



10. Moral Conflict in the Minimally Conscious State

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MCS and Consciousness

After severe traumatic or anoxic brain injury, some patients enter into the minimally conscious state (MCS). MCS patients evince awareness of self and environment by way of inconsistent but discernibly purposeful behaviors—for example, visual fixation and pursuit, command following, and intelligible verbalization (Giacino et al., 2002). According to most, these behaviors are indicative of at least minimal conscious mental life: MCS patients are thought to possess consciousness. Further, by virtue of possessing consciousness, MCS patients are thought to possess a type of moral significance not attributed to patients who lack consciousness (e.g., patients in the vegetative state). How ought this inform decision making regarding MCS patients?

A complication accompanies the fact that the term consciousness can be taken to connote a number of distinct phenomena. Most relevant here is Ned Block's (1995) well-known distinction between access consciousness and phenomenal consciousness. A mental state is access conscious if the information it carries is poised for use in reasoning and in control of behavior. By contrast, a mental state is phenomenally conscious if there is something "it is like" to be in it. Conceivably, these forms of consciousness dissociate in subjects: For all we know, it is possible that an MCS patient can possess access consciousness even though there is nothing "it is like" to be in MCS.

Arguably, both access and phenomenal consciousness are morally significant. According to Walter Sinnott-Armstrong and Franklin Miller (2013), the abilities an agent possesses have moral significance. They argue that killing is morally wrong because it causes the loss of all abilities. Their position could be leveraged to generate a view in which the moral significance possessed by MCS patients is tied (at least in part) to the mental abilities they retain—the abilities that access consciousness enables. Alternatively, Charles Siewert (1998, 2013) has argued that phenomenal consciousness has intrinsic moral importance. According to Siewert, the possession of phenomenal consciousness undergirds a subject's irreplaceability as a person, as well as his or her status as an apt target for empathy.

The moral significance of access consciousness deserves further consideration. In what follows, however, I focus on phenomenal consciousness. I do so in part because a treatment of both aspects in the same paper would

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become unwieldy. But more importantly, it seems to me that much of the attention given to recent work on MCS—such as the striking finding by Owen et al. (2006; Monti et al., 2010) that some MCS patients have the ability to voluntarily initiate and maintain mental imagery for protracted periods—accompanies the assumption that there is something it is like to be in MCS,¹ and that this is so because phenomenal consciousness is the central conception of consciousness.

In the next section, I sketch a view in which the possession of phenomenal consciousness (henceforth: “consciousness”) is necessary for possession of (positive or negative degrees of) subjective well-being. It would seem that the possession of consciousness supplies caregivers reason to enhance the well-being of MCS patients. Unfortunately, as I discuss next, matters are complicated by a certain kind of moral conflict that arises in decision-making situations regarding MCS patient care. In many cases, it seems difficult, and perhaps impossible, to respect an MCS patient’s autonomy—as embodied in her autonomously expressed prior wishes or in the wishes she would presently autonomously express were she competent to do so—while promoting the well-being she presently enjoys and will plausibly enjoy in the future. Later, I consider views according to which the moral conflict is only apparent, because considerations of autonomy trump considerations of well-being (or vice-versa). I argue that neither view is satisfying: We are left with genuine moral conflict. However, consideration of these views is salutary, because their weaknesses motivate a mixed view in which considerations of both autonomy and well-being should in many cases be weighed against each other, as well as other relevant moral considerations (e.g., considerations of distributive justice). In the final section, I draw four practical conclusions.

MCS and the Moral Significance of Consciousness

In my view, the type of moral significance that MCS patients possess, and VS patients lack, has to do with the potential for subjective well-being that MCS patients possess and VS patients lack. Subjective well-being is what a person has (to some degree) when it is true to say that her life is going well or poorly (to some degree) for her, or from her perspective. In focusing on subjective well-being, I ignore views of well-being that emphasize the importance of the objective properties of a subject’s life. Such views are often called objective list theories. As Derek Parfit has it, such theories enumerate the objective goods or bads that enhance or diminish well-being “whether or not these people would want to have the good things, or to avoid the bad things” (Parfit, 1984, p. 499; for a recent defense of an objective list theory, see Rice, 2013). I do not claim that proponents of such views misuse the term well-being. I focus on subjective well-being (henceforth: “well-being”) because doing so allows me to direct attention to features of the relevant cases that I regard as both morally important and importantly distinct from debates between subjectivists and objectivists about well-being.

What is the connection between consciousness and well-being? In my view, the possession of consciousness is a necessary condition for the possession of some negative or positive amount of well-being: Possession of consciousness just is possession of the kind of subjective perspective necessary for possession of well-being to some positive or negative degree. Kahane and Savulescu’s observation (2009, p. 13) is apt: “Think of how awry it seems to say ‘He led a good life—but there was absolutely nothing it was like to live that life.’” There must be something it is like for a subject in order for things to go well or poorly for that subject.

What determines one’s amount of well-being? We can distinguish between actual and potential amounts of well-being: Amounts of actual well-being are closely tied to one’s actual experiences, and amounts of potential well-being are closely tied to the types of experiences available to one. Consider two mentally and functionally identical MCS patients. By virtue of their identical cognitive, behavioral, and perceptual capacities, there is a

¹ Tim Bayne (2013) has argued that signs of agency (e.g., command following, intelligible verbalization) are markers of phenomenal consciousness. So, whatever the normative differences between access and phenomenal consciousness, if Bayne is right, then many of the reasons we have to attribute access consciousness to a subject will also serve as reasons to attribute phenomenal consciousness.

sense in which these two patients possess the same amount of potential well-being. But suppose that one is neglected in an uncomfortable bed while the other receives very attentive, state-of-the-art treatment, frequent physical therapy, pain medication, and so on. Thanks to their actual experiences, the actual amount of well-being each enjoys will differ (and, over time, we can expect the amount of potential well-being to shift as well).

When considering the way in which experiences contribute to well-being, it is easy to simplify matters by focusing on simple examples (e.g., intense pleasure and intense pain). Doing so obscures a number of relevant and important issues. For example, are there dimensions other than positivity of experience that are relevant here (e.g., diversity of experience)? What is the relationship between a subject's cognitive sophistication and the experience-types available to her? What phenomenal properties determine an experience-type's contribution to well-being? Answering these difficult questions here would take us far afield. Even so, it is worth noting that human beings enjoy a wide range of experience-types, and that this fact is relevant to an understanding of amounts of well-being. Here is a comment by Peter Railton (2009):

Humans find reward in pleasant experience, to be sure, but also in such things as successful pursuit of abstract ideals, excellence in the exercise of skills and capacities, discovery and the creation of knowledge, friendship, humor, self-expression, aesthetic appreciation, romantic love, and commitment to kith and kin. (p. 94)

Of course, many of the experience-types available to healthy human subjects are not available to MCS patients. But recent neuroscientific work on MCS patients indicates that for at least some in this population, a variety of experience-types remain available. Many MCS patients retain high-level semantic processing of speech (Coleman et al., 2007). At least some MCS patients retain the capacity to deploy top-down visual attention (Monti et al., 2012), as well as the ability to voluntarily initiate and maintain mental imagery for protracted periods for the purposes of answering “yes or no” questions posed by experimenters (e.g., 30 seconds; see Monti et al., 2010; Owen et al., 2006). This seems to indicate a fairly robust mental life—one that includes not only volition, but the higher cognitive capacities that support reasoning (Hampshire et al., 2013). The science of MCS is in its early days, but initial indications support the view that at least some MCS patients retain the capacity to both enjoy substantial amounts of well-being and suffer from a significant deprivation of well-being.

Moral Conflict

We want to know about the moral significance of the consciousness MCS patients possess in part because we want moral guidance regarding the care of MCS patients. But any plausible story about MCS patient care must address not only the moral significance of consciousness but also the interactions between this source of moral significance and other morally relevant considerations (e.g., distributive justice, the value of autonomy). In particular, MCS caregivers must often attend to a conflict that arises between considerations of patient well-being and patient autonomy, where autonomy is understood as the capacity to lead one's own life, often by making decisions (e.g., about care) that define the nature and course of that life (see Dworkin, 1993, p. 222).

The case of *W v. M* (2011) illustrates the difficulties involved. At 43 years of age, M suffered brain damage from viral encephalitis. After she emerged from coma, doctors judged that she had entered the VS. Almost 4 years passed. Her family then sought authorization to remove treatment, at which point further examination of M led to a change in diagnosis, from VS to MCS. The family decided to press on, and the case—the first of its kind in England—went before the English Court of Protection.

Although there was no advance directive in this case, M's prior wishes were clear. Regarding situations similar to her own, M had expressed to family and friends on numerous occasions that she would not want her life to be maintained. However, in court testimony, M's caregivers painted a fairly complex picture of her current well-being. M obviously experienced pain and discomfort, such as when her incontinence pad was changed. When

certain songs were played for her, she reliably wept; once M was shown a video of a wedding, and she made a very distressed sound until caregivers turned off the video. But M's caregivers provided evidence of positive experience as well. According to testimony provided to the court, M tapped her wrist in tune with fast music, relaxed when given hand massages, seemed to enjoy being taken into the garden or out into the sun when it was warm, seemed to smile (especially in response to certain familiar male caregivers, certain music, and television programs), seemed to communicate comfort or discomfort based on different types of moans, and seemed to behave in a playful manner with some caregivers.

As stipulated in the Mental Capacity Act 2005 (MCA) (2007), the English Court of Protection was charged with deciding what was in M's "best interests." Although the MCA gives the court some latitude in determining best interests, the MCA's Code of Practice makes clear that the standard centrally involves a patient's past autonomous wishes and values:

5.32 . . . [I]n particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment. . . .

5.41 The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes). (2005)

However, in determining M's best interests the court awarded little weight to her prior wishes and values. Instead, the court (*W v. M*, 2011) cited a principle of "preservation of life" (paragraph 7) as relevant, as well as M's (actual and potential) well-being: "I find that she does have some positive experiences and importantly that there is a reasonable prospect that those experiences can be extended by a planned programme of increased stimulation" (paragraph 8). As a result of these considerations, the court refused the application to withdraw artificial nutrition and hydration.

Theorists have sharply criticized the court's neglect of M's prior wishes. According to Alexandra Mullock, "The legal requirement to consider the past wishes and views of incompetent patients should . . . be seen as . . . an obligation to respect autonomy" (2012, p. 2). Emily Jackson agreed and emphasized the need for everyone to establish their wishes in a way the court will be unable to neglect: "The moral of this sad story is that all of us—even when we are completely healthy—need to think about whether we would wish to have [artificial nutrition and hydration] withdrawn if we were ever in a MCS, otherwise we risk being played music that makes us cry and being kept alive in part because stopping moaning when one has just had one's incontinence pads changed is said to be evidence of contentment" (2012, p. 3).

Was the court right in privileging the existence of positive experiences, and the potential for extension of such experiences, over M's autonomous wishes?² This depends on one's view about the relative importance of autonomy and well-being in cases involving MCS patient care. As M's case makes vivid, in such cases we come across a moral conflict: As stated earlier, it appears difficult, and perhaps impossible, to respect an MCS patient's autonomy while simultaneously promoting his or her well-being. We can grant that considerations of autonomy and of well-being are both morally relevant. All else being equal, we have reasons to respect a patient's autonomy or to promote a patient's well-being. Our problem is that, in the cases at issue, all is not equal. Considerations of autonomy and well-being seem to conflict. How ought we to adjudicate the conflict?

2 A further question is whether the court was legally right in citing a principle of preservation of life. Because I am interested in certain moral rather than legal aspects of this case, I do not consider this question. For a discussion of some of the case's legal ramifications, see Sheather (2012).

Autonomy Trumps Well-being

Consider the following claim.

Autonomy trumps well-being

When an MCS patient's prior wishes about her present state are clear, properly informed, and sufficiently strong, relevant decision makers should heed these wishes to the exclusion of any considerations of well-being.

Three points of clarification are relevant here. First, a patient's prior wishes (that "P" be done) are clear, roughly, when their content is intelligible and sufficiently specific and when there is no conflicting evidence to the effect that the patient wished something incompatible with P. Second, a patient's prior wishes are properly informed when there is sufficient indication that the patient understood the relevant circumstances surrounding her wishes. The patient need not understand every facet of the relevant circumstances, of course. But as a rule of thumb, a patient should be aware of information that might plausibly cause her to reconsider her prior wishes. Third, the requirement that the wishes be sufficiently strong is intended to exclude cases in which (1) the patient expressed the wish that P be done either hesitantly, or tentatively, or in some way that undermines confidence that the wish was genuine or (2) at any time after expressing the relevant wish, the patient expressed hesitation or anything that undermines confidence that the prior wish remained genuine. (In the case of an advance directive, this requirement might be met by conducting periodic reviews of the advance directive with its author.)

In general, medical and legal practice in related cases is consistent with the claim that *Autonomy trumps well-being*. When patients lack competence to make care-related decisions, advance directives are typically given legal and medical authority. The patient's past wishes, as embodied in the advance directive, take precedence over present well-being, even if the patient appears to enjoy a pleasant existence. In the case of *W v. M*, for example, the court noted that if M had made an advance directive indicating a wish to withdraw treatment, the directive would have determined the court's decision. In a discussion of the perils of decision making for both MCS and VS patients, Joseph Fins and Nicholas Schiff gave voice to a common judgment: "It is our strongly held view that if a patient articulated a preference or completed an advance directive before losing decision-making capacity, the prior wishes should guide care" (2010, p. 23).

Even in the absence of an advance directive, many maintain that a patient's prior wishes (insofar as they can be determined) should trump considerations of well-being. In the United States, when patients lack both an advance directive and the ability to make care-related decisions, it is common to utilize a "substituted judgment" standard. According to this standard, caregivers determine what to do by reference to what the patient would have decided had she been able to make the relevant decision. This standard clearly prizes autonomy over well-being: The patient's hypothetical autonomous decision is taken to be of primary moral importance.³

Why should we think, as many seem to, that the notion, *Autonomy trumps well-being*, is correct? Work on care-related decision making in similar cases proves useful here. For example, although severe dementia differs in many important ways from MCS, structural similarities between severe dementia and MCS are illuminating. Consider Ronald Dworkin's (1993) autonomy-friendly view regarding decision making for incompetent, severely demented patients.

Crucial to Dworkin's position is a distinction between a subject's critical interests and her experiential interests. The latter are tied to experiences we find enjoyable as experiences (e.g., watching football, eating well). The former are tied to "convictions about what makes a life good on the whole"—and these interests "represent critical judgments rather than just experiential preferences" (Dworkin, 1993, pp. 201–202). Dworkin has us consider the case of Margo, a severely demented patient whose prior critical interests not to live on in such a

³ For criticism of the substituted judgment standard, see Torke, Alexander, and Lantos (2008).

state conflict with her present experiential interests. At present, Margo is happy. Even so, Dworkin maintains that Margo's previously held critical interests take moral precedence. "If I decide, when I am competent, that it would be best for me not to remain alive in a seriously and permanently demented state, then a fiduciary could contradict me only by exercising an unacceptable form of moral paternalism" (p. 231).

Three types of consideration seem to ground Dworkin's judgment. First is a view of the moral importance of autonomy, which for Dworkin has to do with an agent's capacity to express her character in leading a life. "Recognizing an individual right of autonomy . . . allows us to lead our own lives rather than be led along by them, so that each of us can be . . . what we have made of ourselves" (Dworkin, 1993, p. 224). Second is a view of what makes a life go better or worse. Whereas Dworkin thinks that recognizing and satisfying the critical interests we ought to have genuinely makes our lives go better, the same is not true of experiential interests. According to Dworkin, "My life is not a worse life to have lived—I have nothing to regret, still less to take shame in—because I have suffered in the dentist's chair" (p. 201). Third is a view of the moral importance of a life considered as a whole. For Dworkin, a life has moral value above and beyond the value that might attach to any of the events in it.

Because experiential interests are morally of little import, satisfying them is of little import as well. More important are a patient's previously held critical interests. The satisfaction of these interests can make the patient's life, when considered as a whole, go better. Thus, Dworkin rejects the view that "in the circumstances of dementia, critical interests become less important and experiential interests more so, so that fiduciaries may rightly ignore the former and concentrate on the latter" (p. 232). Interestingly, he rejects the relative moral significance of experiential interests by way of an analogy between patients in VS and severely demented patients: "Persistently vegetative patients have no sense of their own critical interests, but that is not a good reason for ignoring their fate, and it is not a good reason for ignoring the demented, either" (p. 232).

Insofar as Dworkin rejects the thought that the presence of consciousness makes a morally significant difference, of course, he appears to stray very far from commonsense morality.⁴ Moreover, his justification for doing so appears, in my view, rather thin. One reason is that I fail to find claims about the good of a subject's life as a whole compelling.⁵ Making a full case for this claim is beyond the present scope, but consider briefly the fact that a single life often has many phases and takes many shapes. Values and religious commitments change, as do careers, relationships, capacities, and so on. Short of a well worked-out theory of the best possible shapes for a life, it is unclear to me what grounds judgments about the good of a subject's life as a whole: The worry is that the tacit normative theory of life's shape informing these judgments will not withstand critical scrutiny.

But grant momentarily that something like the good of a subject's whole life exists. It remains possible to reject Dworkin's judgments about what that implies. We can presume for present purposes that the patient in question experiences some positive level of well-being: Positive experiences are available to her, and we know how to provide them. There is thus an obvious sense in which the positive well-being she has experienced over the

4 A recent survey by Gipson, Savulescu, and Kahane (2013) found that 40.2% of participants found it morally acceptable to remove treatment from VS patients, but only 20.6% found it morally acceptable to remove treatment from MCS patients. Further, 17.6% found it morally unacceptable to remove treatment from VS patients, and 41.2% found it morally unacceptable to remove treatment from MCS patients. This constitutes some evidence for the claim that the presence of consciousness has a significant role in commonsense morality.

5 Although differing from Dworkin at many places, Jeff McMahan agrees with his verdict concerning the relevant cases. Although McMahan judges that what is good for a relatively happy demented patient at present is the continuance of life, he maintains that the patient's life as a whole, as well as the part of her life that occurred before dementia, have moral value. And he judges that the goodness of both of these are negatively affected by a failure to implement the patient's prior wishes. Further, McMahan judges that because the healthy part of the patient's life "is overwhelmingly the dominant part, its good should have priority . . . the Demented Patient's present good ought to be sacrificed for the greater good of her earlier self, which is also the greater good of her life as a whole" (McMahan, 2002, pp. 502–503). Insofar as McMahan's judgment depends on a view of the good of life as a whole, my criticisms of Dworkin apply.

course of her life continues to rise. Perhaps her whole life is better if it contains several years of pleasant, even if cognitively impaired, experience.

Dworkin will not like this suggestion, of course. Because Dworkin finds experiential interests of minor moral importance, he accords them little weight. In my view, this part of Dworkin's approach is implausible: The satisfaction of experiential interests is centrally important to a subject's well-being. Human agents go to great lengths—justifiably, it seems to me—to fulfill experiential interests (e.g., tasting a rare scotch, skiing a difficult backcountry chute). And it is arguable that the satisfaction of a critical interest is valuable in part because of the experiences such satisfaction engenders—experiences of meaningfulness, achievement, love, and so on.⁶ Notice again, however, that one can agree with Dworkin about the minor importance of experiential interests while disagreeing with his judgment about whether considerations of autonomy trump those of well-being. Whatever the moral significance of our critical interests, we need additional reasons to think this significance persists across massive changes to a subject such as occur when patients enter MCS. And we might also wonder—even granting that a whole life has its own kind of moral value—why the value of a whole life is so much more important than the value of a subject's present experiences. Perhaps it is not.

In this connection, consider a case in which an MCS patient's prior wishes were to remain alive, no matter what. And suppose that the patient's case is a horrible one. She is in constant pain. Following Dworkin, we should keep her alive out of respect for her autonomy: Doing so will give her whole life the shape she intended it to have. In such a case, it is difficult to disagree with Seana Shiffrin's verdict: "It seems cruel in such cases to force such people to live through agony so that they will fulfill a critical interest . . . they no longer recognize, accept or even understand" (Shiffrin, 2004, p. 210). In my view, this kind of case demonstrates that it is not in general true that considerations of autonomy trump considerations of well-being. The proposition that Autonomy trumps well-being is false.⁷

One might object to this line of reasoning as follows.⁸ A properly informed subject who decides 'to remain alive, no matter what' has expressed a wish to endure constant pain rather than having treatment withdrawn. But this is irrational: All else being equal, it is irrational to choose pain over pain's cessation. And irrational decisions are not properly expressive of autonomy.

It is true that autonomy requires the capacity for rational behavior in general (see Berofsky 1995, p. 10). But particular decisions may properly express autonomy even if they fall short of optimal rationality. Smoking is an irrational activity, indicative of irrational desires, preferences, and decisions, and yet decisions to smoke can nonetheless express an agent's autonomy. Because rationality and autonomy come apart, it seems possible that a subject can irrationally, but autonomously, decide to remain alive in the face of great pain.⁹ And if so, then cases likely exist in which considerations of well-being override considerations of autonomy.

6 Recall Wilfred Sellars' reaction to Daniel Dennett's eliminativism about qualia (the purportedly intrinsic, ineffable properties of experience): "But Dan, qualia are what make life worth living!" Dennett commented: "If you didn't have qualia, you would have nothing to enjoy (but also no suffering, presumably). It is generally supposed—though seldom if ever expressed—that it would not be any fun to be a zombie" (Dennett, 2005, p. 91).

7 One might worry that because of moral asymmetries between negative and positive hedonic experiences, this case does not generalize to cases involving positive amounts of well-being. Perhaps, for example, there is a duty to prevent negative hedonic experiences if possible, but no duty to promote positive hedonic experiences if possible. If so, perhaps an MCS patient's positive well-being never overrides considerations of autonomy. But I think this worry, as expressed, goes too far. Plausibly a patient's prior wishes are more easily outweighed when that patient is in pain, but it is too strong (in my view) to claim that no amount of positive well-being could outweigh a patient's prior wishes.

8 Thanks to Walter Sinnott-Armstrong for suggesting this line of response.

9 Both irrationality and the pain a patient endures come in degrees. So one might argue that, at a certain point, the irrationality of a decision undermines autonomy: Some decisions are too irrational to count as autonomous. And perhaps decisions to endure a great amount of pain cross the relevant threshold. But all I need is a case that does not cross this

Well-being Trumps Autonomy

Although Autonomy trumps well-being is probably the majority view (at least among medical and legal professionals), one finds pockets of dissent.¹⁰ In this section I consider an argument for a view on the opposite end of the spectrum.

Well-being trumps autonomy

When an MCS patient's present and potential future well-being is clear, relevant decision makers should aim to promote patient well-being to the exclusion of any considerations of autonomy.

The line of argumentation I am interested in (although others exist¹¹) goes as follows.¹²

Not Really Autonomous

1. An agent J's prior wishes regarding her care have moral weight regarding decisions about her care only if they are rightly considered expressions of J's autonomous judgments or decisions.
2. An agent J's judgment or decision is rightly considered autonomous only if J's judgment or decision is appropriately informed.
3. For any human agent J, no judgment or decision J makes regarding J's care in MCS can be appropriately informed.
4. Thus, for any MCS patient J, J's prior wishes regarding care do not have moral weight for decisions regarding her care.

Should we accept this argument? I find point (1) plausible: Non-autonomous judgments or decisions are not the kinds of things typically taken to be enforceable on a patient's behalf. I find point (2) plausible as well. Although some work is needed to specify what counts as being appropriately informed, some such condition seems to apply. Judgments or decisions that proceed from bad information are paradigmatically nonautonomous. Much of the work in this argument is done, it seems, by point (3). Why think that no human agent—even one apprised of the relevant scientific and clinical literature—can meet the relevant information condition regarding her own care while minimally conscious?

Begin by appreciating our ignorance about what it is like to be minimally conscious. MCS patients have undergone radical cognitive, perceptual, and behavioral changes, and the nature of their day-to-day experience is difficult to fathom. It is unclear whether their experience is analogous to that of less cognitively sophisticated creatures, or of other brain-damaged humans, or whether analogies simply fail here. The patient M reliably wept when she heard Elvis sing, "You were always on my mind." What was hearing this song like for her? Was she experiencing vivid memories of some painful experience? Was this simply a reaction to stimuli, the result of the song's tune triggering some behavioral schema oddly unconstrained because of her injury? Might it have been pleasant for her to weep—a kind of rudimentary experience of catharsis? At present, it is impossible to say.

threshold, and in which the patient's well-being overrides the (somewhat) irrational, autonomous decision to "stay alive, no matter what." It is plausible that some cases fall at this point along the spectrum.

10 Consider Rebecca Dresser's complaint: "Legal decision-makers have been preoccupied with safeguarding incompetent patients' rights of self-determination and privacy, largely overlooking these patients' more immediate interests in having their present well-being maintained. This legal approach is . . . insufficiently protective of the incompetent patient's genuine interests" (Dresser, 1986, p. 373).

11 Some suggest that considerations of autonomy are either irrelevant or diminished because, in cases of severe brain injury, the patient is no longer the same person as she was when she expressed her prior wishes. For discussion of this kind of thought, see Dresser (1986), DeGrazia (1999), Shiffrin (2004).

12 For an argument similar to Not Really Autonomous concerning severely demented patients, see Wrigley (2007).

How much should we make of our ignorance concerning what it is like? Matters are complicated by our present lack of a rigorous account of what level or quality of information is sufficient to render a judgment, or a decision based upon it, autonomous. Even so, it is plausible to think that many judgments or decisions about care when in MCS that people would and will in the near future make would and will be insufficiently informed, simply because they would and will be based on either misinformation about MCS or untutored (and implausibly vivid) acts of imagination.

In a recent study of lay attitudes toward withdrawal of treatment decisions, Jacob Gipson, Guy Kahane, and Julian Savulescu (2013) gave participants a clinical description of MCS and asked them to respond to a statement to the effect that they would want treatment withdrawn if they were in such a state. Some 41% agreed, 36% were unsure, and 22% disagreed. Participants were also given a clinical description of locked-in syndrome (LIS), a condition in which patients retain normal consciousness and cognitive functioning but are almost totally paralyzed. Often, such patients can communicate with others only by moving their eyes. Interestingly, participants' responses to a statement that they would want treatment withdrawn if they were in such a state mirrored their responses to the statement about MCS: 36% agreed, 39% were unsure, and 25% disagreed.

We know—although presumably most of the participants did not—that patients in LIS report relatively high degrees of subjective well-being. Reporting on a recent survey of LIS patients, Bruno et al. (2011a) noted: “Our data show that a non-negligible group of chronic LIS survivors self-report a meaningful life and their demands for euthanasia are surprisingly infrequent” (p. 7). More specifically, 72% of their LIS patients reported positive levels of happiness, 8% reported having suicidal thoughts often (and 24% reported suicidal thoughts occasionally), and 13% reported feeling depressed. It is thus plausible that a high proportion of the participants in Gipson et al.'s study who judged that they would want treatment withdrawn if in LIS would not, in fact, want treatment withdrawn when in LIS.¹³ This supports the following two claims. First, the judgments these participants made regarding LIS were insufficiently informed regarding what it is like to be in LIS and thus nonautonomous in the relevant sense. Second, the judgments these participants made regarding MCS, because they were based on a similar lack of relevant information concerning what it is like to be in MCS, are insufficiently informed and thus nonautonomous in the relevant sense.

The problem is compounded by medical and legal experts who offer insufficiently informed assertions from a position of authority. Consider Emily Jackson's assertion, made in the context of criticizing the court's decision in *W v M*: “Imagining myself in M's shoes, I would regard a life in which I was totally dependent on others for all aspects of daily care; immobile; doubly incontinent; moved by a hoist; being played songs that made me cry and uttering occasional words like ‘where am I’ and ‘bloody hell’ as, to put it bluntly, a living hell” (Jackson, 2012, p. 1). Jackson's assertion appears to be based primarily on an untutored act of imagination, with additional justification offered by a selective portrayal of M's condition.

In a frequently quoted passage, Ashwal and Cranford (2002) asserted that “if there were a better understanding of MCS, especially the critical issues of consciousness and likelihood for pain and suffering, a broader consensus would develop, that being in a permanent MCS would actually be worse than being in a permanent VS” (p. 29). Aside from an odd claim about what we would judge if we knew more, Ashwal and Cranford's assertion appears to be based on the thought that because they are conscious, MCS patients can feel pain. But MCS patients can feel pleasure as well. Plausibly, some can undergo a wider range of experience-types than pain and pleasure. Ashwal and Cranford's assertion is unhelpful.

It seems plausible, then, that some (perhaps even most) judgments or decisions about care for MCS patients are insufficiently informed. (This raises important practical questions about how best to inform authors of advance directives as well as MCS patient caregivers and family: see the next section of this chapter for discussion.) But

13 Of course, someone in LIS could rationally demand the withdrawal of treatment. Moreover, we might be morally bound to honor such a decision.

this is not enough to deliver the conclusion of Not Really Autonomous. One might plausibly maintain that our inability to know what it is like to be minimally conscious is an epistemic constraint future science will overcome. Once we know more about the brain, more about the etiology of brain injury, more about prospects for recovery, more about methods of treatment, more about the cognitive abilities of MCS patients, we will be able to make rough-and-ready judgments about what it is like. Already in M's case, caregivers estimated that 30% of M's days were unpleasant. Perhaps soon we will be able to say "MCS patient Z has cognitive abilities A, B, and C, but lacks D and E; she is in pain for X minutes a day, principally when she undergoes experience-types F and G; she enjoys experiencing H and I, and there is reason to expect that with proper treatment she will one day be able to spend much of her time enjoying L, M, and N." If this is right, then it would seem Not Really Autonomous fails. In principle, it should be possible to make judgments or decisions about MCS care that meet plausible criteria for being appropriately informed.

A proponent of Not Really Autonomous might reply that the change to experience brought on by brain injury is so radical that our characterizations of it—no matter how empirically informed—will fail to meet plausible criteria for being appropriately informed. The thought here is that whatever characterizations of life in MCS we are able to give will fail to respect the radically different phenomenal character of life in MCS. If we cannot know what it is like to be in MCS—what it is like for an MCS patient to be in pain; to experience pleasure; to experience auditory, tactile, or visual stimulation; to have one's mind wander; or to focus one's attention on something—then we cannot make an informed decision about whether we want to carry on in such a condition.¹⁴

But there are two significant problems with this reply. First, if it is taken seriously, it threatens to undermine the argument's chief aim. For, if we face radical ignorance about what it is like to be minimally conscious, then we face radical ignorance about how to enhance the well-being of an MCS patient. But in the present context, the point of Not Really Autonomous is to undermine considerations of autonomy without simultaneously undermining considerations of well-being.

Second, it is dubious that we can know nothing about what it is like for an MCS patient. Certainly our ignorance is vast, but we have little reason to believe that experience in a human being would take a form totally inaccessible to us. We believe, after all, that the conscious lives of healthy adults share many similarities in spite of huge differences in cognitive, perceptual, and behavioral capacities. Plausibly, we should believe the same thing about MCS patients. We should expect that pain is bad for them, that pleasure is good, that a variety of experiences is better than a life of monotony, that greater cognitive sophistication tracks greater potential for well-being, and that behavior—even if confined primarily to neural responses to stimuli—is a fair indicator of what things are like for such patients.

Not Really Autonomous fails to secure victory for the position represented by *Well-being trumps autonomy*. Even so, a weaker form of the argument—one that emphasizes the epistemic difficulties we face when making decisions about MCS care, without claiming that they are in principle surmountable—is very plausible. Decisions about MCS care that wish to accord significance to a patient's prior wishes should pay far closer attention than is now common to the information on which those wishes were based.

14 In a recent paper, L. A. Paul (2015) emphasized our ignorance about "what it will be like" for a whole class of transformative experiences (she focused on having a child). According to Paul, in light of our ignorance, decisions about courses of action that involve transformative experiences are neither rational nor irrational. There are obvious affinities between this argument and the one explored in the previous paragraph, but the point made there is distinct from Paul's. Autonomy and rationality are distinct properties of a judgment or decision.

Conclusion

In the view I have sketched, a certain amount of well-being is available to MCS patients by virtue of their possession of consciousness. This fact generates a moral reason to promote MCS patient well-being. But I have also noted the difficulties that arise in decision-making situations concerning MCS patient care. Because considerations of autonomy often conflict with considerations of well-being, we are faced with difficult choices. It would be easier if one type of consideration systematically outweighed another. However, troubles beset both the view that autonomy trumps well-being and the view that well-being trumps autonomy. The failures of these extreme views motivate a mixed view, in which considerations of both autonomy and well-being should in many cases be weighed against each other, as well as other relevant moral considerations (e.g., considerations of distributive justice). To finish, I wish to draw four practical conclusions from this discussion.

First, more attention should be paid to the informational deficits facing authors of advance directives and MCS patient caregivers and family. Given the gravity of decisions about MCS patient care, such attention might focus on (1) better ways to educate the relevant decision makers about emerging empirical work on MCS (e.g., work of the sort featured in this volume) and (2) the implementation of practical decision procedures that are sensitive to the informational needs of the relevant decision makers. Short of the proper educational and decision-making procedures, injunctions to consider “what the patient would have wanted” or what is in the patient’s “best interests” might not be good enough. It is, of course, difficult to say from the armchair what decision-making procedures would be best. In my view, such procedures should be developed by those who are sensitive to the very practical constraints and difficulties attending these decisions. For example, Joseph Fins (2006) noted a difficulty arising from local features of health care in the United States:

[B]ecause of the geographic separation of acute care and rehabilitation settings, many acute care clinicians have little idea about the course of their patients after hospital discharge. This can lead to distortions among acute care practitioners about what might be achieved over time. This may breed a sense of nihilism about the value of ongoing care because patient prognosis is based upon their limited perspective and contextual experiences. (p. 174)

Decision-making procedures should be designed to reflect the fact that informational deficits (such as overreliance on a limited clinical perspective) often influence care decisions in important ways. Ideally and minimally, regarding decisions to withdraw treatment, both physicians and family members (and, if competent, MCS patients themselves) should be given the time and opportunity to assess the same body of relevant information and to jointly consider diagnostic prospects.

Second, the moral authority generally accorded to considerations of autonomy in end-of-life decision making is, in cases of MCS patient care, out of place. Short of good reasons to think so, we should not let advance directives or clearly expressed prior wishes trump considerations of well-being. Rather, advance directives or clearly expressed prior wishes should be assessed based on the quality of the information on which they were based. Further, even when prior wishes are thought to meet the relevant informational requirement, these wishes should not trump considerations of well-being. Prior wishes should be allowed to offer guidance without dictating the decision to be made.

Third, in such decision-making situations, more attention should be given to considerations of distributive justice. I have not focused on such considerations here, but they are clearly relevant. Any decision to withdraw treatment from an MCS patient who enjoys some amount of positive well-being harms that patient to some degree—at least in the sense that it causes the patient loss of potential well-being. Some argue that considerations of autonomy, or the shape of a patient’s whole life, justify this harm. Considerations of distributive justice are another potential justifier. Dominic Wilkinson and Julian Savulescu (2012) argue that in some cases—and they suggest M’s case is one of these—considerations of distributive justice support the

withdrawal of treatment. The reasoning is straightforward. Caring for an MCS patient is expensive. Funds are limited. If all else is equal, we should distribute funds in a fair way: We must answer the “relative question of whether one life is more worth living or less expensive to support than another” (p. 2). Of course, whether one life is more worth living than another depends crucially on the amount of well-being available to a subject, as well as on how the distribution of funds will influence relevant subjects. More work is required to sort out the best ways to think about how distributive justice should influence care-related decisions for MCS patients.

Fourth, the moral importance of a patient’s amount of well-being provides an urgent moral reason to support research that improves our diagnostic capacities. MCS is not a static condition. Retained cognitive, perceptual, and behavioral capacities vary widely among MCS patients. Recognizing this, Bruno et al. (2011b) recently proposed a refinement of the diagnosis of MCS, into categories of MCS+ and MCS-. They draw the distinction as follows:

MCS+ was defined by the presence of (a) command following, (b) intelligible verbalization or (c) gestural or verbal yes/no responses. In contrast, MCS- patients only show minimal levels of behavioural interaction characterized by the presence of non- reflex movements such as: (a) orientation of noxious stimuli, (b) pursuit eye movements that occur in direct response to moving or salient stimuli, (c) movements or affective behaviors that occur appropriately in relation to relevant environmental stimuli. (p. 1375)

The categorization of MCS is likely to undergo additional refinement as our understanding of MCS increases. Plausibly, token cases of MCS permit large differences in potential for well-being. Therefore, although MCS is rightly thought to be morally different from VS, it is possible that token cases of MCS admit of moral differences at least as large. Decision-making regarding MCS patient care should be based on as accurate an understanding as possible of the capacities each MCS patient retains, as well as those capacities they might, with adequate treatment, one day recover.

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