative retain some degree of consciousness, this may not turn out to be morally significant, at least as it pertains to sustaining their lives.

The authors argue that the moral significance of consciousness is actually grounded in the moral significance of interests. Consciousness, specifically phenomenal

consciousness, “might be a general condition for an entity’s having interests” (Kahane & Savulescu, 2009, p. 13). The presence of consciousness explains how certain entities have interests, whereas other entities do not; consciousness is necessary (though perhaps not sufficient) for an entity to have a subjective point of view, and it is from this perspective that an individual’s welfare can be affected in some way by the satisfaction or frustration of its interests. In short, in order to be made better or worse off, one must have a subjective point of view, which requires phenomenal consciousness.

Having established a connection between consciousness and interests, Kahane and Savulescu turn to the question of how the presence of consciousness impacts the satisfaction or frustration of an individual’s interests. The authors present three different types of prudential interests—following the three traditional theories of welfare—the satisfaction or frustration of which can affect an individual’s welfare. On a hedonist account of welfare, prudential interests consist in pleasant experiences. According to desire-satisfaction theories, prudential interests consist in having one’s desires satisfied. Finally, on objective accounts of welfare, certain activities or experiences (e.g., developing personal relationships and talents, knowledge) are intrinsically prudentially valuable, and the possession of these goods makes one non-instrumentally, fundamentally better off.

Thus, the authors claim that it is the presence of interests, and not simply the presence of consciousness, which makes a moral difference. To determine our moral obligations to patients diagnosed as vegetative with covert awareness, we need to take into consideration their hedonic (experiential), desiderative, and objective interests, and on this basis, determine what is in the best interests of their welfare. And, they claim, if



we analyze these patients according to these interests, we will find that they are, by and large, frustrated. Accordingly, these patients are faring poorly, and as such, considerations of welfare may obligate us to withdraw life sustaining treatment.

How do Kahane and Savulescu interpret the interests of these patients? Consider first their experiential interests. Kahane and Savulescu argue that it is plausible to assume that these patients have experiential interests, which gives us a good reason to alleviate their suffering, as well as make them as comfortable as possible while they are alive. However, they argue, experiential interests may not justify sustaining their lives; even if we could be highly confident that a patient experienced only highly pleasant states of consciousness, “it is not clear that she would be significantly harmed if her life ended earlier than was possible” (Kahane & Savulescu, 2009, p.18).

What about their desiderative interests? Here, the authors suggest that beyond the most rudimentary desires, any desiderative interests the patient might have would be generated by past desires; for example, the desire one may have had prior to injury to not go on living in something like the vegetative state. In fact, they seem to suggest that many people would not desire to continue living in a vegetative state (pointing out that many people sign advanced directives to this effect), though they do acknowledge that this desire may not be shared by everyone. By continuing to exist in a vegetative state, their previously expressed desire—albeit one we are only assuming they would still endorse—is frustrated, thereby reducing their welfare.

Finally, when considering a patient’s objective interests, Kahane and Savulescu seem to think that the frustration of these interests is inevitable given the patient’s condition, and thus, patients diagnosed as vegetative with covert awareness exist in a

state “more meaningless and degrading than to lose consciousness completely, and thus stop existing as a psychological entity” (Kahane & Savulescu, 2009, p.19). Importantly, the fact that the patient is unaware of the frustration of their objective interests is irrelevant to their impact on the patient’s welfare. If the achievement of knowledge, or the cultivation of personal relationships and talents are objective goods, their absence from the life of these patients necessarily makes them worse off, even if the patient is unaware that these goods have been lost. Moreover, the presence of evils, such as immobility or ignorance, would also make such a patient worse off.

Kahane and Savulescu clearly state that they are not attempting to defend any particular view of welfare. Rather, they suggest that all three capture important aspects of well-being. The authors are correct that there are certain states of affairs that are likely prudentially valuable on multiple theories of welfare. For example, it seems plausible that an objective-list theory or desire-satisfaction theory would hold that experiencing pleasure is prudentially valuable. Of course, the explanation given by each theory for why a particular state of affairs is an ingredient of welfare is very different. Furthermore, using multiple theories to determine the welfare of the patients under discussion makes it difficult to assess their welfare when these theories conflict. I will set this issue aside for now. In the next section three sections, I will critically examine Kahane and Savulescu’s analysis of the experiential, desiderative, and objective interests of these patients, and argue that the interests of these patients fails to support Kahane and Savulescu’s conclusion about what is most consistent with their welfare.

#### **4.3 The Experiential Interests of Patients Diagnosed as Vegetative with Covert Awareness**

Kahane and Savulescu argue that patients diagnosed as vegetative with covert awareness, likely can experience pleasure and pain, and thus, have experiential interests. On a hedonist account of welfare, these patients are faring well insofar as they experience a greater balance of pleasure over pain. Accordingly, Kahane and Savulescu argue that if these patients are experiencing extreme suffering, and moreover, that there is no prospect of this suffering being alleviated, continuing to exist is a source of great harm—and no benefit—to these patients; their welfare is so poor that continued existence is no longer a benefit to them. However, Kahane and Savulescu also suggest that even if these patients did not experience pain, but only highly pleasant states of consciousness, it is not clear that we ought to keep them alive for as long as we can. Yet, if the patient is experiencing highly pleasant states of consciousness, without suffering, it certainly seems as though she is experiencing a greater balance of pleasure over pain, and thus, is faring well, at least on the hedonist account Kahane and Savulescu present.

Why then, do the authors conclude that perhaps we ought not to keep a patient like this alive as long as possible? They speculate that these patients “do not possess self-consciousness, or a desire to go on living, and little to no psychological connectedness over time,” (Kahane & Savulescu, 2009, pg. 18) and for this reason, they would not be harmed if their lives were to end earlier than they otherwise might. And, in light of this, considerations of distributive justice may justify the removal of life-sustaining treatment.

There are a few points to consider here. First, the authors seem to move from making a claim a narrow claim about a certain conception of patient welfare (i.e. whether their lives are on balance more pleasurable than painful), to a much broader claim about the worthwhileness of a life, and the just allocation of health care resources. They seem

to suggest that when an individual gains only a minor amount of benefit from continued existence, countervailing considerations (e.g., financial considerations, scarcity of health-care resources) may obligate us to withdraw life-sustaining treatment. Yet this claim is different from the one than Kahane and Savulescu had erstwhile been defending, specifically, that patients diagnosed as vegetative with covert awareness were likely to be faring poorly on various accounts of welfare, and on *these* grounds, we may have a moral obligation to withdraw life-sustaining treatment. Of course, it may be the case that a patient's welfare is not the only relevant consideration in determining whether or not we should withdraw life-sustaining treatment. Perhaps this is what Kahane and Savulescu want to argue; I will not dispute this line of reasoning here. Nevertheless, such a claim would require a distinct argument, one which the authors do not provide. Thus, insofar as these patients are experiencing a positive balance of pleasure over pain, they are faring well on the hedonist account; accordingly, this account of welfare would not support the withdrawal of life-sustaining treatment from these patients.

Perhaps what Kahane and Savulescu are arguing is that the sort of pleasurable experiences that contribute to welfare require self-consciousness, or psychological connectedness, such that even if these patients experience states of sensory pleasure, these sensory states do not contribute to their welfare. In support of this claim, they cite Jeff McMahan's notion of 'time-relative interests'. McMahan develops a complex series of arguments in support of this idea; I will provide only a rough account here.

#### ***4.3.1 'Psychological Unity' and Experiential Interests***

McMahan argues that the degree of rational egoistic concern one has about one's own future varies with the degree of 'psychological unity' that exists between oneself

now, and oneself in the future (McMahan, 2002). Psychological unity depends on the connectedness and continuity of an individual's psychological makeup over time.

Psychological unity may consist of having the same mental states (e.g., beliefs, desires, or dispositions of character) over time, or it may consist of different mental states which contain some internal reference to one another, such as an experience, followed by a memory of that experience. The degree of psychological unity within a life is a function of the "proportion of the mental life that is sustained over that period, the richness of that mental life, and the degree of internal reference among the various earlier and later mental states" (McMahan 2002, pg. 75).

An individual's time-relative interests, on the other hand, are what an individual has egoistic reason to care about now (or what a third-party has reason to care about for the individual's own sake). McMahan claims that the strength of these interests is affected by the degree of psychological unity which exists between the individual in the present, and the individual in some future state. If there is a high degree of psychological unity between Joe in the present, and Joe\* at some future time, then it is rational for Joe to have a strong time-relative interest in what happens to Joe\*, because it makes sense for Joe to think of Joe\* as a future state of himself. Conversely, if there is only a minimal degree of psychological unity between Joe and Joe\*, it would be rational for Joe to have only a weak time-relative interest in what happens to Joe\*; Joe\* is, in a manner of speaking, a different person than Joe.

Kahane and Savulescu seem to think that while patients diagnosed as vegetative with covert awareness may have pleasurable experiences, their lack of psychological unity over time implies that these pleasurable experiences are not accruing to the 'same

person'. Each experience is a discrete, isolated event, with little or no connection to experiences that precede or follow it. The absence of any persisting structure to the lives of these patients, in anything but a merely biological sense, suggests that even if these patients were to experience pleasurable states in the future, the patients are not related to their future selves in the sort of way that would allow these pleasurable experiences to contribute to their welfare. In other words, these pleasurable experiences are not good for the patient (i.e., they are not prudentially valuable), because there is no persisting patient which they can be good for.

The problem with this line of argument is that it is based on an empirical claim about the cognitive capacities of these patients, about which Kahane and Savulescu provide little evidence. Conversely, there is evidence to suggest that at least some patients diagnosed as vegetative with covert awareness do possess a 'psychological unity' over time. For example, some patients have used the mental imagery task to communicate with researchers through yes-or-no questions, accurately answering questions about their location in space and time (i.e., the correct date, their current location), and the names of family members. One patient was able to correctly name his personal support worker, whom he had only met after his accident, which suggests that this patient was able to form new memories (Fernandez-Espejo, 2013). This evidence supports the idea that these patients may retain a degree of psychological unity, such that the experience of pleasure and pain accrues to 'the same person', and thus, contributes or detracts from the individual's welfare.

Clearly, these patients appear to have experiential interests, the satisfaction of which are capable of contributing to their welfare. In fact, philosophers who support a

hedonist account of welfare in the tradition of Bentham or Mill—such that one’s life is going well when one has on balance more pleasure than pain—would argue that the satisfaction or frustration of these experiential interests is all that is relevant to the welfare of these patients. My aim here is not to defend a hedonist account of welfare.<sup>1</sup> Indeed, an individual’s experiential interests seem relevant to a determination of their welfare, even if one does not adopt a hedonist account (e.g., a desire-satisfaction account need not reject the role of pleasurable experience in contributing to welfare, nor does an objective list account). Rather, my aim here is to show that the patients under consideration do have experiential interests, and contra Kahane and Savulescu, the satisfaction or frustration of these interests do contribute or detract from their welfare.

#### **4.4 The Desiderative Interests of VS Patients with Covert Awareness**

Another way we might evaluate the welfare of patients diagnosed as vegetative with covert awareness is by appealing to desire-satisfaction theories of welfare. According to desire-satisfaction theories, welfare consists in the satisfaction of desires, wants or preferences. Thus, some object or state of affairs has prudential value in virtue of satisfying a desire that I have; I am faring well to the extent that my desires are satisfied, and faring poorly to the extent that I am not getting what I want (Sumner, 1996; Griffin, 1986; Hare, 1981; Raz, 1986; Arneson, 1999).

In discussing the desiderative interests of patients diagnosed as vegetative with covert awareness, Kahane and Savulescu suggest that patients diagnosed as vegetative with covert awareness “have, at best, only the most rudimentary desires” (Kahane &

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<sup>1</sup> For recent defenses of a hedonist account of welfare, see Feldman, 2004; Crisp, 2006. For objections to traditional hedonist accounts, see Nozick 1974; Sumner, 1996.

Savulescu, 2009 p. 18) and that any desiderative interests they do have would not be generated by present desires, but rather, would be generated by past desires. This suggests that for Kahane and Savulescu, a patient might have an experiential interest in not experiencing pain, but nevertheless lack the desire to not experience pain. Although I will not attempt to offer a comprehensive account of desire here, it is plausible to suppose that insofar as patients diagnosed as vegetative with covert awareness experience suffering and enjoyment as a result of physical pleasure or pain (i.e., they experience the affective-motivational dimension of pain), they have a desire not to experience pain, and to experience pleasure. Thus, they would have one sort of present desiderative interest.

Nevertheless, what Kahane and Savulescu seem to be suggesting is that patients diagnosed as vegetative with covert awareness lack the sorts of complex desires which would form the ingredients of one's welfare on a desiderative account. For example, they state that such a patient lacks "a desire to go on living." Part of the reasoning behind this claim seems to be that these patients lack the degree of psychological connectedness to their future selves which is required to have a desire about future states of themselves. Again, they seem to be appealing to something like McMahan's notion of time-relative interests, to argue that because these patients lack the necessary psychological connectedness to their future selves, they cannot have a strong interest that their future selves might continue to live. I have already argued that this claim is likely false, at least for some patients, who do seem to demonstrate a significant degree of psychological connectedness over time.

Of course, the fact that these patients may possess a degree of psychological connectedness sufficient to have present desires, does not entail that they are capable of



forming the desire to continue living, or even if they can form such a desire, that they actually have such a desire. While there is some evidence to suggest that patients diagnosed as vegetative with covert awareness may be able to conceive of themselves in the future, which I will discuss in the next chapter, there is insufficient evidence about the cognitive capacities of these patients to say with sufficient confidence that they can or cannot have the sorts of present or future directed desires which would provide a clear determination of their welfare. The range of residual cognitive function in this patient population is such that some patients may be capable of forming preferences, while others are not. However, given the barriers to communication in this patient population, many of these patients would be unable to communicate any preferences they did have. Moreover, concerns about the rationality/autonomy of these patients might make us skeptical about the authenticity of any preferences they did express. In particular, if a patient lacks the ability to understand and appreciate the consequences of a certain desire being realized (i.e., if the desire is not informed) we might be skeptical about whether the patient actually desires it, and thus, whether its satisfaction would actually enhance their welfare.

On the other hand, because it is unclear what the extent of the desires that these patients have, if any, Kahane and Savulescu suggest that we ought to appeal to their past desires to determine their welfare. The authors assert that because most healthy individuals would not desire to be given life-sustaining treatment if they were in a vegetative state, their current prudential interest in not living in a vegetative state is frustrated by their continued existence. In support of this claim, they point out that many

people complete advance directives or living wills to ensure that they do not go on living in states of extreme dementia, or something like the vegetative state.

It is somewhat puzzling that Kahane and Savulescu would assert that an individual's past desires would have such a strong bearing on their present interests, given that they seem to also hold that the patients under discussion lack psychological connectedness over time. If the patient in the present is so psychologically disconnected from her past self, why should the desires of her past self bear on what is in her interests now?

Nevertheless, suppose that Kahane and Savulescu are correct in presuming that because many people complete advanced directives, most patients diagnosed as vegetative with covert awareness had a past desire not to continue living in a vegetative state. It does not follow that the satisfaction of their past desires is now in their best interests, for two reasons. First, this past desire may be misinformed, such that the satisfaction of this desire may not be consistent with their welfare. Second, the satisfaction of a past desire may fail to benefit me in the present, because I may no longer endorse this past desire. A past desire that an individual no longer endorses would not contribute to an individual's welfare when satisfied. To show that patients diagnosed as vegetative with covert awareness have their desiderative interests frustrated by continuing to live, Kahane and Savulescu need to give reasons not only for thinking that these patients may have had such desires in the past (i.e., prior to their injury) and that these desires were well-informed, but also that they still endorse these desires in the present.

#### ***4.4.1 Desiderative Interests: The Problem of Misinformed Desires***

Let us begin with the first objection raised above, that a patient's past desire not to go on living in a vegetative state may be misinformed. A standard objection to desire-satisfaction theories of welfare is that the satisfaction of our desires does not always lead to an increase in our welfare (Sumner, 1996). Because desires are for some future state of affairs, my desire for a future state of affairs is based on the expectation that when I do experience it, the satisfaction of the desire will make my life go better for me. However, as virtually everyone can attest to, sometimes things are not as we expect them to be; we might have a desire which, if we satisfied it, would nevertheless fail to make us better off. For example, suppose I have a strong desire to buy a particular car. However, I am unaware of the fact that the car needs a new engine, such that it would not actually be in my best interests to purchase the car. If I purchase the car, my desire to do so is satisfied, yet I do not seem to be better off. Thus, the mere satisfaction of *any* desire does not necessarily make us better off.

Of course, the problem in the above example was that I didn't know an important fact about the car, one that if I had known it, my desire for the car would have been different. Informed-desire theories of welfare attempt to control for the extent to which our desires diverge from the way things actually turn out by placing various information requirements on our desires (Rawls, 1971; Brandt, 1979; Griffin, 1986; Railton, 1986; Arneson, 1999). In this way, the satisfaction of our desires only contributes to our welfare if they are properly informed. What intrinsically contributes to my welfare is getting what I *would* want, were I aware of all the non-evaluative facts.

For example, I might think that living in Canada is most consistent with my welfare, but only because I have never lived in another country. If I was informed of what

it was like to live in Norway, for example, I may not have the desire to live in Canada, but would desire to live in Norway instead, and the satisfaction of that desire would make me better off. Similarly, I might desire to become a professional athlete, without knowing that most professional athletes suffer from significant physical ailments after their careers are over. If I were more fully informed about the object of my desire, I would cease to have it, and thus, would avoid satisfying a desire that would turn out to make me worse off.

An information requirement thus rules out some of our actual desires as candidates for improving our welfare; only those about which we are sufficiently informed contribute to our welfare when they are satisfied. Yet it still seems that some desires, no matter how well informed, may fail to increase our welfare when they are satisfied (Sumner, 1996). Suppose when I am in university, my strongest desire is to become a journalist. I have always enjoyed writing, and I find the pressure of a deadline exciting. After my graduation, I am fortunate enough to gain a position writing for a leading news magazine, where I find that the demands of my new career are more or less just as I had expected. All of the expectations upon which I based my desire to become a journalist have been met. However, as time passes, I come to realize that a career in journalism simply isn't for me. After devoting years of my life to establishing myself in my career, I begin to feel frustrated and depressed, and eventually quit my job. Yet it is unclear how we can attribute this failure of my desire to increase my welfare to a lack of information. On the contrary, it seemed I was fully informed about my desire. All of the information I had gathered turned out to be correct; I was simply mistaken in thinking that I would be satisfied with this sort of career.

This potential incongruence between my expectations of future states (no matter how well informed), and the actual experience of those states seems inherent in the nature of desires. At this point, a desire theorist might be tempted to stipulate that a desire does not count as informed—and thus, its satisfaction does not count as affecting my welfare— whenever it turns out that the satisfaction of my desire fails to make me intrinsically better off. Yet, as Sumner argues (1996) this suggests that what matters to our welfare is satisfaction with our experience, and not simply that our desires are satisfied. Alternatively, a desire theorist might argue that what is best for me is what my idealized self would desire in a particular situation; what I would desire were I fully informed about all of the relevant facts is what is best for me, even if I do not desire it now. Yet, one might object that at this point, the desire theory is no longer giving an answer about what has prudential value for *me*, insofar as I am not my idealized self, but rather, my *actual* self (Heathwood, 2016).

In any case, there are good reasons for thinking that a past desire not to continue living in a vegetative state with covert awareness might not be sufficiently informed (and thus, that its frustration does not compromise an individual's welfare). Several studies have demonstrated that healthy individuals often misrepresent the degree to which a particular ailment will affect their quality of life, and that this may lead to an unduly pessimistic evaluation of the level of welfare of patients with disease or disability, including those diagnosed as vegetative with covert awareness. In fact, patients with severe disability or illness tend to systematically evaluate their own lives much more favorably than healthy individuals; this phenomenon has been referred to as the 'disability paradox' (Albrecht et al., 1999). While contextual factors may introduce some

bias into patients' self-reports of their own welfare, the available evidence suggests that healthy individuals also tend to inaccurately predict the degree to which disability or chronic illness will negatively affect their lives (Schkade & Kahnemann, 1998; Ubel et al., 2001; Ubel, Loewenstein, Schwartz, & Smith, 2005). For example, when imagining an unfamiliar circumstance, people tend to narrowly focus on the most obvious differences between those circumstances, and their current circumstances. This 'focussing illusion' may cause individuals to misrepresent how a particular disability will affect their life.

Similarly, many patients with chronic illness or disability are able to adapt to their circumstances, and are able to find meaning and purpose in other aspects of their lives (Lepore & Eton, 2000). As Ubel and colleagues argue, if healthy people do not take this adaptation process into account, it is likely that they will overestimate the degree to which a disability or illness will compromise their happiness or welfare (Ubel et al., 2005).

#### ***4.4.2 Desiderative Interests: The Potential for Changing Desires***

Let us now turn to the second objection given above, that an individual's desires may change over time (Brandt, 1982; Heathwood, 2016). It seems that even if a desire for X was well-informed, it may be the case that when the time comes for X to be satisfied, the individual may no longer desire X. Thus, the fact that an individual desired something in the past is not a guarantee that the satisfaction of this past desire will promote their welfare in the present. In the case of patients diagnosed as vegetative with covert awareness, it may be the case that these patients had past desires not to continue living in

a vegetative state, but now that they actually are in a vegetative state, they no longer hold that desire.

We can see a concrete example of the potential for an individual's past desires to inaccurately reflect their current welfare by considering a patient population which in many ways resembles the patient population under consideration: patients with locked-in syndrome. Locked-in patients are incapable of voluntary movement (except, in most cases, for vertical eye movement) or verbal communication, although they remain fully aware. Nevertheless, many of these patients report a meaningful quality of life (Laureys et al., 2005). A recent study by Bruno and colleagues surveyed a group of 65 patients with locked-in syndrome, 72% of whom indicated that they were happy. Moreover, a greater period of time in the locked-in state correlated with patient happiness, although 58% of patients did not wish to be resuscitated in the case of cardiac arrest (Bruno et al., 2011). Similarly, Lulé and colleagues found that patients with locked-in syndrome had perceptions of personal health, well-being, and life satisfaction that were often discordant with their objective health status and disability (Lulé et al., 2009). A study by Rousseau, Pietra, Nadji, & Billette de Villemeur (2013) compared locked-in patients and healthy controls on several quality-of-life measures, and found that patient-evaluated quality of life was not significantly different from healthy controls (with the exception being on scales of physical function). The fact that these patients report that they are happy in their state suggests that it may not be in their best interests to withdraw them from life sustaining treatment now.

#### ***4.4.3 Adaptive Preferences***

One potential concern with appealing to the self-report of locked-in patients is that we may have reason for being skeptical about the preferences they express. Specifically, the preference to continue living in the locked-in state may be an ‘adaptive preference.’ On the standard account, an adaptive preference is a preference formed in response to a deprived set of options, and consequently does not reflect on individual’s true interests (Elster, 1983; Nussbaum, 1992). Individuals who claim to prefer to remain in abusive relationships, or women who claim to be satisfied in oppressive societies are typically cited as paradigm examples of holding an adaptive preference, although it is a matter of some dispute whether the autonomy of these individuals is thereby compromised (Friedman, 2003; Taylor, 2009).

It is worth noting that many problematic cases of adaptive preferences involve deeply-rooted moral and political problems, which might influence the ability of an individual to critically reflect on their adaptive preferences. The adaptive preferences of an individual who has spent their entire lives in an oppressive social system may be so strongly habituated that they would fail to repudiate these preferences, even after critical reflection. It is not clear how we can ensure that an individual’s ability to reflect critically on her own adaptive preferences has not been compromised by factors like oppression, or indoctrination. Nevertheless, these complicating social and political factors do not seem applicable to patients in the locked-in state, so I will set them aside.

Should we think that the preferences of locked-in patients are adaptive? On many accounts, adaptive preferences are problematic insofar as they are irrational, resulting from causal processes that are non-autonomous (Elster, 1983), or are justified by factors that do not actually support the adaptive preference (Bovens, 1992). However, there seem



to be many preferences we form in response to a restricted set of options, but which we would not think are irrational. For example, if I cannot afford my dream car (i.e., my car-purchasing options are constrained), I would likely be happier, and fare better, if I came to prefer owning a more economical car, rather than settling for the economical car, and continuing to long for the dream car. This preference is formed in response to my restricted set of options, and reflects what is best for me in light of these options; why should we think that such a preference is irrational?

Accordingly, Bruckner has argued that there ought to be a presumption in favor of the normativity of an individual's preferences, including his or her adaptive preferences, unless, if the agent were to reflect on this preference, she would not endorse this preference as her own (Bruckner, 2005). In the car example, I may have good reasons for preferring the more economical car (e.g., it is more affordable, it is more environmentally friendly), and these reasons are consistent with values that I hold in general. Even though it is an adaptive preference, I can reflect on this preference and endorse it as my own; I am not simply 'fooling myself.' (Sumner makes a similar point when he argues that a condition of an individual's life is prudentially valuable—including, but not limited to, the satisfaction of their adaptive preferences—just in case they authentically endorse it. For Sumner, part of having autonomous values comes from an individual's identifying with them, or acknowledging them as her own after critical reflection. See Sumner, 1996 p.161-171).

The question then becomes, would locked-in patients (or patients diagnosed as vegetative with covert awareness) reflectively endorse their preference to remain in a locked-in state? While this would need to be determined on a case-by-case basis, there is

no reason to think that a locked-in patient's adaptive preference to remain in such a state could not be reflectively endorsed. Locked-in patients are fully conscious, rational beings, who are aware of the limitations imposed by their conditions, and on this basis, could critically evaluate whether or not continuing in this state is something they genuinely prefer.

Granted, there are significant differences between patients with locked-in syndrome, and patients diagnosed as vegetative with covert awareness (e.g. ability to communicate, cognitive capacities), such that the degree of welfare reported by locked-in patients may be different from what would be reported by patients diagnosed as vegetative with covert awareness. However, the example of locked-in patients illustrates how an individual might view a potential state of affairs with disapprobation, and yet, when actually in this state, view it much more favorably. In fact, the potential for changing desires on the part of these patients seems closely connected with the potential for having a misinformed desire in these sorts of cases. Because living in a vegetative state with covert awareness is a highly foreign experience, as well as being a condition about which our scientific knowledge is still developing, it is plausible that one's desire to not go on living in a vegetative state might be misinformed. And, once it becomes evident that this desire was misinformed, it would be reasonable in this case to revise one's desires. As the case of locked-in patients shows, the satisfaction of a past desire is not always consistent with my welfare in the present; this case is a counter-example to Kahane and Savulescu's assertion that if patients diagnosed as vegetative with covert awareness had a past desire not to continue living in such a state, withdrawing them from life-sustaining treatment is most consistent with their present welfare.

The above discussion is not meant to show that patients diagnosed as vegetative with covert awareness have a desiderative interest in continuing to live, nor is it even meant to show that the desiderative interests of these patients are, on balance, satisfied. It is meant to show that a desire-satisfaction account of welfare does not obviously support Kahane and Savulescu's conclusion that patients diagnosed as vegetative with covert awareness are faring badly, such that we may have a moral obligation not to sustain their lives. First, the empirical evidence suggests that these patients may have desires in the present, the satisfaction or frustration of which may contribute to their welfare. Insofar as we are ignorant of those desires and whether they are satisfied, we cannot confidently make a claim about the welfare of these patients. Second, the authors argue that most people would not desire to continue living in a vegetative state, such that continued existence in a vegetative state compromises their welfare. However, I point out that the satisfaction of our actual desires does not always lead to an increase in welfare (and conversely, that the frustration of our desires does not always lead to a decrease in welfare), because there are cases in which our desires are not sufficiently informed. I then present evidence to suggest that a desire not to continue living in a vegetative state may be an ill-informed desire, such that its frustration may not compromise the welfare of the patients under discussion. For these reasons, it is not clear what the desire theory would say about the welfare of these patients, much less that they are faring badly on this conception of welfare.

Nevertheless, I think that Kahane and Savulescu's strongest argument for their conclusion that patients diagnosed as vegetative with covert awareness are faring badly lies in their appeal to the objective interests of patients. Whereas the experiential and

desiderative interests of these patients —and the impact their satisfaction or frustration has on patient welfare— are open to speculation, the claim that they are lacking in certain objective goods seems on much firmer ground. However, I suggest that we may have reasons for objecting to objective theories of welfare, and thus, that Kahane and Savulescu’s most substantive claims about the putative welfare of these patients can be undermined.

#### **4.5 Objective vs. Subjective Theories of Welfare**

What does it mean for a theory of welfare to be ‘subjective’ rather than ‘objective’? As Sumner states, a subjective theory of welfare holds that prudential value depends on the attitudes of the welfare subject; something is good for me only if I have a pro-attitude with respect to it (Sumner, 1996). When I have an attitude towards something, I am inclined one way or another with respect to it, it matters in some way to me, I care about it or mind it, or it is of some concern to me. My attitude towards the thing is positive if I am disposed towards it, and negative if I view it with disfavor. Thus, for any potentially prudentially valuable object or state there will be some characteristic (e.g., its appearance, its function, or some other aspect of its nature) that elicits some attitude (e.g., pleasure, wanting, disliking, repulsion) on the part of the subject, under certain conditions (e.g., the absence of factual errors about the nature of the object) (Sumner, 1996). Desire-satisfaction theories as discussed in the previous section are one such form of subjective theory; some X is good for me, or has prudential value for me, because of my pro-attitude towards it, specifically, that I desire it. (Although the distinction between subjective and objective theories is widely used in the literature, philosophers like Haybron and Tiberius appeal to a broader distinction between

‘internalist’ and ‘externalist’ theories of welfare (Tiberius 2007; Haybron 2008; Hall & Tiberius, 2016). Internalist theories hold that the constituents of an agent’s welfare are determined by the particulars of the agent *qua* individual, —particulars like attitudes, but also values, or emotional conditions—rather than *qua* group or class member. Externalist theories reject internalism).

While subjective theories make our welfare dependant on our attitudes of favor and disfavor, objective theories of welfare hold that at least some things that are intrinsically good or bad for us do not essentially involve our positive or negative attitudes towards them. Some things have prudential value in virtue of their intrinsic nature, rather than in virtue of our attitudes towards them. On an objective theory of welfare, I need not have a favorable attitude towards some objective good X, in order for the presence of X to make my life go better for me, or for the absence of X to make my life go worse, for me.

We can see how subjective theories of welfare cohere with the subject-relativity of welfare. Subjective theories of welfare make welfare depend on one’s own concerns, or attitudes. The things that *you* care about, or that *you* view favourably are what determine your level of welfare. It is these attitudes that form the basis upon which your welfare is judged; your life is going well for you to the extent that it contains objects or states of affairs that you have a positive attitude towards. While various subjective theories will offer differing accounts of what has prudential value, all subjective theories of welfare hold that it is the attitudes of the welfare subject that give certain objects or states of affairs their prudential value, and in turn, determines the level of welfare of the subject. Conversely, objective theories of welfare hold that the attitudes of the welfare

subject are not always necessary for determining how various goods affect her welfare. How then, can these theories explain the perspectival character of prudential value? How can an objective theory of welfare explain how an object or state of affairs is ‘good for me’, without recourse to my own attitudes towards it? In the next section, I will consider various objective theories of welfare, to see if any can adequately respond to this challenge.

#### **4.6 Objective List Theories of Welfare**

One of the challenges of discussing objective theories of welfare in a general way is that objective theories cover a fairly wide range of theories of welfare. I stated above that a common element to all objective theories of welfare is their denial that welfare necessarily depends on one’s attitudes, or schedule of concerns. At least some factors that contribute to—or detract from—our welfare, do so *independently* of our attitudes towards them. In addition, most paradigmatic objective list theories are pluralistic; they are committed to the idea that there is more than one non-instrumental, prudential good. This is contrary to theories like hedonism and desire satisfaction —both monistic theories— which hold that there is only one non-instrumental, prudential good.

Perhaps not surprisingly, there are many differing theories about what sorts of objects or states of affairs objectively contribute to our welfare. Some theories, typically referred to as ‘objective list theories,’ list items that are constitutive of or contribute to individual welfare, but are not in every case dependent on the attitudes of the welfare subject. One such example is given by Finnis (2011), who argues that there are seven basic components of human welfare, (life, knowledge, play, aesthetic experience, friendship, practical reasonableness, and religion) which are independent of our

inclinations, or attitudes towards them. Similarly, Brink (1989) claims to provide an objective theory of welfare, in which he enumerates the primary components of valuable lives, which include “reflective pursuit and realization of agents’ reasonable projects”, and “certain personal and social relationships”. Fletcher (2013) has argued for an objective list theory that includes “achievement, friendship, happiness, pleasure, self-respect, and virtue”.

Certainly, the examples given above are plausible sources of individual welfare. Indeed, one of the reasons that objective list accounts are appealing is that possessing the goods that typically appear on such lists does seem to make our lives go better. This is presumably what motivated Kahane and Savulescu to argue that because patients diagnosed as vegetative with covert awareness lack the cognitive capacities to enjoy these sorts of goods, they must be faring poorly. As Fletcher argues, objective list theories of welfare typically track common-sense morality; our pre-theoretic, intuitive judgments about what has prudential value tend to closely resemble objective list theories (Fletcher, 2016).

Additionally, objective list theories might be thought to occupy a middle ground between what might be thought to be the inadequate number of prudential goods given by hedonist accounts, and the excessive number of prudential goods given by desire-satisfaction accounts. To briefly recapitulate much of what has been discussed above, an objection to hedonism is that pleasure, while an important prudential good, likely isn’t the *only* thing that contributes to our welfare. Similarly, an objection to desire-satisfaction theories is that we may have desires for a wide range of things, the satisfaction of which

probably doesn't increase our welfare. Objective list theories appear to avoid both of these problems of scope.

#### *4.6.1 Objections to Objective List Theories*

However, this appealing aspect of objective list theories is also a source of criticism. Specifically, objective list theories have been criticised for being arbitrary. Objective list theories, insofar as they merely *list* components of individual welfare, do not typically provide an account of why a particular item is on the list of goods. Why should X, Y, and Z be on the list of objective goods, but not W? What do X, Y, and Z have in common that makes them, and nothing else, something that contributes to my welfare?'

Objective list theorists might respond to this objection in several ways. On the one hand, they might dispute the idea that the items on the list should have anything in common, beyond contributing to individual welfare. Alternatively, they might simply point out that many items on an objective list do share important commonalities. For example, a list containing happiness and pleasure could point to the fact that these goods share a common positive affective quality.

However, the most significant objection to objective list theories is that they do not adequately account for the subject-relativity of welfare. Specifically, it seems possible that the items on a list of objective goods may fail to properly 'engage' an individual who possesses them. For example, knowledge is often argued to be an objective good. Yet, we can certainly imagine someone who has a great deal of knowledge, but who fails to be made better off by it, with respect to her welfare, simply because she does not care about having knowledge. Thus, objective list theories are



potentially problematic insofar as they might hold that a person is faring well according to the theory, but whom we would not want to say is actually faring well. We can also frame this objection in reverse; if an individual were affectively unmoved by a particular objective good, it would seem that lacking that good would not make them any worse off.

Fletcher (2013; 2016) has offered an innovative response to this type of objection, which he calls a *constitutive strategy*. Roughly, he points out that some putatively objective goods are necessarily constituted by affective, attitudinal, or volitional states of the person. For example, we might think that happiness is an objective good. Yet, because happiness is constituted by having a certain favorable attitude, it is impossible for an individual to be happy, while also lacking the requisite positive attitude. In this way, a person cannot have the objective good, without also being engaged in the proper way by it. This solves the worry about an individual possessing an objective good, but nevertheless feeling alienated by it (Fletcher, 2013).

However, it is not clear that the constitutive strategy fully accounts for the concern about alienation. Even if we agree that some objective goods are constituted by positive attitudes, such that one cannot have the putative good without having the corresponding positive attitude, it might still be the case that the individual fails to have a positive attitude towards the good. Consider again happiness as an objective good. We can imagine an individual who has the sort of positive attitudes which constitute happiness, but who nevertheless does not value happiness. If this is the case, why should we think that the possession of happiness contributes to her welfare?

Perhaps the objective list theorist can accommodate the subject-relativity of welfare in some other way. Alternatively, they might argue that insofar as alienation is a

legitimate worry, it is addressed by the constitutive strategy. In any case, the relevant issue here is whether or not the sorts of objective goods which Kahane and Savulescu have in mind are vulnerable to an alienation objection, and thus, whether their absence from the lives of the patients under discussion really detracts from their welfare.

Although Kahane and Savulescu only specify a small number of objective goods — knowledge, achievement, development of talents, and having deep personal relationships— they suggest that they have in mind the sort of items which typically appear on objective list theories. However, as we have seen, at least some of those putatively objective goods are vulnerable to an alienation objection, and moreover, do not seem to be constituted by an individual's attitudes (e.g., knowledge, development of talents). Thus, even if we grant that things like deep personal relationships are objectively good (because they are necessarily non-alienating), and further stipulate that patients diagnosed as vegetative with covert awareness are incapable of achieving these objective goods, the objective goods which these patients lack may not be so numerous that their welfare is compromised to the extent that Kahane and Savulescu suggest. It may be the case that these patients do possess some objective goods (e.g., happiness, pleasure), and lack others (e.g., achievement). Thus, how they are faring on an objective list view is somewhat unclear. Answering this question would require a clear account of what items belong on the list of objective goods, which of these items these patients plausibly lack and which they may possess, as well as the relative contribution each of these goods makes to an individual's welfare.

#### **4.7 Perfectionism**

One way of avoiding the objection of arbitrariness sometimes levelled against objective lists is to argue that the elements of an objective list theory are good for me because they contribute to the development and promotion of my distinctly human nature. On a perfectionist account, welfare consists in perfection, which holds that the development and exercise of my distinctly human capacities is prudentially valuable. Although they do not explicitly argue for a perfectionist account of welfare, Kahane and Savulescu emphasize the importance of an individual's cognitive and motivational states—a 'rich mentality'—to the realization of objective goods. The kinds of goods which are objectively valuable on their account require a high degree of cognitive sophistication (which is why patients diagnosed as vegetative with covert awareness are presumed to lack them); one way of accounting for this is to argue that the goods the authors have in mind are those which contribute to the development of one's distinctly human nature. The cognitive and functional limitations of patients diagnosed as vegetative with covert awareness renders them incapable of exercising their distinctly human capacities; accordingly, they must be faring poorly.

One of the earliest perfectionist theories comes from Aristotle. In the *Nicomachean Ethics*, Aristotle attempts to determine the 'highest good' for human beings; something desirable in itself, which is not desirable for the sake of anything else, and for which all other goods are desired (Aristotle, 1984). He claims that the highest good is 'eudaimonia', which can be understood as 'happiness', or, 'the condition of living well.' Everything else we might desire or consider good—health, wealth, honor, sensory pleasure—we desire because they promote our welfare. So what is it that our welfare ultimately consists in, for Aristotle? He attempts to answer this question by arguing that

the good of a thing depends on its function (i.e. its 'ergon'). For example, the function of the heart is to pump blood around the body. If the heart performs this function well, it is a good heart. Aristotle argues that the function of a human being must depend on a function of our soul that is uniquely human, namely, the exercise of the rational capacity of our soul. And, to perform this function well, he argues, we must do so in accordance with virtue. Thus, human good turns out to be activity of the rational aspect of the soul in accordance with virtue. Furthermore, welfare is best achieved through theoretical inquiry, and as such, a good human life is one devoted to philosophy.

Other perfectionist theories follow roughly this same structure, though they may differ slightly with respect to their account of human nature, and the relevant capacities to be developed and exercised. Most perfectionist accounts include capacities like rationality, autonomy, as well as physical and emotional capacities. Importantly, it is not merely the possession of these capacities that has prudential value, but the exercise and development of these capacities. By engaging in certain activities that manifest these distinctly human capacities, we are able to fare well, or flourish, as human beings. Various perfectionist theories offer slightly differing accounts of how the prudential value of certain activities is to be calculated (i.e., the relationship between quality and amount of capacity development).

We can understand perfectionist theories of this kind as making three important claims. First, perfectionist theories hold that welfare is teleological; our welfare consists in the fulfillment of our natures. Second, perfectionist theories are *externalist* about welfare. What is important about my nature, with respect to my welfare, depends not on facts about me, but facts about my kind (e.g., the human species). What contributes to my

welfare is what contributes to my functioning in a characteristically human way. Third, perfectionist views claim that welfare consists, non-derivatively, in perfection, excellence, or virtue. (A desire-theory might hold that welfare consists derivatively in perfection or excellence, were this desired by the individual). Fulfillment of one's characteristically human nature involves some sort of perfection, excellence, or virtue; human flourishing depends, at least primarily, on perfection or excellence.

We can see how grounding welfare in this way is appealing as an objective account of welfare. Recall that an objective account needed to explain how certain objects or states of the world could have prudential value, (i.e. how they could make my life go better, for me) without appealing to their mind-dependant properties. First, making welfare depend on the satisfaction of certain functions requires no appeal to the subjective attitudes of the welfare subject, and thus is appropriately mind-independent. Second, whether I am faring well or badly depends on the degree to which I am functioning well; the extent to which a certain state of affairs affects my functioning thus seems to explain how I might view such a state of affairs as good or bad for me.

#### ***4.7.1 Objections to Perfectionism***

Perfectionism does faces significant challenges, however (Sumner, 1996; Haybron, 2009). First, philosophers like Sumner not only deny that objective theories like perfectionism are adequate conceptions of welfare, they deny that objective theories like perfectionism are even talking about the concept of welfare. Sumner has argued that perfectionism rests on a confusion between perfectionist value, and prudential value (Sumner, 1996). While prudential value is relativized to the subject, perfectionist value is relativized to the subject's kind. Thus, because welfare is concerned with prudential

value, the perfectionist is not really talking about welfare at all. As Sumner points out, this fatal flaw is easy enough to overlook when we are considering relatively simple organisms (Sumner, 1996). For example, in the case of a tree, we have no way to measure its flourishing, other than by considering those features of the tree which we typically count as excellences in trees, such as healthy leaves, a healthy root system, and the absence of disease. But this means that we only have one mode of value that is applicable to trees, namely its perfectionist value. While we may sometimes speak of the ‘welfare’ of the tree, we are not talking about welfare in the strict sense in which we do when we are talking about human beings, for example. This is because while certain states of the world may be good or bad for the tree, they are only good or bad with respect to its being a better or worse example of its kind.

Conversely, when we are talking about entities with a subjective point of view, there is a clear distinction between prudential value and perfectionist value. Prudential value is concerned with what is good for the particular individual whose welfare is under consideration; what counts as good for me depends in some way on what I am like. Because Sumner accounts for the subject-relativity of welfare by appealing to the attitudes of welfare subjects, he holds that a concept of welfare which holds that prudential value is based on something other than an individual’s attitudes or values (e.g., characteristic human capacities) is not talking about the concept of welfare at all (Sumner, 1996).

Nevertheless, at least some perfectionist theories are theories about welfare, arguing that it is good for a subject to develop and exercise those capacities central to human nature. Yet it is not obvious that welfare requires perfection. There are many

instances of individuals who fail to develop their characteristic human capacities, but who nevertheless seem to be faring well. We can imagine Gene, who is endowed with incredible talents for rationality, autonomy, and the other distinctively human capacities, but who nevertheless chooses to watch television all day, because this is simply all that interests him. In fact, he gains a great deal of pleasure and satisfaction from watching television, and would say that he is extremely happy. While we might be reluctant to say that he is flourishing, it seems less easy to deny that he is faring well.

Similarly, as Haybron points out, sometimes the pursuit of a life which more fully exercises our capacities as human beings seems to require sacrificing our welfare (Haybron, 2008). He gives the example of Angela, a career diplomat forced to choose between her planned retirement, and an important political post. On the one hand, her retirement would be tremendously satisfying. On the other hand, her political efforts might help avert a potentially bloody political crisis, and while her work is demanding and often highly stressful, she does take satisfaction in doing what she does best. Intuitively, Haybron argues, what is best for Angela's welfare is retirement; by accepting the position she has sacrificed her welfare. Yet on a perfectionist view, accepting the position is best for Angela, because accepting the position results in a greater exercise of her distinctively human capacities. Haybron states: "by any reasonable measure, the diplomatic assignment involves greater perfection: it is obviously more virtuous, more admirable...and involves a greater degree of human functioning" (Haybron, 2008 p. 162). While there may be some aspects of human life (e.g., personal relationships, leisure) that Angela might pursue with greater excellence in retirement, "there is no credible sense,

non-moral or otherwise, in which Angela, or her activities, would exhibit more excellence on the whole if she retired” (Haybron, 2008 p. 163).

Finally, like the objective list theories considered above, perfectionist accounts may be criticised for failing to adequately account for the subject-relativity of welfare. On a perfectionist account, what is good for me is to develop my distinctly human capacities. Thus, what is good for me on such an account depends on what I am like *qua* human being (or perhaps, *qua* person), but not what I am like as an individual, with my own idiosyncratic tastes, dispositions, values, desires, and needs. Certainly, knowledge about species-level or group-level traits might be useful to a certain extent in making predictions about what might be prudentially valuable for a given member of that group. However, when we are considering whether X will promote the welfare of this particular person, in this particular situation, we do seem to appeal to traits about the individual herself, rather than whether X results in the fullest development of my distinctly human capacities. Why should we think that facts about what other individuals are like (i.e., group-level traits), determine what is prudentially valuable for me? People may have a wide range of values, attitudes, preferences, desires and concerns; it stands to reason that what it means for one individual to be faring well might be different from what it means for another person to be faring well, because they are different people. What is good for me may be different than what promotes my distinctively human functioning, because what matters to me may be different from those capacities that make me distinctively human. On a perfectionist account, what is good for me is just what is good for all other entities like me; in this way, it fails to account for the subject-relativity of welfare. Consequently, the fact that patients diagnosed as vegetative with covert awareness are



unable to exercise their distinctly human capacities may not in and of itself entail that they are faring poorly.

#### **4.8 Welfare as Emotional Self-fulfillment**

Interestingly, some objective accounts of welfare which appear to account for the subject-relativity of welfare may actually contradict Kahane and Savulescu's claim that patients diagnosed as vegetative with covert awareness are faring poorly. One such theory has been offered by Haybron (2009). Haybron proposes an account of welfare which rejects the idea that prudential value depends exclusively on an individual's attitudes, (and is thus objective), while also accepting internalism.

Like the perfectionist accounts considered above, Haybron argues that welfare consists in the fulfillment of our natures. However, while perfectionist accounts ground welfare in the fulfillment of our distinctively human capacities, Haybron's account grounds welfare (at least partly), in the authentic happiness of the individual. And, he argues, because authentic happiness is central to the fulfillment of our individual natures, and thus, central to our welfare, authentic happiness is non-instrumentally prudentially valuable.

The idea of happiness is central to Haybron's conception of welfare. Haybron offers an emotional state account of happiness, a theory which takes happiness to consist in a person's overall emotional condition, that is, their central affective states (e.g., moods, emotions), and their mood propensities. On this view, the contribution a particular affective state makes to one's happiness is a function of both its intensity, and its centrality. Haybron defines central affective states as those which dispose us to experience certain affects rather than others. For example, depression is a central

affective state, because it influences how we experience other affective states.

Additionally, Haybron describes central affective states as being persistent, pervasive, and profound; when they occur, these states “amount to what are much like short-lived alterations in one’s temperament, or personality.” (Haybron, 130). In contrast, peripheral affective states are those such as amusement or annoyance; they do not generally affect our emotional conditions.

We can further describe these moods and affective states along three dimensions, each representing a different mode of emotional response to one’s life. Haybron claims that all emotional states instantiate one or more of these basic modes of affective response. *Attunement* can be understood as a sort of tranquility or peace of mind (as compared to anxiety or insecurity). *Engagement* concerns an individual’s feelings of exuberance or vitality towards aspects of her life, as opposed to feelings of depression or listlessness. Finally, *endorsement* involves feelings of joy or cheerfulness, as opposed to sadness or irritability.

Accordingly, to actually be happy is, roughly, for one’s emotional condition to be broadly positive—involving positive stances of attunement, engagement, and endorsement—with only minor negatives, embodying a stance of what Haybron calls ‘psychic affirmation’ in response to one’s own life.

Haybron argues that the central role of happiness in his account of welfare is a result of the deep connection between happiness, and our individual identities. Haybron uses a ‘thick’ notion of identity, which encompasses aspects like our social roles, our character, and our temperament, as well as our emotional nature. Our emotional nature is our disposition to be characteristically happy in certain circumstances and not others, and

can be influenced by our temperament, desires, values, and other character traits. Because our unique individual nature is in part constituted by our emotional nature, achieving self-fulfillment —faring well— requires (at least in part) the satisfaction of our emotional nature; it requires happiness.

Haybron claims that happiness as a prudential good satisfies the subject-relativity of welfare. What makes us happy, and thus, what contributes to our welfare, depends on who we are as individuals; it depends on our emotional natures. However, one might object that insofar as Haybron's account appeals to the prudential value of nature fulfillment (even if it is the fulfillment of our individual natures), it fails to adequately address subject-relativity. For Haybron, happiness contributes to our welfare insofar as it contributes to the fulfillment of our natures (and, Haybron presumes, it is good to fulfill our natures). Accordingly, it is an objective value; happiness is intrinsically good for the individual who has it, whether they want it, or would want it after sufficient reflection, or not. Yet, we can imagine someone who is happy in Haybron's sense, but simply does not care about being happy. Perhaps this individual is the rare person who values being *unhappy*. Why should we think that being happy is nevertheless intrinsically good for him? Indeed, it seems that this sort of individual would be better off if he lacked happiness.

Of course, this is the same sort of objection which was levelled against the objective list theorist, and so a similar rejoinder might be offered. Nevertheless, my aim in introducing Haybron's theory is to demonstrate that a plausible objective theory might show that patients diagnosed as vegetative with covert awareness are not necessarily faring poorly, insofar as they possess certain objective goods.

#### 4.9 Satisfying an Objective Good: Happiness in the Vegetative State With Covert Awareness

Could a patient diagnosed as vegetative with covert awareness be happy on Haybron's account? In other words, could the life of an individual diagnosed as vegetative with covert awareness be emotionally fulfilling? It seems at least *possible* that it might be. Recall the earlier examples of locked-in patients who reported overall feelings of happiness. Even though the physical capacities of these patients are highly limited, it is nevertheless possible for these patients to maintain a broadly positive emotional condition. Similarly, there seems to be no reason that patients diagnosed as vegetative with covert awareness necessarily could not be happy on Haybron's account. The fact that their physical (and perhaps cognitive) capacities are limited does not seem to rule out the possibility of their holding a positive stance towards the affective states they experience.

A potential concern, however, is Haybron's requirement that a central component of welfare is *authentic* happiness. Haybron adopts an account of authenticity given by Sumner, and argues that our happiness must be a response to our lives that is truly ours. For Haybron, our emotional nature cannot be the subject of manipulation, or be otherwise non-autonomous, or else our happiness will be inauthentic. Further, authentic happiness seems to require proper cognitive function, at least to a certain degree (e.g., a brain pathologically stuck on 'happy' would not be authentically happy). Finally, authentic happiness for Haybron requires a degree of richness. Haybron asserts that "happiness increases, other things being equal, to the extent that it is grounded in richer, more

complex ways of living. For such ways of living more fully express one's nature” (Haybron, p. 186).

It seems reasonable to think that patients diagnosed as vegetative with covert awareness could satisfy the first two requirements for authenticity (i.e., that their putative happiness is not a result of manipulation, and that they are not pathologically happy). One potential area of concern might be that these patients are unaware of the full extent of their condition, in which case their happiness might be argued to be inauthentic; their putative happiness would not be a response to their own lives, and thus would not contribute to their self-fulfillment. However, Haybron states that the prudential value of happiness “*qua* self-fulfillment is undermined in proportion to the shortfall in authenticity” (Haybron p. 189). This suggests that even if a patient diagnosed as vegetative were ill-informed about certain aspects of her condition, there might still be aspects of her life about which she might be authentically happy, insofar as she was not mistaken about these aspects of her life.

Could a patient diagnosed as vegetative with covert awareness satisfy the richness requirement? Haybron states that happiness increases as the individual more fully expresses his nature; typically, a more complex and richer life more fully expresses one's nature. For example, an individual leading an ‘impoverished life’ in which he did nothing but count blades of grass might be happy, insofar as he had a broadly positive emotional condition, but would not be *authentically* happy in a way that contributed to his self-fulfillment, because other ways of living would better express his nature. Yet, it seems conceivable that a patient diagnosed as vegetative with covert awareness might lead what would be considered an ‘impoverished life’ for a healthy individual, but that nevertheless

expressed her nature. Given her limited capacities, a relatively limited life may nevertheless fully express her nature. And, if this individual had a broadly positive emotional condition with respect to her life, it seems that such a patient would be authentically happy on Haybron's view.

While the above discussion of objective theories of welfare does not exhaust all possible iterations of the general theory, I believe that it provides a representative sample of both their intuitive appeal, as well as their weaknesses. On the one hand, most objective list theories contain items which seem plainly constitutive of welfare; in fact, with respect to the actual items presented as prudentially valuable, objective theories would likely overlap significantly with their subjective counterparts. However, objective list theories can be criticised for being arbitrary; they may fail to provide an account of why certain items appear on the list of objective goods, and not others. A potential solution to this concern is to appeal to perfectionist theories, which hold that something is intrinsically good for me insofar as it exercises my distinctly human capacities. However, perfectionist views introduce other concerns, including, that they are not sufficiently subject-relative.

Some objective theories do appear to appear to accommodate at least some idea of subject-relativity. For example, Haybron's account holds that welfare is at least partly constituted by the fulfillment of our individual emotional natures. Our emotional natures are not determined by group-level traits about us; rather, they are closely connected to our unique, individual 'self.' However, I have argued that it is at least possible for patients diagnosed as vegetative with covert awareness to possess this objective good. Accordingly, even on an objective account of welfare, it may be the case that patients

diagnosed as vegetative are not faring so poorly that we ought to withdraw life-sustaining treatment.

I have not argued that patients diagnosed as vegetative with covert awareness actually are happy. Nor have I argued that happiness is the only prudentially valuable objective good, such that if a patient were happy, they would be faring well. Happiness may be only one aspect of individual welfare; even if these patients were happy, they might nevertheless be faring poorly on an objective account, if they were lacking enough other objective goods (or possessed enough other objective evils). At the same time, happiness is widely accepted as a paradigm objective good; if anything is intrinsically good for an individual, happiness seems to be. Thus, even if these patients were lacking in other objective goods, insofar as they possessed happiness, this might plausibly contribute to their welfare more than lacking those other goods might detract from it. To fully pursue this line of argument, however, some account would need to be given about how to weigh the relative prudential value of various objective goods. Providing such an argument here goes beyond the scope of this project.

I do take myself to have shown that appealing to the 'objective interests' of patients diagnosed as vegetative with covert awareness in the way that Kahane and Savulescu do, does not obviously show that these patients are faring poorly. On the one hand, some of the objective goods which these patients lack may not actually be relevant to their welfare (because they are not sufficiently subject-relative). On the other hand, of those objective goods which do seem to plausibly contribute to individual welfare (e.g., because they depend for their prudential value on the subject's individual nature), these patients may possess at least some of them (e.g., pleasure, happiness).

#### 4.10 Summary

As we have seen, Kahane and Savulescu's assessment of the welfare of patients diagnosed as vegetative with covert awareness faces some difficulties. The authors' goal is to demonstrate that the mere presence of consciousness is not a sufficient reason for preserving the lives of these patients; it is a patient's interests—interests which the presence of consciousness is necessary but not sufficient for—that are relevant to a determination of their welfare. To do this, they adopt a common-sense, pluralist notion of welfare, and argue that on this sort of account, these patients are faring poorly, such that our concern for their welfare may obligate us to withdraw life sustaining treatment from them. I argue that their analysis of these patients is ultimately mistaken; considerations of patient welfare do not clearly support the withdrawal of life-sustaining treatment. First, Kahane and Savulescu argue that the mere experience of pleasurable states may not be sufficient for sustaining the lives of patients diagnosed as vegetative with covert awareness, even though experiential interests do contribute to welfare. They speculate that the kinds of experiential interests these patients are capable of do not supply enough benefit to them to justify preserving their lives. Conversely, I argue that there is empirical evidence to suggest that these patients may be capable of significant experiential interests, which may be sufficient to justify sustaining their lives.

Kahane and Savulescu also argue that if we consider the welfare of these patients from the perspective of their desiderative interests, their welfare is likely to be poor. They claim that these patients likely have only the most basic desires in the present, and consequently, considerations of their welfare should appeal to those desires they held in the past. The authors point out that many people would not desire to continue living in a



vegetative state, and infer that this is a desire held by patients who are actually in a vegetative state. Thus, the past desires of these patients should weigh against preserving their lives. Contrarily, I argue that these patients may have present desires, and moreover, that these present desires may be relevant to their current welfare. We should be cautious in speculating on their desires in the absence of any evidence one way or another. I also point out that even if we restrict our consideration to the past desires of these patients, it is not obvious what they tell us about patient welfare. This is because it is possible that the satisfaction of certain desires may not contribute to our welfare. Not only can our desires be ill-informed, but they also may change over time, such that when the time comes to satisfy a past desire in the present, we may no longer endorse this desire. This is especially relevant with respect to the patients at hand. It is an open question whether an individual's past desire not to live in a vegetative state is well-informed, as well as whether they would still hold this desire when they are actually in a vegetative state with covert awareness. Thus, it is not clear whether withdrawing life-sustaining treatment (thereby satisfying their previous desire) is actually consistent with their welfare.

Finally, Kahane and Savulescu argue that the objective interests of patients diagnosed as vegetative with covert awareness are frustrated by their condition, and as such, their welfare is compromised. However, objective theories of welfare face a significant challenge in explaining the subject-relativity of welfare; without appealing to the attitudes and values of the individual, on what grounds can we say that a certain condition or state of affairs is good for the individual whose life it is? And, if we do not accept a theory of welfare based on objective goods, why should we think that a lack of objective goods implies that a patient is faring poorly?

The pluralistic theory of welfare which Kahane and Savulescu adopt leaves us with an indeterminate answer with respect to the welfare of patients diagnosed as vegetative with covert awareness. While our pre-reflective intuitions may support Kahane and Savulescu's contention regarding the welfare of these patients, closer analysis shows that these intuitions may be mistaken. When we consider the experiential, desiderative, and objective interests of these patients collectively, we simply do not have a clear answer about how these patients are faring. And because how these patients are faring remains unclear, I argue that we should reject the strong conclusion that we have an obligation to withdraw life sustaining treatment. So where does this leave us? Kahane and Savulescu are correct that it is the interests of patients (and not merely the presence of consciousness) which must guide our moral obligations to them. Yet, as we have seen from the foregoing discussion, traditional theories of welfare are not easily applied to these patients, because we know so little about their present attitudes, desires, values and experiences. Thus, to determine whether something has prudential value for these patients, we first need to gain some sense of what these patients actually value, desire, have pro-attitudes towards, and even more fundamentally, what they actually experience. While this may not provide us a clear answer to how these patients are faring according to traditional theories of welfare, it will give us some sense of what the mental lives of these patients are like, and from this, we can begin to generate some account of how their lives are going, for them.

## **Chapter 5: Model Patient Groups and Covert Narrative Capacity: Novel Strategies for Assessing Welfare in Patients Diagnosed as Vegetative With Covert Awareness.**

As I have argued in the previous chapter, determining the welfare of patients diagnosed as vegetative with covert awareness is challenging. In the last chapter, I critically examined an attempt by Kahane and Savulescu to argue that these patients are faring poorly, such that we may not have an obligation to sustain their lives, and, in fact, we may have an obligation to end their lives. Kahane and Savulescu considered three types of interests that might ground an individual's welfare, and argued that these interests were likely frustrated in patients diagnosed as vegetative with covert awareness. I argued, on the other hand, that this conclusion is too strong.

Thus, while Kahane and Savulescu may have been too hasty in their conclusion about the welfare of these patients, it remains unclear what exactly we *can* say about their welfare. As the previous chapter has shown, we do not yet know enough about the subjective experiences of these patients to say whether or not their putative experiential, desiderative, or even (some) objective interests are, on balance, satisfied or frustrated. Thus, even if we could adjudicate between the various conceptions of welfare on offer, it may be challenging to fruitfully apply a specific conception of welfare to a member of this patient group, and generate a clear assessment of their welfare.

For example, suppose that an informed desire-satisfaction theory turned out to be the correct theory of welfare. In order to determine how these patients were faring, we would need to know, at least, most of the patient's informed desires, as well as whether these desires were satisfied. Yet, as I discussed in the previous chapter, it seems that we currently know few (if any) of these patient's desires. And, even if we did know the

patient's desires, we may be unable to say whether they are satisfied. While the situation may be slightly more positive with respect to a patient's experiential desires, insofar as prudential value is subjective-relative, any theory of welfare will be challenging to apply, insofar as we know very little about a patient's attitudes and values. Still, without a clearer understanding of the subjective experiences of these patients, we risk making an erroneous inference about their welfare, which in turn may shape future treatment or care decisions made on their behalf.

At the same time, as I will demonstrate in this chapter, it is clear the cognitive capacities of these patients are such that, at least practically speaking, we are past the point of questioning whether these patients ought to be provided with life-sustaining treatment. While it is an open question whether or not these patients are *actually* faring well, the arguments presented in the last chapter, as well as additional empirical evidence which I will discuss later in this chapter, should be enough to show that these patients are at least capable of possessing sufficient prudential goods that considerations of welfare would rule out ending their lives. Thus, our priority with respect to these patients should be ensuring that they are able to live lives of at least decent quality. What we need to better understand is how we can promote their welfare.

How might we gain a clearer sense of the welfare of these patients? Ideally, we could investigate the welfare of these patients directly, by determining the relevant ingredients of their welfare, and inquiring how they are faring with respect to these goods. With this information, both family members and the health care team could develop strategies for promoting the welfare of these patients, as well as using this information to help make decisions on the patient's behalf. However, directly

investigating the welfare of patients diagnosed as vegetative with covert awareness in this way faces several difficult challenges. Not all patients who are able to perform the mental imagery task are also able to do so to communicate with researchers. For these sorts of patients, self-report about their welfare is not possible. Moreover, even for those patients who can communicate using mental imagery, communication is limited to yes-or-no questions, is highly time-consuming and exhausting for patients, and it requires the use of expensive technology that may not be widely available. How, then, might we proceed?

In this chapter, I will outline a potential method for determining a preliminary account of the welfare of patients diagnosed as vegetative, with covert awareness. This method mirrors the basic goal of the ideal approach given above, in attempting to determine the ingredients of patient welfare, and whether or to what extent these patients possess these ingredients. However, the ideal approach starts with a conception of welfare and generates an assessment of welfare based on this conception, and facts about the individual. Conversely, the method I propose begins with facts about the patient, and attempts to construct a plausible, piecemeal assessment of welfare based on these facts. Based on the cognitive and experiential capacities of these patients, and given reasonable assumptions of what might be prudentially valuable for these patients (in a way that is, as much as possible, subject-relative but does not entail any particular conception of welfare), what can we plausibly say about their welfare?

Accordingly, I propose two complementary strategies. The first is to appeal to the subjective experiences of a variety of patient populations, outside those with disorders of consciousness—specifically, patients with traumatic brain injury, locked-in syndrome, amyotrophic lateral sclerosis, dementia, and Huntington’s disease—and explore various

methods that have been used to assess the welfare of these patients. While patients diagnosed as vegetative with covert awareness are a unique patient population, there may be some overlap, or some common underlying themes, between these patients and other patients experiencing severe physical and/or cognitive limitations, with respect to the domains of life which are most relevant to their welfare. Thus, by investigating those domains which are relevant to the welfare of these other groups of patients, and the methods in which their welfare is assessed, we may gain some insight into the potential welfare of patients diagnosed as vegetative with covert awareness. Importantly, the purpose of this exercise is not to generate a comprehensive account of the domains contributing to the welfare of patients diagnosed as vegetative with covert awareness. Rather, it is to gain a general sense of the sorts of life domains which may contribute to their welfare, and provide a potential starting point for efforts to promote their welfare.

Two additional points should be noted here. First, this strategy is intended to be consistent with the subject-relativity of welfare; I do not commit to any particular conception of welfare (although this strategy may be inconsistent with some objective theories). Accordingly, the prudential goods which I infer from the various populations I will discuss may be prudentially valuable in virtue of being pleasurable, satisfying an informed desire, satisfying a pro-attitude, etc. My interest here is a plausible account of some of the ingredients of patient welfare, rather than an explanation of their prudential value. However, I am not simply stipulating a list of prudential goods, but attempting to generate a plausible collection of prudential goods from those goods that other, similar patients actually do value. Second, instead of considering specific prudential goods, I will focus on more general domains of welfare. Rather than trying to determine whether a

particular patient values this or that putative good (e.g., the absence of pain in my foot, or the desire to walk without assistance), I focus on whether a particular patient values the sorts of goods which roughly translate to specific domains of their life (e.g., physical functioning). While this approach sacrifices a degree of sensitivity to the potentially idiosyncratic values or attitudes of particular patients, it is useful in gaining at least a general sense of the ingredients of welfare for these patients.

The second strategy involves further investigation into the kinds of subjective experiences these patients can, and do, have. To illustrate, suppose that the cognitive capacities of these patients go beyond language comprehension and working memory (i.e., two of the cognitive capacities required to perform the mental imagery task), or that their subjective experiences go beyond the enjoyment or suffering as a result of physical pleasure or pain. This could make an important difference to their overall welfare, because it introduces a much wider range of possible prudential interests. By incorporating this information about the capacities of these patients for certain experiences with inferences about the domains of life which might plausibly be relevant to their welfare, we may gain a clearer sense not only of what is important to these patients, but also practical ways that we can satisfy these interests.

For example, suppose that a patient's physical functioning is a central component of their welfare. If it is the case that this patient lacks the capacity for non-reflexive movement, we would have good reason for thinking that, at least within this domain, the patient is faring poorly. On the other hand, suppose that social interaction is a central component of a patient's welfare. Having some insight into how the patient experiences social interactions —whether the patient can recognize familiar faces or voices, if they

can experience emotions, or recognize them in others— may help to determine whether such an experience contributes to the patient’s welfare, and moreover, how such an interaction might proceed to best promote their welfare. Determining further psychological capacities of these patients might provide insight into additional ways in which their welfare can be enhanced, including the satisfaction of a broader range of experiential interests, and perhaps even higher-order interests.

### **5.1 Assessing Welfare: Analogues of Patients Diagnosed as Vegetative With Covert Awareness**

Let us begin with the first task, outlined above: determining the domains of life potentially relevant to the welfare of patients diagnosed as vegetative, with covert awareness. As we saw in Chapter 4, on a subjective account of welfare, prudential value depends on an individual’s attitudes; the prudential value of X for person A depends on person A having a favorable attitude towards X. Thus, even if it turns out that the patients under consideration are capable of experiencing a variety of mental states, beyond physical pleasure and pain, why should we think that these sorts of experiences are prudentially valuable for them? In other words, why should we think that these experiences contribute to their welfare? To answer this question, we need to have some idea of those domains of life that are most important for the welfare of these patients.

### **5.2 Quality of Life and Health-related Quality of Life**

One of the ways in which individual welfare is often quantified is through an assessment of ‘quality of life’. For example, the World Health Organization defines



quality of life as “individuals’ perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns” (Szabo, 1996). Accordingly, the World Health Organization’s Quality of Life Assessment attempts to provide a measure of quality of life that covers “key physical, psychological, social, and spiritual domains of life” (WHOQOL, 1998). A related concept is ‘health related quality of life’, which attempts to define quality of life in terms of the impact one’s physical health has on the physical, emotional, and social domains that encompass quality of life in general.

Assessments of health-related quality of life can take a number of forms. First, generic health-related quality of life assessments may ask patients to rate their level of disability across a number of domains, either by filling out questionnaires, or participating in semi-structured interviews. For example, the Short-Form 36 Health Survey measures patient quality of life across eight sections: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, social role functioning, and mental health (Ware & Sherbourne, 1992). Similarly, the McGill Quality of Life Scale assesses patients’ health-related quality of life according to four subscales: physical symptoms, psychological symptoms, outlook on life, and meaningful existence (Cohen, Mount, Strobel, & Bui, 1995). Other generic measures of health-related quality of life, which appeal to similar domains of patient welfare, are the Sickness Impact Profile (Bergner, Bobbitt, Carter, & Gibson, 1981), and the Nottingham Health Profile (Hunt, McKenna, McEwen, Williams, & Papp, 1981).

The problem with these sorts of generic health-related quality of life assessments is that in attempting to evaluate participant quality of life according to a prescribed set of

domains, they may overlook certain domains of life that are highly relevant to the participants, or overemphasize those domains of life that are less relevant. For example, a health-related quality of life assessment may ask a participant to evaluate their degree of social connectedness with others, in light of a certain disability. If the patient evaluates this domain as poor, one might infer that their overall quality of life is thereby diminished. However, if the participant simply does not value social connectedness, the poor quality of their social connectedness likely does not factor into their overall quality of life. In this example, the quality of life assessment may provide an inaccurate account of the individual's quality of life, because it fails to evaluate quality of life according to domains relevant to the participant; specifically, it overestimates the importance of a particular domain to a patient's overall welfare. This becomes a problem when trying to develop quality of life assessments for patients with significant disabilities or illness, because, for example, their unique health needs or limitations may alter the dimensions according to which they evaluate their quality of life. Additionally, research suggests that accounting for the relative importance of certain life domains provides a better indication of overall subjective welfare than using a summary or average of these life domains (Hsieh, 2003). For these reasons, it is critical to ensuring an accurate representation of a patient's subjective welfare, that assessments of individual welfare focus on domains of life which the patient genuinely (i.e., rationally, authentically, etc.) values.

In response to this problem, specialized quality of life assessments have been developed for a number of patient groups, including those with HIV, dementia, and stroke. However, some of these specific quality of life assessments, such as many of those for patients with dementia, focus on observable aspects believed to be indicative of

quality of life, such as symptom severity and physical function (Trigg, Skevington, & Jones, 2007). For this reason, disease or disability-specific quality of life assessments may provide an inaccurate assessment of patient quality of life, for the same reason as generic quality of life assessments. As Leplege and Hunt argue, the medical model of quality of life places a significant emphasis on functional capacity; one of the most important aspects of quality of life is the ability to perform everyday tasks, and fulfill social and occupational roles in the same way as before one's illness or injury (Leplege et al., 1997).

Implicit in this claim is the idea that a certain level of physical function is an essential component of individual welfare; to the extent that one has an impairment or experiences a deficit in one's physical functioning, one is incapable of faring well in one's life (or at least, of faring nearly as well as an individual without such impairments). Indeed, this assumption is exemplified by what is referred to as the 'disability paradox'; the tendency of patients with significant disability or illness to report higher levels of subjective welfare or quality of life than would be predicted by others, based on objective factors such as their level of physical function (Albrecht et al., 1999; Amundson, 2010). The fact that healthy individuals tend to systematically evaluate the welfare of individuals with disabilities or severe illnesses as poor, suggests that they judge these disabled or ill individuals as lacking certain prudentially valuable goods; they are deficient in at least some of the domains contributing to welfare. For example, while some research has shown moderate agreement between proxy evaluations of patient quality of life and patient self-evaluation for patients after moderate and severe traumatic brain injury (Cusick et al., 2000; Schmidt et al., 2010) and stroke (Sneeuw et al., 1997; Hilari et al.,

2007), research involving patients with dementia has shown less agreement between proxy and patient evaluations (Moyle et al., 2012; van der Wilt et al., 2013).

Moreover, the agreement between patient's and proxies tends to pertain to directly observable factors, such as a patient's level of physical function, whereas agreement is often poor concerning more subjective factors, such as social functioning or perceived health (Novella et al., 2001; Tamim, McCusker, & Dendukuri, 2002; von Essen, 2004). This divergence between the self-report of patients about their quality of life, and the reports of proxies about patient quality of life, suggests that proxies may be evaluating the quality of life of patients according to a different value set than patients themselves. That is, they may be applying their own prudential values to the circumstances of the patient, rather than assessing the patient's quality of life from the patient's own perspective.

Conversely, the fact that disabled individuals often report high levels of welfare suggests that they are reasonably satisfied within the domains of life which they feel contribute to their welfare. By focussing on those domains of life which patients themselves report as being most relevant to their welfare, quality of life assessments can generate a more accurate picture of how the patient is actually faring, as opposed to whether or not they satisfy certain objective criteria that may not be related to the patient's welfare.

### **5.3 Adaptation, Response Shift, and the Validity of Patient Self-Report**

One potential issue with relying on patients' self-reported quality of life arises from the possibility of the patient adapting to the circumstances of their illness or

disability over time. After undergoing a significant change in one's health status (e.g., a severe injury, illness, or disease), a patient may alter their behaviour, desires, attitudes, goals, and values to conform to their new circumstances. As Menzel, Dolan, Richardson, and Olsen (2002) argue, adaptation to illness or injury may take on a number of forms, both positive and negative, including cognitive denial of functional health state, suppressed recognition of full health, skill enhancement, activity and goal adjustment, and an altered conception of the meaning of health.

Within the quality of life literature, a patient's ability to adapt to an illness or injury is often conceptualized in terms of 'response shift.' Response shift refers to a recalibration, reconceptualization or reprioritization of a patient's values in response to significant changes in their circumstances, in a way that affects their self-evaluation. (Sprangers & Schwartz, 1999; McClimans et al., 2013; Blome & Augustin, 2015). Thus, because of the potential for response shift, a patient's values may not remain stable over time, and accordingly, what may have had significant prudential value at one time (e.g., prior to a patient's injury), may no longer have the same level of prudential value (e.g., at some time point after their injury).

Sprangers & Schwartz (1999) distinguish between three different dimensions of response shift. 'Recalibration response shift' refers to when a patient understands the response scale differently in pre-test than in post-test. 'Reprioritization response shift' occurs when a patient changes the value she assigns to various elements of her life over time; domains of life which at one time were assigned a very high value become less important, and vice versa. Finally, 'reconceptualization response shift' refers to when a patient changes her definition of what quality of life is. Similar to reprioritization,

reconceptualization involves the patient basing his assessment of his quality of life on different factors than before. However, in reconceptualization response shift, the areas of one's life that are important to welfare undergo change, as opposed to changing the perceived importance of factors which determine one's welfare. Response shift is understood by some as representing a confounding factor in patient's evaluations of their own quality of life (Sprangers & Schwartz, 1999; Schwartz, Andresen, Nosek, & Krahn, 2007; Oort, 2005). Because the standards according to which the patient is evaluating her quality of life have changed over time, the argument goes, it is difficult to determine whether a change in a patient's evaluation of her quality of life represents a genuine improvement in her condition, or whether the change is simply a result of the patient having altered her internal standards of evaluating her condition. This makes it challenging to compare patient-reported health-related quality of life over time (Barclay-Goddard, Epstein, & Mayo, 2009).

Yet, it is unclear whether response shift actually undermines the validity of patients' self-reports about their quality of life. While response shift may distort the effects of a particular health-care intervention, and thus, make it difficult to determine whether improvement has occurred according to some objective measure (e.g., recovery of function), this seems to be a separate issue from the question of a patient's subjective welfare. Insofar as we are interested in a patient's perceptions of her own welfare—how her life is going for her—response shift does not necessarily undermine the validity of a patient's self-report. The fact that a patient's values have undergone recalibration, reprioritization, or reconceptualization, does not entail that these values are necessarily inauthentic or irrational; in fact, response shift of this sort may be a rational response to

one's situation. This is consistent with the idea of 'hedonic adaptation', sometimes referred to as 'the hedonic treadmill' (Frederick & Lowenstein, 1999; Diener, Lucas, & Scollon, 2006). First proposed by Brickman and Campbell (1971), the hedonic treadmill model holds that one's emotional system adjusts to one's current life circumstances; periods of extreme happiness or sadness are typically followed by an eventual return to a neutral baseline. (Brickman & Campbell, 1971; Brickman, Coates, & Janoff-Bulman, 1978). The original model has been substantially refined by subsequent theorists, in order to reflect that fact that individual baselines of subjective welfare may vary across individuals, and may not be based on a single factor (Diener et al., 2006), or that the factors to which one attends (such as whether a condition is permanent or temporary) can play a significant factor in adaptation (Wilson, 2005; Wilson, 2006), for example. Nevertheless, the crux of the model has repeatedly been supported by empirical studies. (Lykken & Tellegen, 1996; Fujita & Diener, 2005; Lucas & Donnellan, 2007).

What these studies collectively suggest is that human beings, including those living with severe injury or illness, may adapt to their circumstances, and as such, their self-reports about the perceived quality of their lives can be taken as reliable indicators about their welfare, even if these self-reports are at odds with the expectations of others. In fact, research has shown that one of the primary reason that healthy individuals produce unrealistically low estimates of the quality of life of individuals with disabilities is due to a 'focussing illusion' (Strack, Martin, & Schwarz, 1988; Schkade et al., 1998). When estimating the quality of life of an individual with a disability, healthy individuals tend to focus their attention on the disability, rather than developing a holistic estimate of all the aspects of the individual's life; consequently, they tend to produce a distorted

judgement about quality of life. Interestingly, when asked to estimate the quality of life of people with disability, healthy individuals who know someone with a disability tend to produce estimates much more closely aligned with disabled persons themselves. This suggests that greater knowledge about living with a disability allows one to more accurately predict the quality of life of individuals who actually do live with a disability. (Schkade et al., 1998).

Still, it may be the case that response shift might present problems in evaluating the efficacy of a particular treatment intervention, insofar as it may be difficult to determine whether a patient's reported improvement in quality of life is due to the intervention, or simply due to reprioritization or recalibration of their values. Nevertheless, the inability to determine the mechanism of change does not render a patient's report that a change has taken place as invalid or suspect in some way. For this reason, the possibility of response shift is not a viable objection to appealing to the self-report of patients about the factors that are relevant to their quality of life.

The above discussion of adaptation and response shift is not meant to suggest that patients always provide a perfect assessment of their own quality of life. Indeed, self-reporters are prone to biases in their estimation of their own quality of life as well (Pavot, 2008). For example, patients may remember a previous health state as being better or worse than it actually was, which in turn influences how they report their condition has changed (McPhail & Haines, 2010), or they may infer that their overall health status has improved, simply because they feel well at the time of measurement (Kamper et al, 2010) (For an overview, see Blome & Augustin, 2015). Similarly, Haybron (2008) has argued that there are a variety of factors that can distort our self-assessment of our own affective



states, including factors which we may be unaware of. Further, he points out that because self-assessments of life-satisfaction can be significantly influenced by the ethical norms we adopt, or other perspectives we take, the degree of satisfaction with our lives we espouse may have little to do with how well we are actually faring (Haybron, 2007). Taken together, this suggests that judgments about our life-satisfaction and affect may not be as reliable as we think, and that self-reports of happiness or life-satisfaction may be liable to significant error.

Does this mean that an individual's self-report is not a useful measure of their quality of life, life-satisfaction, or happiness? Not necessarily. As Diener, Inglehart, and Tay argue (2013), while responses to life-satisfaction scales can be influenced by factors beyond an individual's actual satisfaction with her life (e.g., participant mood, question order), people do not seem to heavily weight factors that they believed are unimportant to their overall quality of life. As such, many life-satisfaction scales validly reflect the quality of respondents' lives. Specifically, they point out life-satisfaction scales provide results which tend to converge with other measures of welfare that are not based on self-reports, such as reports of family and friends (Pavot & Diener, 1993), and physiological variables thought to track positive moods (Steptoe, Wardle, Marmot, & McEwen, 2005). Accordingly, we have good reason for appealing to the self-report of patients in order to find out what factors are relevant to their quality of life, and we should not merely rely on objective factors, or proxy evaluations. At the same time, we should not simply assume that a patient's self-report is a perfect reflection of their welfare, and we need to be cognizant of the possibility for error or bias. Again, however, my aim in this section is not to definitively establish those domains of welfare which are relevant to patients

diagnosed as vegetative with covert awareness, but rather to provide a reasonable starting point; individual judgements about those domains relevant to their welfare are at least relevant to this question.

How might we identify those domains that are most relevant to the welfare of patients diagnosed as vegetative, with covert awareness? Unfortunately, given the barriers to communication with these patients I mentioned at the outset of this chapter, we cannot simply ask them directly. Alternatively, I argue, we might begin by identifying individuals whose health condition resembles these patients in specific ways, and use these individuals as a model to get some sense of those domains of life that are most relevant to the welfare of patients diagnosed as vegetative with covert awareness.

On what grounds might such a comparison be drawn? We can point to several features of these patients' condition which might plausibly be thought to affect their welfare, and that are also found in other patient populations. First, patients diagnosed as vegetative with covert awareness, though capable of language comprehension, are incapable of verbal or non-verbal communication (excepting those cases in which patients have communicated with researchers using the mental imagery task). Accordingly, we might consider a patient population with similarly severe barriers to communication, such as patients with locked-in syndrome, or patients with aphasia following a stroke. Second, these patients are incapable of voluntarily bodily movement. Accordingly, we might consider a patient population with similarly severe motor limitations, such as locked-in patients, patients with amyotrophic lateral sclerosis, or patients with quadriplegia. Third, these patients are likely to have significant deficits to cognition (including attention, memory, arousal and executive function), behaviour,

mood, and personality functioning, all of which are characteristic of diffuse axonal damage (Carlozzi, Tulskey, & Kisala, 2011). For this reason, we might investigate the domains of welfare relevant to patients with similar cognitive, behavioural, and emotional deficits, such as other patients who have experienced traumatic brain injury, and patients with neurodegenerative diseases like Huntington's disease.

Naturally, because patients diagnosed as vegetative with covert awareness are a highly unique patient population, it is challenging to identify a population which resembles them in each of these respects, *and* whose members are also able to provide reliable information. For example, patients in the minimally conscious state seem to be, at least *prima facie*, a patient population that closely resembles the patients under discussion. However, assessing the subjective welfare of patients in the minimally-conscious state faces many of the same challenges as patients diagnosed as vegetative with covert awareness, given the similar challenges in communicating with these patients. Although some minimally conscious patients are able to make intelligible verbalizations, or vocalizations to command, these behaviours occur inconsistently (Giacino et al., 2002).

Moreover, it is important to bear in mind that the domains relevant to an individual's welfare are influenced by a range of complex factors. An individual's illness or disability will almost certainly have some effect on those domains of life which are relevant to their overall welfare, especially when the illness or disability is as pervasive as being in a vegetative state with covert awareness, (or the other illness and disabilities which I will discuss below). Nevertheless, it would be a mistake to think that all patients in the vegetative state with covert awareness, simply in virtue of their similar health

condition, would have an identical collection of prudential values. This fact is particularly relevant to the proceeding discussion, because some patient populations who have similar symptoms as patients diagnosed as vegetative with covert awareness—and thus, who may be thought to have similar domains relevant to their welfare—may fail to be a representative population. For example, like patients with diffuse axonal injury—such as patients diagnosed as vegetative with covert awareness—patients with dementia experience cognitive deficits to memory, attention, and executive function, as well as personality changes and impaired reasoning. However, dementia is a chronic, progressive condition, while the cognitive deficits experienced by patients diagnosed as vegetative with covert awareness are much more abrupt, given the typically sudden, catastrophic nature of their injury. Moreover, whereas most patients diagnosed as vegetative tend to be relatively young at the time of their injury, patients with dementia are typically elderly. Because these factors may play an important role in determining those domains which are relevant to an individual's welfare, the fact that patients diagnosed as vegetative with covert awareness and those with dementia differ in this way suggests that patients with dementia may not be a representative population for the purposes of assessing the welfare of patients diagnosed as vegetative with covert awareness.

In the following sections, I will examine several patient populations who resemble patients diagnosed as vegetative with covert awareness with respect to one or more of the key features mentioned above, to determine if there are some commonalities with respect to the domains these patients report as relevant to their welfare that might plausibly apply to patients diagnosed as vegetative with covert awareness. Although there are important differences between patients diagnosed as vegetative with covert awareness, and

members of the comparison groups, my aim in this exercise is merely to gain some insight into the domains of life which may be relevant to the patients under discussion, and provide a starting point for future inquiry into their welfare. As such, this is not meant to be an exhaustive survey of similar patient populations; further analysis of additional populations might provide additional insight into the domains of welfare relevant to patients diagnosed as vegetative with covert awareness.

#### **5.4 Comparison Populations for Patients Diagnosed as Vegetative With Covert Awareness: Domains of Life Relevant to Welfare**

##### ***5.4.1 Domains of Life Relevant to Welfare: Traumatic Brain Injury***

Perhaps the most reasonable place to begin our discussion of life domains potentially relevant to patients diagnosed as vegetative with covert awareness is with those patients who share a common etiology. Traumatic brain injury is an alteration in neurologic function caused by an external force, which if severe, can result in widespread damage to brain tissue in the cerebral cortex, and other sub-cortical structures (Carlozzi et al., 2011). Traumatic brain injury may result in numerous chronic impairments, across a range of domains. Cognitive impairments may include deficits in attention, arousal, memory, and executive function (Draper & Ponsford, 2008) while behavioural impairments may include apathy, irritability, impulsivity, and denial or ignorance of other deficits (Roebuck-Spencer & Sherer, 2005). Anxiety and depression are also common (Rogers & Read, 2007), as are numerous other dysfunctions, including balance and motor coordination difficulties, hemiparesis (weakness on the left or right side of the body), fatigue, headache, sleep disturbances, seizures, sensory impairments, hydrocephalus (an

abnormal accumulation of cerebrospinal fluid in the brain), endocrine dysfunction, cranial nerve deficits, spasticity, tremors, problems in urinary control, dizziness, and vestibular dysfunction (Carlozzi et al., 2011).

Patients diagnosed as vegetative represent a subset of patients with traumatic brain injury, although because of the range of severity of traumatic brain injury, the extent of the impairment of patients diagnosed as vegetative with covert awareness may go beyond those experienced by patients with traumatic brain injury considered in this section, particularly with respect to motor impairment and the ability to communicate with others. Nevertheless, the fact that these two patient groups may share a similar collection of cognitive and behavioural impairments (given their common etiology)—even if these impairments turn out to be more extensive in patients diagnosed as vegetative with covert awareness—makes it worthwhile to examine the domains of life which contribute to the subjective welfare of patients with traumatic brain injury.

What sort of domains are relevant to the subjective welfare of patients with traumatic brain injury? Many quality of life assessments of patient with traumatic brain injury focus on four domains widely considered to be constitutive of quality of life: the physical domain, the psychological or emotional domain, the social domain, and the cognitive domain (Berger, Leven, Pirente, Bouillon, & Neugebauer, 1999; Bullinger et al., 2002; Dijkers, 2004). One exception is a study conducted by Brown and Vandergoort (1998), which assessed the quality of life of patients with traumatic brain injury along fifteen dimensions. They found that patients ranked health and personal safety as most important for quality of life, followed by self-understanding, interesting work, close relationships with relatives, and close relationships with a significant other (Brown &

Vandergoort, 1998). Interestingly, there was no significant difference between patient rankings of the importance of particular life domains and a comparison group of healthy individuals in the majority of domains, and those differences which we present were small. It is worth mentioning, however, that the patients surveyed were all currently residing in the community, meaning that patients who just recently suffered their injury and patients with more severe symptoms were not included. As Djikers points out, further research is needed to determine to what extent certain standard domains of life are sufficient to capture the subjective welfare of patients with traumatic brain injury, as well as the extent to which their relative importance varies across individuals or groups (Djikers, 2004).

More recent efforts to assess the subjective welfare of patients with traumatic brain injury have incorporated a wider variety of potentially relevant domains, and rely more closely on patient's own reports of what domains are important to them. For example, Carlozzi and colleagues found that emotional health was the most relevant domain to patient subjective welfare (Carlozzi et al., 2011). Specifically, they found that individuals with traumatic brain injury often reported feelings of anxiety or fear, depression, and feelings of stigma. Other issues which emerged were patients' feelings of resilience about their condition, as well as feelings of low self-esteem, as well as a sense of loss over previous functional states. The second most frequently cited domain of relevance to these patients was social participation, specifically interpersonal relationships, leisure, vocation, independence, and autonomy. Physical and medical health was also cited as an important domain, (especially motor function), as well as cognitive health, and personality change (Carlozzi et al., 2011).

Similarly, Gould and Ponsford (2015) conducted a longitudinal study of patients who had suffered a moderate or severe traumatic brain injury, interviewing them 6, 12, 24, 36, and 48 months after their injury. They found that patients rated 'friends', 'play', and 'goals and values' as the most important domains for their quality of life pre-injury, while 12 months after injury, 'friends', 'health' and 'goals and values' were most important. After 24 months and 36 months, these domains remained the same (with health superseding friends in importance), while at 48 months, 'health', 'self-esteem', and 'relatives', were rated as the most important domains for patient quality of life. Additionally, this study found that while the subjective welfare of the patient population decreased overall pre-injury to 48 months post-injury, one third of patients had significantly higher post-injury vs preinjury ratings of subjective welfare, suggesting that patient subjective welfare could improve. However, patients whose subjective welfare did not improve tended to have greater post-injury disability, and were prone to idealizing their pre-injury life, which may have contributed to an inability to adapt to their new circumstances (Gould & Ponsford, 2015).

Taken together, these results highlight the importance of managing patients' emotional needs, cognitive deficits, and social participation, in addition to managing physical symptoms. Moreover, it highlights the importance of fostering self-esteem, resilience, stress management, and a sense of autonomy and control, in contributing to the subjective welfare of these patients. While the subjective welfare of patients with traumatic brain injury is generally somewhat lower than that of healthy comparison groups, the difference is fairly small (Dijkers, 2004) However, it is important to bear in mind that in more severe cases of traumatic brain injury, a patient's decreased awareness



of deficits (i.e., anosognosia), may influence those domains of life which are reported as relevant by patients, as well as the degree to which patients report their needs within these domains are met (Mackenzie Alfred, Fountain, & Combs, 2015).

#### ***5.4.2 Domains of Life Relevant to Welfare: Locked-In Syndrome, Amyotrophic Lateral Sclerosis, and Spinal Cord Injury***

Another potentially useful area of inquiry concerns patients with severe motor impairments, specifically, patients with locked-in syndrome, patients with amyotrophic lateral sclerosis (ALS), and patients with spinal cord injury. Like patients diagnosed as vegetative with covert awareness who are unable to produce voluntary bodily movements, patients with locked-in syndrome typically suffer from quadriplegia, and although some retain the ability to move certain facial muscles, in the classic case they are only capable of vertical eye movements (Bauer et al., 1979; Laureys et al., 2005). Similarly, ALS causes the death of motor neurons that control voluntary muscles, and results in an inability to walk, use one's hands or arms, and eventually, swallow or breathe without mechanical assistance. Also, like patients diagnosed as vegetative with covert awareness, locked-in patients and advanced-stage ALS patients are unable to produce speech. However, unlike patients diagnosed as vegetative with covert awareness, whose level of cognitive function is unknown, patients in the locked-in syndrome, as well as ALS patients, have relatively normal levels of cognitive function.

Several studies have shown that the self-reported quality of life of locked-in patients is within the same general range as that of healthy individuals (Laureys et al., 2005b; Lule et al., 2009; Bruno et al., 2011; Rousseau et al., 2013; Snoeys, Vanhoof, & Manders, 2013; Rousseau et al., 2015). For example, Rousseau and colleagues

administered a battery of quality of life assessments—including the McGill Quality of Life Single Item Scale, Short-Form Survey (Mental and Physical Component Summary), Beck depression Inventory-II, and the Toronto Alexithymia Scale—to 19 patients with locked-in syndrome, and compared their responses to those of 20 healthy controls. They found that there was no significant difference between locked-in patients and controls on the McGill scale, the Mental Component Summary of the Short-Form Survey, or the Toronto scale. Not surprisingly, scores on the physical component summary of the Short-Form Survey were significantly higher in healthy controls, while frequency of depressive symptoms were slightly higher in locked-in patients than healthy controls (Rousseau et al., 2013). This suggests that the quality of life of these patients is not dependent on their level of physical functioning, results that have also been shown in patients with amyotrophic lateral sclerosis (Simmons, Bremer, Robbins, Walsh, & Fischer, 2000; Neudart et al., 2004).

If a locked-in patient's level of physical functioning is not a significant contributing factor to their subjective welfare, what domains of life are most central their quality of life? Bruno and colleagues (2011) invited 168 locked-in patients (of which 65 respondents were included in the study) to complete a structured questionnaire reporting on their subjective quality of life. They found that 72% of respondents declared overall happiness with their lives, with 82% of respondents satisfied with their personal relationships with others. They also reported that only 21% of respondents were engaged most of the day in activities they considered 'important', while 12% of respondents were dissatisfied with their participation in recreational activities, and 40% dissatisfied with their social participation (Bruno et al., 2011). Similarly, Rousseau and colleagues suggest

that the ability to communicate with others, and as a consequence increase participation in family and community life, are significant determinants of quality of life in patients with locked-in syndrome (Rousseau et al., 2013).

Similarly, studies of patients with ALS suggest that psychological, supportive, and spiritual factors are most associated with patient welfare, particularly the patient's perception of the quality of social and family support. (Simmons et al., 2000; Chio et al., 2004; Neudart et al., 2001). Simmons, Felgoise, Bremer, Walsh, Hufford, and Bromberg (2006) developed a disease specific quality of life assessment for amyotrophic lateral sclerosis, based on a modified version of the McGill Quality of Life Questionnaire, which incorporated the results of personal interviews with patients, as well as the responses of patients to open-ended questions during the administrations of the McGill questionnaire. They found that patients' physical symptoms, emotions, level of intimacy, religiosity, and interaction with people and the environment were relevant contributors to patient quality of life (Simmons et al., 2006).

Patients with spinal cord injury represent another potentially informative patient population. While most of these individuals do not suffer from cognitive deficits as a result of their injury, in severe cases their motor limitations (as well as the acute onset of these limitations) are similar to those of patients diagnosed as vegetative with covert awareness.

Chapin, Miller, Ferrin, Chan, & Rubin (2004) administered the Sense of Well-Being Inventory, as well as the World Health Organization's Quality of Life Brief Version, to 132 participants with spinal cord injuries living in the community. They found that the subjective welfare of patients with spinal cord injury is underlined by four

domains: psychological well-being, financial well-being, family and social well-being, and physical well-being. Interestingly, they also found that years since disability onset was strongly related to psychological well-being, which mirrors separate findings that as time since injury increases, so too does quality of life (Dijkers, 1999; Duggan & Dijkers, 2001).

Manns and Chad (2001) conducted semi-structured interviews of 15 patients between 22 and 63 years of age, who were a mean of 13 years post injury, eight of whom had complete paraplegic injuries, and seven of whom had complete quadriplegic injuries. They found that patients reported nine themes that composed their quality of life: physical function and independence, accessibility, emotional well-being, stigma, spontaneity, relationships and social function, occupation, financial stability, and physical health and health behaviours. While many of these themes are often identified as components of quality of life in non-disabled populations, some (e.g., stigma) are not typically included as components of well-being for non-disabled persons.

#### ***5.4.3 Domains of Life Relevant to Patient Welfare: Huntington's Disease***

A final potential comparison group for patients diagnosed as vegetative with covert awareness, is patients with Huntington's disease. Huntington's disease is a fatal neurodegenerative disease resulting in severe motor, cognitive, and psychiatric disturbances, over a period of 15-20 years after symptom onset (Paulsen, 1999; Ho et al., 2004). Unlike the case of patients diagnosed as vegetative with covert awareness, the symptoms of Huntington's disease are gradual; however, in its advanced stages, patients with Huntington's disease, like patients diagnosed as vegetative with covert awareness, are unable to move their limbs (due to loss of muscle control and strength), unable to

speak, incapable of self-feeding, and in some cases, of swallowing. Huntington's disease may also result in dementia, and impair the patient's ability to comprehend, perceive, and interact with others (Nance, 1998).

While generic measures of health-related quality of life have been used to assess patients with Huntington's disease (Helder, Kaptein, van Kempen, van Houwelingen, & Roos, 2001; Ho et al., 2004), there are very few validated, Huntington's disease-specific measures of health-related of life (Carlozzi et al., 2012). While generic instruments may be useful in measuring the functional impact of symptoms across different disease or age groups (Ready, Mathews, Leserman, & Paulsen, 2008), they tend to focus on the functional impact of symptoms, and may overlook particular disease-specific factors impacting a patient's function. Further, even disease-specific health-related quality of life measures—because they focus on the impact of disease on patient function—may overlook other life domains or contextual factors which can impact a patient's overall quality of life. Ready and colleagues conducted a study of patients with Huntington's disease, which used a single-item measure to assess quality of life (Ready et al., 2008). 22 participants (whose symptoms fell within the mild to moderate range on the Unified Huntington's Disease Rating Scale) were asked to simply rate their overall quality of life on a five point response scale (1-bad, 2-fair, 3-good, 4-very good, 5-excellent). These patients reported an average quality of life of 3.41, while caregivers rated patient quality of life as being an average of 2.73 (Ready et al., 2008). Additionally, the functional and cognitive capacity of patients (as determined by the Unified Huntington's Disease Rating Scale) was found to have the strongest correlation with patient's self-reported quality of life. However, while other studies of the quality of life of patients with Huntington's

disease have found that neuropsychiatric symptoms (e.g., symptoms of depression) are the most robust indicator of quality of life (Helder et al., 2001; Ho et al., 2004; Ho, Gilbert, Mason, Goodman, & Barker, 2009), Ready et al., found that such symptoms were not significantly associated with patient quality of life (Ready et al., 2008).

These results seem to suggest that for patients with Huntington's disease, physical function and cognitive capacity are important domains of quality of life, and as functional ability begins to decline in these areas, overall quality of life declines as well, although patient's overall ratings remain relatively high. However, it is important to point out that in the above studies, the patients under consideration were suffering mild to moderate symptoms of dementia that were gradually increasing in severity. Further research is needed to determine how patients with more severe symptoms rate their quality of life, as well as which factors are most associated with quality of life. Indeed, Ready and colleagues (2008) reported evidence of response shift by patients, which suggests that adaptation or coping on the part of patients may affect their self-assessment of quality of life.

As mentioned above, while health-related quality of life assessments tend to focus on functional impairment as a result of disease or injury, the development of disease-specific health-related quality of life measures often involves interviewing a sample of patients about the domains which underlie their quality of life, in order to derive a meaningful profile of health-related quality of life. Thus, while ratings of health-related quality of life may not accord with ratings of overall quality of life (because a patient's valuation of a particular domain may vary, or their individual quality of life may be based on domains not included in the assessment) valuable information about the domains

which patient's report as relevant to their quality of life can be extracted from the development of health-related quality of life assessments.

One such study conducted semi-structured interviews with 31 patients living with Huntington's disease, ranging from pre-symptomatic to late-stage, and derived an initial set of factors relevant to quality of life, which was then rated by an additional 281 participants living with different levels of Huntington's disease severity (Hocaoglu, Gaffan, & Ho, 2012). These researchers reported six specific domains which measured meaningful aspects of quality of life in these patients: cognitive factors (e.g., memory, concentration, comprehension); hopes and worries (e.g., personal/family worries about disease, financial worries); adequate services; physical and functional factors; mood; and self and vitality (e.g., motivation, social role, moving on with life).

A second study, conducted by Clay and colleagues (Clay et al., 2012), also used semi-structured interviews, as well as focus groups, to generate a set of domains of quality of life meaningful to patients with Huntington's disease, from which a health-related quality of life assessment could be generated. Clay et al. reported three domains most relevant to patient quality of life: motor impairment; psychology; (e.g., guilt about burden placed on family, worry about symptom progression, difficulty accepting health problems); and socializing (e.g., feeling isolated or disconnected from others).

### **5.5 Patients Diagnosed as Vegetative with Covert Awareness: Inferences about Welfare**

What inferences might we draw about the factors contributing to the welfare of patients diagnosed as vegetative with covert awareness, from our examination of these

other patient populations? To begin with, it is important to emphasize that the purpose of this discussion is not to argue that the domains of life relevant to the welfare of patients diagnosed as vegetative are the same as those of the patient groups above. Indeed, there are numerous factors that differentiate these various patient groups, and these differences may have an important influence on what these patients consider important for their quality of life. What examining these various patient groups can show us, however, are a few broad themes about what matters to patient quality of life in these cases, and which may be applicable to patients diagnosed as vegetative with covert awareness.

First, there is good evidence to suggest that even in the face of severe mental or physical disability (or both), patients may report a reasonably high quality of life, often much higher than we would expect based on the severity of their condition. As was discussed above, there may be a few reasons for this, including the potential for patients to readjust the values upon which they base their evaluations of their own quality of life, or recalibrate their internal standards of measurement. In any case, this seems important when we consider patients diagnosed as vegetative with covert awareness. As we saw in Chapter 4, there is the potential for underestimating the quality of life of these patients, especially when we attempt to determine their quality of life in terms of those values that seem to be most relevant to healthy individuals. Because there is the possibility for a change in patient values, and a concomitant change in the self-evaluation of one's quality of life, we must exercise caution in simply assuming that the welfare of these patients are poor, without first reflecting on the basis upon which we are making this evaluation, and whether or not this is how the patient would evaluate their lives.



Second, based on the patient populations examined, there appears to be at least a general agreement that relationships with others and perceived social support are two domains that are particularly important for quality of life amongst such patients. Interestingly, many of these patients consider their physical or cognitive limitations to be less relevant to their quality of life, while emotional and social domains are seen as having a greater relevance. While it is an open question whether this would be true of patients diagnosed as vegetative with covert awareness as well, this observation seems consistent with the nature of response shift, as discussed above, and thus, it seems plausible that it may be the case with these patients.

As the examples discussed above appear to show, in many cases, when an individual has a severe chronic illness or disability which limits their physical, mental, or social function in some way, those domains of life which are impaired eventually come to be viewed as less important for quality of life. Patients do seem to adapt to their conditions. This suggests that patients diagnosed as vegetative with covert awareness may adapt to their circumstances as well, such that the domains of life which remain accessible to them in some way may come to be viewed as more central to their welfare than those which are no longer accessible. For example, insofar as these patients are capable of positive hedonic experiences—including physical pleasure and the absence of physical pain or discomfort, but also the pleasure of listening to music or an audiobook, or watching an enjoyable movie, or being out in nature—and other positive affective experiences (e.g., positively-valenced emotions), these are likely to be things which contribute to their welfare. Rather than focussing on the ways in which their condition has disrupted their life-plans, or previously held desires (as Kahane and Savulescu

suggest), it seems possible that patients diagnosed as vegetative with covert awareness might focus on those aspects of life from which they can still benefit. I am not arguing that patients diagnosed as vegetative with covert awareness are likely to be faring well. Indeed, it seems likely that patients diagnosed as vegetative with covert awareness would continue to view some experiences or capacities as prudentially valuable, even though these were no longer available to them. In this respect, the welfare of these patients would be frustrated. Rather, I am arguing that there is evidence to suggest that the ingredients of welfare for these patients may be such that there is the potential for their welfare to be affected in a positive way. Some of the things that have prudential value to them may remain accessible.

The fact that members of the patient populations discussed above report a relatively high level of welfare does not mean that any particular patient diagnosed as vegetative with covert awareness would report a similarly high level of welfare. Indeed, there may be a number of factors which contribute to a patient's ability to adapt to their situation, including personality characteristics, the specifics of one's medical condition, social support, and financial resources. Some patients may simply be unable (or unwilling) to adapt to their condition, or to overcome the loss of valued capacities. For example, depression is one of the most significant predictors of patient's evaluating their quality of life as low, across a wide range of illnesses and disabilities, and may influence a patient's ability to adapt to their situation. (Tate et al., 2015; Williamson et al., 2013; Ilse et al., 2015; Ho et al., 2009). If a patient diagnosed as vegetative with covert awareness is suffering from depression, then, this presents a significant risk to their welfare, because it may influence their perception of what counts as a prudential good.

Moreover, the importance of emotional and social domains highlights the need for attention to these domains of life for patients diagnosed as vegetative with covert awareness. Insofar as these patients are capable of emotional experiences, or future-directed concerns, or relationships with others, attending to these domains may be highly important to their subjective welfare. Similarly, the potential for suffering within these domains further underscores the need for greater understanding of patient's subjective experience, as well as strategies for mitigating potential suffering. As the above discussion has shown, many of the patients within the populations considered experience feelings of anxiety or depression, loss of self-esteem, loss of agency or autonomy, and feelings of isolation or loss of social role. While it may be difficult to improve a patient's level of physical or cognitive function, attention to a patient's emotional and social needs may provide a practical avenue for improving their welfare.

### **5.6 The Potential Cognitive Capacities of Patients Diagnosed as Vegetative, With Covert Awareness**

At the outset of this chapter, I described two complementary strategies for beginning to determine the welfare of patients diagnosed as vegetative, with covert awareness. The first involved determining what domains of life are relevant to the welfare of these patients. To do this, I suggested that examining other patient populations who resemble this patient group in key ways, and investigating what domains of life are relevant to these other patient groups, might provide some direction regarding the domains of life which are relevant to the welfare of patients diagnosed as vegetative with covert awareness. The second strategy, which I will discuss in the remainder of this

section, involves an examination of how we might enhance patient welfare within these relevant domains. Specifically, I will discuss a recent study involving patients diagnosed as vegetative with covert awareness, and suggest several inferences that might be drawn from it about the potential psychological capacities of these patients. The presence of these capacities in these patients greatly extends the range of their potential prudential interests, and accordingly, may provide new opportunities through which we can enhance patient welfare.

### **5.7 Potential Cognitive Capacities of Patients Diagnosed as Vegetative, With Covert Awareness: Inferences from a Novel Brain Imaging Paradigm**

A recent study by Naci, Cusack, Anello, & Owen (2014) provides a new method for investigating the experiences of these patients, without relying on their self-report, or interpreting their behaviour at the bedside. Using a naturalistic stimulus (an engrossing movie) to drive executive function in healthy participants, Naci and colleagues were able to show that a common ‘neural code’ supported the similar conscious experiences of these participants, while watching a short film. Furthermore, when a behaviourally non-responsive patient was presented with the same stimulus, this patient demonstrated executive engagement similar to the healthy controls. This provides evidence not only that the patient was aware, but also that the patient had a conscious experience when watching the movie that was similar to healthy controls.

Naci and colleagues began by acquiring fMRI data from two groups of 12 healthy participants. The first group was shown an 8-minute Alfred Hitchcock video clip, while the second was shown a scrambled version of the same film in which there was no

discernible plot. The first group showed widespread cross-subject synchronization within the auditory and visual cortex, as well as in higher-order supramodal regions, with different individuals showing the same peaks and dips in activity at identical points of the movie. By contrast, the second group showed significant cross-subject synchronization only within the auditory and visual cortex. This shows that the cross-subject synchronization within higher-order brain regions observed in the first group was not simply tracking variations in the audiovisual information, nor was it the result of automatic attention effects triggered by the similarity of audiovisual stimuli across participants. Rather, the processing of higher-level properties of the movie itself, namely its plot, was driving the synchronized activity in these regions across participants.

These results were confirmed through two additional studies. First, a third group of 27 participants was shown the same Hitchcock film, while simultaneously being required to respond with a key press to a series of randomly presented digits, but withhold response to a pre-specified digit. Because executive function is a finite resource, the demands on executive function of one task will affect the performance of a second executively demanding task. Thus, performance on the second task (i.e., the reaction time of the participants in pushing the key) provides a direct, quantitative measure of the executive demands of watching the film. By comparing the reaction times of the dual-task group (which measured the executive demands of the film across time) with the fluctuations in activity in the frontal and parietal regions observed in the first group, Naci and colleagues found that the quantitative measure of executive function observed in the dual-task group predicted the neural activity of the first group, which confirmed that the

cross-subject synchronization observed in the first group was driven by the executive load of the film.

Next, a fourth group of healthy participants was asked to watch the film, and rate how suspenseful it was, at various points. Because ongoing engagement with the plot of the film requires significant executive processing, the suspense rating of a single subject provided a measure of the executive demands of the film across time. Consistent with the results of the dual-task study, Naci and colleagues not only found significant inter-subject correlation between ratings of suspense at various points in the film, but also that the suspense ratings predicted activity in the frontal and parietal regions of the original participant group, which confirmed that the participants in this first group were having a highly similar conscious experience of the film.

These experiments provide robust evidence that synchronized activity fluctuations in the frontal and parietal regions track the common cognitive experience of different individuals, while watching the same movie. In their final study, Naci and colleagues examined the neural activity of two patients diagnosed as vegetative while watching the same Hitchcock film, and compared this activity to the common pattern observed in the healthy participants. They reasoned that if a patient engaged in executive processing while watching the film, this patient would exhibit similar patterns of activity as the healthy participants in frontal and parietal regions. While Patient 1 showed synchronous activity in the auditory cortex, when compared to the healthy participants, the patient did not show any evidence of visual response or executive function similar to the healthy participants. In stark contrast, Patient 2 showed synchronous activity with the healthy participants in both the auditory and visual cortex, as well as in the frontal and parietal

regions which support executive function, while watching the film, indicating that the patient was having a similar conscious experience as the healthy participants, and moreover, that he was capable of continuously engaging in the sort of complex thoughts about real-world events, unfolding over time, required for comprehending the plot of a film.

The results of this study show that at least some patients diagnosed as vegetative with covert awareness maintain conscious experiences similar to healthy controls, when presented with a real-world stimulus. In light of these findings, what might we reasonably infer about the subjective experiences of such a patient? What do these results tell us about their experiences of the world around them, and moreover, about their potential welfare?

***5.7.1 Patient retains visual and auditory functioning, including recognition of familiar objects, faces, and voices***

Probably the most basic requirement for understanding the plot of a film is the ability to see and hear what the characters onscreen are saying and doing. Of course, this alone may not be sufficient (as anyone who has ever watched a foreign-language film without subtitles can attest). One must also be able to understand the meaning of the dialogue. Similarly, one must be able to identify certain characters from one scene to the next, as well as recognize objects and environments presumed to be familiar to the viewer, especially those critical to the plot. (Imagine how difficult it would be to follow the plot of a film if one were unable to distinguish between any of the characters). In order to account for the patient's highly similar conscious experience of the film, when compared to healthy controls, they must not only perceive visual and auditory stimuli, but

consciously processing these stimuli. This is supported by the observations of Naci et al., who state that “activity in [the patient’s] auditory and visual cortex synchronized to that of the healthy group in these regions, suggesting intact processing of both auditory and visual information in the movie.”

These results are in stark contrast to the behavioural definition of the vegetative state, according to which patients diagnosed as vegetative show no signs of visual pursuit or object recognition in his environment, including his family members. Indeed, this patient had been repeatedly assessed at the bedside over the course of a 16-year period, and had not shown evidence of movement to command, or any behavioural signs of functional or nonfunctional communication. Moreover, he displayed no signs of localization of sound and no visual recognition or interaction with objects or people in his environment, including his family members. On the contrary, the fact that the patient had a similar conscious experience to healthy controls when watching the film strongly suggests that the patient can understand language, and can recognize familiar objects, including people and faces.

### ***5.7.2 Patient retains executive functioning***

In addition to consciously processing visual and auditory stimuli, a critical component of following a complex narrative (such as a film) is the ability to integrate auditory and visual information with one’s prior knowledge and experiences into a meaningful whole, in order to continually engage with the plot. This includes relating events in the film to one’s experience of the real world, which allows for predictions about what will happen next. For example, a key aspect of the film’s plot is a young boy pointing a loaded gun at various people, not knowing it is a real gun (and not just a toy).



Understanding these scenes requires that the viewer recognize the object as a gun, but also draw on their prior knowledge of such objects (i.e., that guns can kill people when fired), and make the prediction that *this* gun might kill someone if fired. Engagement with the plot also requires the ability to focus one's attention on the relevant stimuli, such as the gun, filter out relevant information and avoid distractions, as well as employ one's working memory.

The sorts of capacities mentioned above are often referred to under the umbrella term 'executive function.' As Naci and colleagues articulate, executive function refers to those processes that "coordinate and schedule a host of other more basic cognitive operations, such as monitoring and analyzing information from the environment and integrating it with internally generated goals, as well as planning and adapting new behavioural schemas to take account of this information." The executive capacities required for the conscious experience of the film strongly suggests that the patient retains the capacity for highly complex mental processes.

### ***5.7.3 Patient possesses a 'theory of mind'***

An important part of engaging with a complex narrative is making inferences about the mental states of the characters, in a variety of dynamically unfolding social contexts. Because characters often do not explicitly state their beliefs, desires or intentions, the viewer must repeatedly infer these mental states in order to understand story events, and character actions. Possessing a 'theory of mind' refers to the ability to infer and understand the mental states of others, as well as one's own. In order to understand and predict the behaviour of others, we have to account for their unique

perspective of the world, as well as the state of the world from our own perspective, and be able to differentiate between and compare these two perspectives.

The movie used in the study is a good example of a complex narrative that requires a theory of mind for its comprehension. It requires the viewer to make inferences about the mental state of a single character, as well as inferences about what one character thinks about another character's mental states. For example, the viewer must infer that the boy believes that the gun is a toy, as well as that the boy's parents believe that the boy believes the gun is a toy, and thus, that he is likely to fire it. The viewer's ability to comprehend the narrative is thus dependent on their capacity for attributing beliefs—both true and false—to the characters, in order to explain and predict their behaviour. Similarly, the viewer will often need to infer the emotional state of a character in order to properly contextualize their language or behaviour. For example, a character perceived as agitated or distressed saying 'don't shoot' must be interpreted differently than a character perceived as cheerful or insouciant saying the same thing.

Attributing mental states to others is an important part of our normal interactions. Individuals with theory of mind impairments, such as those with autism spectrum disorder or schizophrenia, have difficulty determining the intentions of others, have difficulty with social reciprocity, and often lack understanding about how their behaviour will affect others; this significantly impacts how they experience the world, and interact with others (Baron-Cohen, Leslie, & Frith, 1985; Tager-Flusberg 2007). Conversely, the results of this experiment suggest that patients showing an adequate response to the film may retain the ability to attribute mental states to others.

A further question involves the capacity of these patients for ‘emotion recognition’, the ability to infer the emotional state of another individual. Some studies have demonstrated a correlation between performance measures on theory of mind tasks and emotional recognition tasks, as well as overlapping activation in brain structures known to be associated with emotion processing and intention recognition (i.e., the amygdala, superior temporal sulcus, and inferior prefrontal gyrus) in healthy participants (Meir, 2010). However, studies comparing healthy volunteers and patients with traumatic brain injuries showed a similar correlation between theory of mind and emotion recognition in the healthy volunteers, but no statistically significant correlation between theory of mind and emotion recognition in the patients with traumatic brain injury (Henry, Phillips, Crawford, Ietswaart, & Summers, 2006). However, the study by Henry and colleagues also showed a significant correlation between executive function (operationalized as phonemic fluency) and theory of mind, but not emotion recognition, in the patients with traumatic brain injury. These results suggest that while emotion recognition and theory of mind may be correlated, they may ultimately be dissociable. Further research is needed to determine if patients completing the movie task retain the capacity for emotion recognition.

#### ***5.7.4 Patient can make morally significant distinctions***

The ability to discern right actions from wrong actions is a highly important aspect of normal human functioning; we are regularly faced with decisions about what we ought morally to do in a given situation. The process by which we determine whether a particular action is right or wrong is referred to as ‘moral reasoning.’ When an individual reasons morally, she begins with some set of moral beliefs (e.g., moral

principles), and tries to determine what she reasonably ought to do, all things considered, in light of these beliefs, her other attitudes and values, and other relevant moral facts about the situation.

A foundational component of moral reasoning, then, is the capacity to recognize moral issues when they arise. More specifically, the individual reasoning morally must be able to mark out particular features of a situation as being morally salient, to determine whether a certain situation is morally problematic or not. We would expect that individuals capable of making these sorts of distinctions would recognize that it is morally bad to shoot a person with a gun, whereas it is not morally bad—or at least, much less so—to shoot a tree or a window. Various accounts of how individuals perceive the morally relevant features of a situation have been offered by both classical and contemporary theorists (Haidt, 2001; Greene, Sommerville, Nystrom, Darley, & Cohen, 2001; Mikhail, 2008), most of which can be roughly distinguished as either deliberative, reason-based accounts, or intuitive, emotion-based accounts (Guglielmo, 2015).

In the film used in Naci and colleagues' experiment, the young protagonist repeatedly points a loaded gun at various objects, including other people. Participants demonstrated greater neural activation when the boy pointed the gun at other people (e.g., a shopkeeper, a mailman, a housekeeper), as compared to morally-neutral objects (e.g., a mirror). Furthermore, participants showed greater activation when the child pointed the gun at his mother, as compared to non-related characters.

One possible interpretation of this result is that it reflects the ability of the participants to make a distinction between entities with moral significance or value, and those without. It may also suggest that the participants attribute an added salience to the

child's mother, perhaps reflecting an appreciation of the moral significance of the familial relationship that is absent in the characters other interactions. Because these changes in neural activation were observed in one of the patients as well, this suggests that this patients' experience of the film may have been shaped by similar moral considerations.

Another important component of moral reasoning is the capacity to attribute mental states to moral agents; in other words, to have a theory of mind (Baird & Astington, 2004; Borg, Hynes, Van Horn, Grafton, & Sinnott-Armstrong, 2006; Young & Saxe, 2008). Research has shown that adult moral judgment is informed not only by the consequences of the action, but also by the intentions of the actor (Young, 2008). While the evidence generated by the film study is not sufficient to show that these patients are capable of moral reasoning, it does suggest that they may retain at least some of the capacities required for moral reasoning. Indeed, neuroimaging studies have shown that emotional processing plays a significant role in moral reasoning in healthy participants; specifically, the ventral and medial portions of the prefrontal cortex. (Greene et al., 2001; Young, 2007; McGreer, 2008). Further research is required to determine whether the patients under discussion here are capable of any degree of moral reasoning.

Nevertheless, even if these patients are only capable of appreciating moral distinctions, such as those between entities that do and do not warrant moral consideration, this reflects a further layer of complexity in their experience of the world around them. Not only are these patients able to recognize certain objects, and ascribe certain functions to these objects, but also assign particular moral value to them.

### *5.7.5 Patient is capable of experiencing certain emotions or affective states*

Suspense is a complex affective state, involving excitement, tension, anxiety, and anticipation or expectation (Ortony, Clore, & Collins, 1998). Similarly, the resolution of suspense may be accompanied by positive feelings of satisfaction, relief, or elation, as well as negative feelings like disappointment, sadness or anger (Carroll, 1996; Lehne et al., 2015). Moreover, most theorists agree that a critical component of the experience of suspense is the presence of a protagonist towards whom the viewer has either a positive or negative affective disposition (Zillman, 1991; Vorderer 1996). The nature of the viewer's affective disposition towards a particular character, as well as the strength of this disposition, influences the suspense which the viewer feels about the unknown fate of the character; the viewer hopes for a good outcome—and fears for a bad outcome—for characters to which they are positively disposed (Zillman, 1996; Vorderer, 1996). If this is correct, the participants in the experiment who experienced suspense while watching the film must have had some affective dispositions towards at least some of the characters.

The complexity of the affective experience of suspense suggests that those individuals who are capable of experiencing it are also capable of experiencing a variety of more basic affective states. Moreover, while measuring suspense was a focal point of this particular study, it seems plausible that participants may have experienced a variety of affective states, in addition to suspense, while watching the film; all of which would have contributed to their conscious experience of the stimulus. If this is the case, this would lend further support to the supposition that the patient is capable of experiencing a variety of affective states. Further research specifically focused on measuring other kinds

of conscious experiences (e.g., the experience of humor, sadness) would be useful in further investigating the emotional capacities of these patients.

#### ***5.7.6 Patient is capable of reflection***

A critical component of the experience of suspense is the sense of anticipation or expectation over an uncertain future outcome. This requires that the individual experiencing suspense have certain beliefs about the past—events that have occurred prior to the moment of suspense—as well as certain beliefs or expectations about what may happen in the future. In order to form predictions about future states of affairs, an individual must continually incorporate her prior knowledge and beliefs with new information as it is presented. Indeed, research suggests that the experience of suspense recruits brain regions involved in making strategic inferences (Chow, Kaup, Raabe, & Greenlee, 2008; Lehne & Koelsch, 2015). Thus, the fact that the patient is capable of engaging with a suspenseful stimulus suggests that they are capable of making inferences about possible future states of affairs, based on their prior knowledge and certain contextual factors.

The fact that the patient is capable of making inferences/predictions about the future allows for the possibility that they may be able to make inferences/predictions about their own (possible) future experiences. They are capable of conceiving of a series of events as a cohesive narrative; they perceive one event as following from another in some meaningful way. This in turn may be relevant to the potential capacity for future-directed desiderative interests. Moreover, a great deal of evidence suggests that the ability to think about another's mental states (i.e., to have a theory of mind) is closely related (though not reducible to) the ability to reflect on one's own mental states (Dimaggio,

Lysaker, Carcione, Nicolo, & Semerari, 2008; Morin et al., 2011). According to ‘Simulation Theory’, we use our knowledge of our own mental states as a basis for attributing mental states to others. Our own self-reflection thus influences how we understand the thoughts and feelings of others. (Gallese & Goldman, 1998; Saxe, Moran, Scholz J, & Gabrieli, 2006). Additionally, empirical studies using fMRI have shown that self-referential thought activates many of the same brain areas as mentalizing about other persons perceived as similar (Mitchell, Macrae, & Banaji, 2006; Saxe et al., 2006). The possibility emerges, then, that insofar as patients are capable of inferring others’ mental states—as required for the experience of suspense—they may also be capable of reflecting on their own mental states, and organizing their own experiences according to some sort of structure as well. Rather than existing merely ‘moment-to-moment’, the patient may be capable of reflecting on and interpreting the events of her own life in light of her past experiences, and her potential future experiences. Further research is needed, however, to determine the exact relationship between the capacity for self-reflection and theory of mind, how these capacities influence one another, and the potential for dissociation between these capacities (Dimaggio et al., 2008).

### **5.8 Covert Narrative Capacity: Inferences about Welfare**

Clearly, the kind of experiment conducted by Naci and colleagues provides us with a more comprehensive picture of the residual cognitive capacities of some patients diagnosed as vegetative with covert awareness than even the mental imagery task. What potential insights into their welfare might we gain from this enriched—albeit incomplete—understanding of their subjective experiences? First and foremost, the results of this research suggest that patients who respond positively to the movie task may



be far more aware of what is going on around them than the results of a behavioural examination would indicate. While their degree of motor impairments, as well as their inability to communicate verbally, makes it difficult for them to interact with their surroundings, this does not mean that they are unaware of what is going on around them. In fact, the psychological capacities these patients retain—those either directly revealed by, or reasonably inferred from, the results of the movie task—provides a host of potential avenues for promoting the welfare of these patients. Simply put, because these patients may be able to do more than previously thought, there may be more that others can do for them to make their lives better.

To begin with, the wide range of cognitive abilities implicated in the movie task suggests that those patients who successfully complete it are capable of attending to and understanding relatively complex forms of human interaction, and thus, they themselves may benefit from being a participant in such interaction with others. Regular interaction with others is a critical component of human life, and may greatly contribute to the patient's sense of self-worth and welfare; whereas a lack of interaction may contribute to feelings of isolation, or a loss of personhood. Research has shown that strong social networks can promote psychological well-being (Berkman et al., 2000), while the quality of one's social relationships is also a consistent predictor of subjective well-being (Diener et al., 2002; Siedlecki et al., 2014). Indeed, this is supported by our earlier discussion of the domains of life relevant to patient welfare. Those patient groups repeatedly emphasized the importance of their relationships with others, and perceived social support, to their welfare. It is also worth noting that some research has shown a positive relationship between received social support and feelings of low self-worth, potentially

due to a perception of a loss of independence (Lepore & Eton, 2000). Accordingly, families, caregivers and medical professionals may be able to promote the welfare of nonresponsive patients who harbor covert awareness by ensuring that patients are engaged in regular interaction with others, especially in ways that can enhance their feelings of self-worth. For example, regular visits in which a family member or caregiver reads aloud to the patient, or talks to them about the goings-on of other family members or friends may help patients feel more connected with others. Depending on the condition of the patient (i.e., whether they are in a wheelchair, or must remain in a bed), regular outings into the community, to places like the movies, or parks, may also have a positive impact on patient welfare. Even simple things like speaking directly to the patient, or taking into consideration what is said in the presence of the patient, (e.g., avoiding the use of derogatory language, or treating the patient as if they cannot understand what is being said) may have a positive impact on welfare, because it recognizes that the patient is a person, with certain social needs that matter.

Additionally, the fact that the movie study suggests that patients who successfully complete it are capable of experiencing complex mental states like suspense allows for the possibility that the range of affective experiences these patients are capable of goes far beyond physical pain or pleasure. This possibility is especially relevant for a discussion of patient welfare because, as we have seen in the first section of this chapter, the emotional domain may be a highly important constituent of overall welfare in this patient population. For example, as we saw in our discussion of patients who have experienced a severe traumatic brain injury, patients may experience anxiety, depression, apathy, irritability, and other mood disorders as a result of their injury, and may also

experience frustration, sadness, or feelings of hopelessness as a result of lost or diminished abilities. However, in the case of patients with traumatic brain injury (or the other patient populations discussed), patients can express these negative feelings or emotions in a way that is detectable by others, which can thereby precipitate treatment. On the other hand, patients diagnosed as vegetative with covert awareness cannot say to their caregivers ‘I am feeling depressed’, or ‘I am worried about my condition,’ and consequently, they may receive little or no attention to their emotional needs. Being aware of the fact that these patients have emotional needs, including the possibility that these emotional needs may be unsatisfied and thereby detract from their overall welfare, is an important part of taking the welfare of these patients seriously.

Yet, the possibility that these patients can experience a variety of affective states also allows for the possibility of their experiencing positive moods or emotions, like contentment, happiness, excitement, or joy as a result of positive experiences. Through continued interaction and attention to these patients, family members and caregivers can gain a sense of what sorts of experiences the patient enjoys, or is likely to elicit positive emotions or moods.

Furthermore, the demonstration of ‘covert narrative capacity’ on the part of these patients suggests that their level of cognitive function may be sufficient to allow for relatively complex prudential interests, that is, beyond the interest in experiencing enjoyment from pleasurable physical stimuli, and avoiding suffering from painful physical stimuli, as discussed in chapter 3. Indeed, the fact that a patient may retain a level of executive function sufficient for the experience of suspense, as demonstrated by the movie study, suggests that such a patient is capable of collecting newly presented

information, filtering out irrelevant pieces, and integrating this information with prior knowledge, in order to make predictions about potential future states of affairs. If a patient is capable of this sort of anticipation or prediction in the context of watching a movie, it seems at least possible that they might be able to exercise executive function to make predictions about, or anticipate future states of affairs regarding, their own lives. Indeed, this capacity would seem to be supported by the patient's ability to exercise a 'theory of mind'—also demonstrated by the movie task—which requires an individual to distinguish their own thoughts and beliefs from that of others.

The ability to reflect on potential future states of one's own life in this way is significant, because it may critically influence the ways in which a patient's subjective experiences of the world are interpreted, as well as the kinds of prudential values they may have. Indeed, it may be the case that these patients are capable of what we might call 'higher-order' interests, beyond the experience of pleasurable sensations, and the avoidance of painful sensations. For example, the results of the movie study suggest that patients who have a positive result are capable of attending to complex stimuli; it stands to reason, then, that they may benefit from enrichment in their environment. Indeed, if these patients are more cognitively intact than their behaviour might indicate, it seems plausible that they might simply be bored a great deal of the time. Providing patients with various media (e.g., television, audiobooks, radio, music, etc.) may help to alleviate boredom, and improve patient welfare. In fact, patients may even have preferences about the kinds of entertainment they are provided with, as well as regarding the sorts of daily activities involved in their care. For example, they may have preferences about relatively simple issues of comfort, such as how often they are cleaned or turned in their beds,

hunger or thirst, the volume of noise in their rooms, access to natural light or fresh air. They may also have more complex preferences or desires, such as a desire for more (or less) contact from friends and family, desires about their potential recovery, or concerns about their potential burden on family or caregivers, or a sense of loss about the capabilities they no longer possess. In this way, some of these patients may more closely resemble patients in a locked-in state, for example, than patients in the vegetative state.

Moreover, as mentioned above, rather than existing merely ‘in-the-moment’, these patients may be aware of the overall narrative of their own lives, and aware of themselves as beings with a past, present, and future. If patients are aware of their lives prior to their injury, as well as the prospects of their life moving forward, it may be the case that they have particular desires for their own future. This may significantly impact how they interpret their condition, as an aspect of their overall life. On the one hand, this may allow these patients to gradually adapt to their condition, in the way that many of the patients in the populations discussed above are able to. On the other hand, the ability to reflect on their lives may be met with feelings of hopelessness, when compared to the ‘blissful ignorance’ which might accompany being unaware of the extent of one’s limitations or deprivations.

The point of this discussion is not to offer a definitive picture of the welfare of patients diagnosed as vegetative with covert awareness. Although the results of the movie task reveal a great deal about the residual cognitive capacities of some patients diagnosed as vegetative, with covert awareness, (i.e., executive function), there is still a great deal that we do not know about the subjective experiences of these patients. Further, it may be the case that some patients who are capable of preforming mental imagery are incapable

of performing the movie task. For this reason, much of the above discussion of the welfare of these patients depends on plausible inferences and extrapolations from the empirical data, and ultimately may not apply to any particular patient. Nevertheless, they provide potentially valuable insight into what I believe to be a fundamental question about all covertly aware patients: what can we do to help ensure that these patients have lives of at least a decent quality? This is surely a standard to which they are entitled, not only as beings with moral status, but as members of society. While their various limitations—physical, cognitive, or otherwise—may prevent them from living the kinds of lives which we as healthy individuals might want for ourselves, these limitations surely do not justify allowing these patients to live lives in which their various needs—not only physical, but emotional and social needs as well—are neglected. Importantly, attending to the needs of these patients in a way that will positively impact their welfare need not be particularly onerous, or costly. The various ways of enhancing patient welfare described in the previous sections are all inexpensive, relatively easy to implement, and may positively impact patient welfare. Obviously, these sorts of interventions alone cannot ensure that these patients are faring well. Nevertheless, they are critical first steps to ensuring that these patients are living lives of at least decent quality.

Additionally, many of the recommendations for improving patient welfare I have proposed above might justifiably be applied to any patient diagnosed as vegetative with covert awareness, even those who have not yet demonstrated covert narrative capacity by completing the movie task. It may be the case that some patients who are covertly aware may nevertheless lack covert narrative capacity, and thus, lack those capacities that I

have argued can be inferred from covert narrative capacity (i.e., theory of mind, morally significant distinctions). However, the possibility that some patients may retain covert narrative capacity, but not have been presented the opportunity to demonstrate it, seems sufficient to justify implementing at least some of the same strategies to improving their welfare as well. There seems to be very little potential harm which might be caused by trying to promote the social or emotional welfare of a patient through regular visits, or by reading to them, for example, even if that patient lacks the capacity to be benefitted in this way. Conversely, there does seem to be the potential for harm by failing to attend to the social or emotional needs of a patient who would benefit from such attention. For this reason, the prudent course of action is to minimize the risk of potential harms, like depression, to these patients by attending to their potential emotional needs.

Of course, determining the interests of a specific patient, and moreover, what sorts of experiences satisfy these interests, is a significant challenge. Indeed, it is one thing to suggest that a patient would benefit from attention to their social or emotional interests, and another to determine specific measures which will promote the emotional or social interests of this particular patient. How can we determine, with any kind of precision, what interests or preferences a patient has, when they are incapable of responding to their environment? While the lack of communication is obviously a significant barrier to ascertaining patient interests, I do not think it is one that cannot be overcome. First, while it is a possibility that a patient's preferences within the physical, social, or emotional domain will be highly idiosyncratic, it is much more likely that at least some of the experiences which will provide a benefit to them are the sorts of experiences which most people would find beneficial. Having regular interactions with

others, in which the patient is treated with dignity and respect, is the sort of experience likely to be almost universally beneficial.

Second, while a patient's preferences and values may change as a result of their injury, this does not entail that *all* of their preferences and values are different as a result of their injury. Indeed, a patient who enjoyed reading mystery novels prior to their injury is likely to still enjoy mystery novels post-injury. Thus, care-givers might still rely on a patient's past preferences to gauge their potential interests in the present. Similarly, while patients who are behaviourally non-responsive are incapable of responding to their environment, strictly speaking, many care-givers and family members nevertheless report that a patient 'seems to enjoy X', or 'responds positively to Y,' or 'doesn't like Z.' While these reactions may be difficult to discern in the limited time available for a behavioural exam by a neurologist, or may not always be reproducible, they suggest that patients' caregivers and family members may be attuned to a patient's subtle behaviours, simply because they spend so much time around them. If it is the case that caregivers can detect subtle indications of a patient's preferences or emotions, it provides a valuable potential means for them to promote the patient's welfare interests.



## **Chapter 6: Summary and Future Directions**

### **6.1 Summary of Chapters**

In this thesis, I have examined a novel patient population in the field of neuroscience: patients diagnosed as vegetative, with covert awareness. While these patients are behaviourally non-responsive at the bedside, they are capable of following commands issued by researchers through the use of mental imagery in an fMRI scanner. When placed in a functional magnetic resonance imaging scanner, these patients are able to voluntarily modulate their brain activity, by imagining the performance of specific physical tasks when instructed to do so by researchers. This provides conclusive evidence that these patients are aware. In Chapter 1, I provided an overview of the vegetative state, as well as the mental imagery task used to establish awareness in the minority of patients who are diagnosed as vegetative, but are nevertheless covertly aware. I also argued that in light of the discovery of covert awareness in these patients, both their autonomy interests, and their welfare interests, are relevant to the care and treatment of these patients. However, I argued, in the absence of conclusive evidence regarding the decision-making capacity of these patients (and thus, a viable way of investigating their autonomous interests), the welfare interests of these patients become all the more relevant to their care. For this reason, we have an obligation to these patients to investigate these interests.

In Chapter 2, I argued that the welfare interests of these patients are a relevant concern for others because of the moral status of these patients. I provided an overview of the concept of moral status, which holds that individuals with moral status must have their interests taken into consideration by others, when these interests are affected by other's actions. I defended an account of moral status which holds that the capacity for

suffering or enjoyment is a sufficient condition (though not necessary) for the possession of moral status. I examined several alternative accounts of the grounds of moral status, including the possession of sophisticated cognitive capacities, and found these alternative accounts unsatisfactory. Insofar as patients diagnosed as vegetative, with covert awareness are capable of suffering and/or enjoyment, I concluded, these patients had moral status, and their interests must be given consideration by others.

In Chapter 3, I defended the assertion I made in Chapter 2, that these patients were indeed capable of suffering as a result of physical pain. I described most pain experiences as consisting of two dimensions, a sensory dimension and an affective dimension, and argued that it is the affective dimension which is relevant to the morally significant experience of suffering. While patients in the vegetative state do not show activation in those areas of the brain associated with the affective experience of pain, a similar group of patients, minimally conscious patients, do show such activation and are thought to be capable of experiencing pain. I reasoned that because the areas of the brain associated with the affective experience of pain also underpin conscious awareness, the fact that minimally conscious patients can experience suffering, provides good reason for thinking that patients diagnosed as vegetative with covert awareness can as well.

In Chapter 4, I presented the idea that the moral status of the patients under discussion warrants a consideration of their welfare. Because these patients are capable of suffering and/or enjoyment, their lives can go better or worse, for them. And, given their moral status, we have an obligation to examine how our treatment of them affects their welfare, and moreover, what action we may take to avoid frustrating, as well as promote, their prudential interests. I considered one recent attempt to analyze the welfare of these

patients, by Kahane and Savulescu, who concluded that when considered through the lens of three traditional theories of welfare, these patients were overwhelmingly likely to be faring poorly. They concluded that on these grounds, others may have a moral obligation to withhold or remove these patients from life-sustaining treatment. I rejected this conclusion. I argued that Kahane and Savulescu's analysis of the experiential and desiderative interests was not sufficiently supported by the empirical evidence, and presented several objections to their arguments regarding the objective interests of these patients. I concluded that we simply do not know enough about the subjective experiences of these patients, what their lives are actually like for them, to make the sorts of claims which Kahane and Savulescu present.

In Chapter 5, I attempted to resolve the difficulty presented at the conclusion of Chapter 4, that we do not know enough about the subjective experiences or values of patients diagnosed as vegetative with covert awareness to make substantive claims about their welfare. I argued that in order to make such claims, we must first determine what domains of life are valuable to these patients, and then determine the degree to which they are satisfied with respect to these domains. I then presented two strategies for determining these relevant domains. The first examined other patient populations who resemble patients diagnosed as vegetative with covert awareness in key respects, and attempts to glean potential commonalities between these patient groups with respect to the domains of life relevant to their welfare. The second strategy examined recent research into the 'covert narrative capacity' of patients diagnosed as vegetative with covert awareness, and the potential inferences which could be drawn about their cognitive capacities from this research. I argued that the covert narrative capacity of these

patients may open up a number of new ways for family members and caregivers to promote the welfare of these patients.

## **6.2 Future Research Questions**

Over the course of this thesis, I have tried to shed light on a number of important ethical issues concerning patients diagnosed as vegetative, with covert awareness. Nevertheless, I believe there are a number of issues which I have raised, but which will require further research to adequately address. Some of these issues are practical, relating to the care and treatment of these patients, whereas others are more broadly philosophical.

### ***6.2.1 Integrating Patient Welfare into Decision-Making***

The first such practical issue concerns the potential role of information concerning patient welfare in treatment or care decisions. While it should be uncontroversial to suggest that patient welfare ought to be an important concern of those in charge of patient care, as well as those making decisions on behalf of the patient, it is less clear how information about patient welfare should be integrated into decision-making on their behalf. For example, studies like those conducted by Naci and colleagues discussed in Chapter 5 shed important light on the potential subjective experiences of patients, but they only tell us a small part of the story of how these patients are actually faring. If a patient is found to retain covert narrative capacity, and care-givers are informed of the potential residual cognitive abilities this capacity implies, how should this impact their decision-making on behalf of the patient? Indeed, this problem is one which exists for all surrogate decision-makers, tasked with making decisions based on a

patient's 'best interests,' though it is compounded in this context by our lack of information about the subjective experiences of these patients. Further research investigating the subjective experiences of these patients is needed to address this concern, as is further research into the responsibilities of surrogate decision-makers in this unique context.

### ***6.2.2 Balancing Welfare and Autonomy***

Similarly, I stated at the beginning of this thesis that we have *prima facie* obligations of both beneficence and autonomy to patients diagnosed as vegetative, with covert awareness, but that insofar as we are agnostic about the autonomy of these patients, we ought to focus on promoting their welfare. As we have seen, acknowledging the prudential interests of these patients gives us important insights into how best to satisfy our obligations of beneficence to these patients. However, further research is needed to determine how we ought to balance these welfare interests, with the potential autonomy interests of these patients, especially if these patients are found to possess decision-making capacity. For example, should a patient's previously expressed, autonomous desires inform what is in their best interests now, if these desires appear to conflict with their current welfare, and their current decision-making capacity remains in question? What role should the welfare interests of these patients play, in making an 'all things considered' determination of what ought to be done for them? Further research is also needed to determine how we ought to balance considerations of patient welfare, against other potentially competing interests. One might argue—as Kahane and Savulescu suggest—that sustaining the lives of patients diagnosed as vegetative with covert awareness, even if they are capable of faring well to a certain degree, may

represent an unjust distribution of scarce health care resources (Kahane & Savulescu, 2009). Determining an appropriate allocation of scarce health care resources to these patients is a question which requires serious consideration, especially given the fact that as the quality of health care increases, greater numbers of patients are surviving severe traumatic brain injury, and may potentially end up in a vegetative state. Indeed, the appropriate allocation of scarce health care resources is a challenge which extends far beyond the care of patients diagnosed as vegetative with covert awareness. However, given the heterogeneity of these patients, and presumably, the varying degrees to which various interventions may contribute to their welfare, further research is needed to determine the most effective use of resources with respect to these patients.

### ***6.2.3 Applying Philosophical Theories of Welfare to Difficult Cases***

A further issue which requires greater exploration concerns the general application of theories of welfare to patients with severe physical or cognitive deficits. As we have seen, the prospect of patients adapting to their circumstances is a very real possibility, not only for patients diagnosed as vegetative with covert awareness, but for a wide variety of patients who have undergone significant changes in their health. Consequently, many of these patients report a level of welfare seemingly incongruent with their objective health circumstances. As I argued in chapters four and five, this at least suggests that the domains of life which are affected by a patient's illness or disability may be less important to their overall welfare than similar domains are to healthy individuals, or that success within these domains may mean something different for these patients than healthy individuals. What does this tell us about theories of welfare in general? It seems to reinforce the intuition discussed in Chapter 4 that theories of

welfare must be sufficiently subject-sensitive, which in turn suggests that a viable theory of welfare must, at least in part, account for the attitudes and values of the subject. Of course, this may not rule out all objective theories of welfare, nor does it clearly support one subjective theory over another. Furthermore, what can a discussion of the welfare of covertly aware patients tell us about other patients whose ability to communicate their interests is impaired?

#### ***6.2.4 Towards a Theory of Welfare***

Similarly, in Chapter 4, I examined several existing theories of welfare, and considered potential challenges to each. While some of these challenges concerned their application to patients diagnosed as vegetative with covert awareness in particular, many of the problems I discussed were objections to the theories in general, including issues of scope, as well as subject-sensitivity. Because I was concerned with the application of these theories to a specific patient population, I was not able to consider these more general objections in very great detail, nor did I explicitly endorse a particular conception of welfare. Indeed, while I have suggested several items which may have prudential value for the patients under discussion, (e.g., the experience of enjoyment from physical pleasure, the absence of suffering from physical pain, the experience of positive emotions, social contact), I have not explicitly stated what each of these items has in common, in virtue of which they have prudential value. For the purposes of this discussion, this exclusion was not a problem. Because we currently know so little about the subjective experiences of patients diagnosed as vegetative with covert awareness, and because of the barriers to communicating with these patients, our best strategy for promoting their welfare at this stage is to focus on goods which are likely to have

prudential value for these patients, and which they are also capable of realizing. Answering *why* it is that these goods are prudentially valuable is, from a practical standpoint, less important at this early stage. However, as our understanding of these patients progresses, and we are able to do more to promote their welfare, a comprehensive theory of prudential value will play an important role in guiding the care of these patients. Further research is needed to develop such a theory of welfare, one which is capable of capturing both our strongly held intuitions about prudential value, and is applicable not only to healthy adult human beings, but those who exist ‘at the margins’, including patients diagnosed as vegetative, with covert awareness.

#### ***6.2.5 Different Theories for Different Individuals?***

The need for a theory of welfare which is applicable to patients diagnosed as vegetative with covert awareness, as well as other patients with severe physical or cognitive disabilities, suggests a further important question: should such a theory apply equally to all individuals, or do we require a different standard of welfare for individuals with severe physical or cognitive disability? Should the threshold at which one is said to be faring well be lower for these individuals, given their disabilities? Similarly, even if we think, as I have suggested in this thesis, that the prudential interests of covertly aware patients do not clearly support the withdrawal of care (at least, given the available evidence), we might still think that given their condition, a certain level of welfare is simply unavailable to them. This is not an issue I have addressed in this thesis, though it will surely be a critical element of constructing a theory of welfare which can accommodate the lived experience of individuals with disability.



Nevertheless, it is clear that that even in the absence of such a theory, important and meaningful steps can, and must be taken, to ensure that patients diagnosed as vegetative with covert awareness are able to have a decent quality of life. I believe this thesis provides a modest framework for how this obligation can begin to be fulfilled, and just as importantly, marks out a path for continued research into the welfare not only of these patients, but all patients.

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## Curriculum Vitae

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### Peer-Reviewed Articles & Book Chapters

Weijer C., Miller P.B., & **Graham M.** 2015. The duty of care and equipoise in randomized controlled trials. In J.D. Arras, E. Fenton, & R. Kukla (Eds.), *The routledge companion to bioethics*. New York: Routledge.

**Graham M.**, Weijer C., Cruse D., Fernandez-Espejo D., Gofton T., Gonzalez-Lara L.E, Lazosky A., Naci L., Norton L., Peterson A., Speechley K.N., Young B., & Owen A.M. 2015. An ethics of welfare for patients diagnosed as vegetative with covert awareness. *American Journal of Bioethics- Neuroscience*, 6(2), 31-41.

**Graham M.**, Weijer C., Peterson A., Naci L., Cruse D., Fernandez-Espejo D., Gonzalez-Lara L.E, Owen A.M. 2015. Acknowledging awareness: Informing families of individual research results for patients in the vegetative state. *Journal of Medical Ethics*, 41(7), 534-538.

Weijer C., Peterson A., Webster F., **Graham M.**, Cruse D., Fernandez-Espejo D., Gofton T., Gonzalez-Lara L.E., Lazosky A., Naci L., Norton L., Speechley K., Young B., Owen, A.M. 2014. 'Ethics of Neuroimaging after serious brain injury'. *BMC Medical Ethics*, 15(1), 41-54.

Peterson A., Naci L., Weijer C., Cruse D., Fernandez-Espejo D., **Graham M.**, Owen A.M. 2013. Assessing decision-making capacity in the behaviourally non-responsive patient with residual covert awareness. *American Journal of Bioethics-Neuroscience*, 4(4), 3-14.

### **Grants/Fellowships/Awards**

Ontario Graduate Scholarship

Graduate Scholarship \$15,000/three terms (2014)

Rotman Institute of Philosophy Graduate Research Award

Seed Grant, \$5000 (2013, 2014)

Western Graduate Research Scholarship

Graduate Scholarship \$9,000/per year (2010-2013)

### **Teaching**

Course Instructor. Philosophy 2073G. 'Philosophy of Death.' Western University: Jan-May, 2013.

Teaching Assistant. 'Introduction to Philosophy.' Western University: Sept-May, 2014.

Teaching Assistant. 'Critical Thinking.' University of Western Ontario: Sept-May, 2012.

Teaching Assistant. 'Introduction to Philosophy.' University of Western Ontario: Sept-May, 2011.

Teaching Assistant. 'Introduction to Philosophy.' Dalhousie University: Sept-May, 2010.