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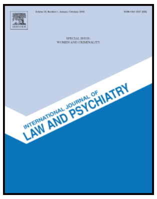

The Minimally Conscious State, the Disability Bias, and the Moral Authority of Advance Directives

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1. Introduction

Richard Rudner noted long ago that many of our decisions to act are made in the setting of uncertainty and thus, deliberation about a course of action must take into account the cost of being wrong. He was speaking in the context of atomic testing and the threat of nuclear chain reactions. *Acting* on the hypothesis that there *will not* be an apocalyptic chain reaction (by developing and testing nuclear bombs) had better enjoy substantial justification. The more general epistemic lesson he relates as follows,

> [O]ur decision regarding the evidence and respecting how strong is "strong enough", is going to be a function of the *importance*, in the typically ethical sense, of making a mistake in accepting or rejecting the hypothesis….*How sure we need to be before we accept a hypothesis will depend on how serious a mistake would be* (Rudner, 1953, 2).

Less dramatic examples are illustrative. Suppose a medical researcher thinks that a toxic ingredient in a drug is not present in lethal quantities. Before acting on this hypothesis as if it were true, she would need very strong justification for it being true. Being *wrong* that it is *not* toxic would mean lives lost. Of course, costs can be symmetrical. If in pre-trial testing a drug shows significant promise for a deadly disease (imagine a vaccine in the setting of a pandemic), then not doing a human trial would also mean numerous lives lost. Cases of this latter sort are symmetrical, cases like nuclear bomb testing have asymmetrical costs.[1]

In this paper, I argue that withholding of artificially delivered nutrition and hydration (hereafter simply tube feeding) from patients in a minimally conscious state (MCS), and that is their only condition, involves asymmetric costs to being wrong. The typical justification for withholding tube feeding from a patient is if the patient has an advance directive (written or oral) indicating so. I argue that this advanced directive argument does not provide sufficient evidence for withholding tube feeding from MCS patients. It would be a serious mistake to let a person who is conscious, and possibly able to recover, to dehydrate to death. Given Rudner's guidance, the justification for withholding tube feeding must be strong.

I proceed as follows. In the second section I explain what the condition MCS involves and the specific clinical circumstances to which my argument applies. The third section explains and defends my argument against the reliability of advance directives for this patient population. Specifically, the third section argues that the advance directives from patients in MCS which have refused tube feeding are not morally sufficient to support withholding tube feeding. The fourth section addresses an important series of rebuttals to my argument. Specifically, in arguing that advance directives are not morally sufficient, I may be accused of ignoring the value of autonomy. The fifth section concludes my argument.

2. The minimally conscious state

Being clear about what the minimally conscious state is, its possible treatment and management, and the clinical circumstances to which my argument applies can go some way towards rebutting obvious "nonstarters" to my argument.

The minimally conscious state is a "condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated" (Giacino et al., 2002, 350–51). MCS patients are conscious and aware. They retain some or all of the following abilities: (a) being able to follow simple commands, (b) being able to respond to yes/no questions, (c) intelligent verbalization, and (d) purposeful behavior such as responding appropriately to the semantic content of a question (Giacino et al., 2002, 351). Large-scale neural activity in the "higher-cortices" is a feature of MCS that distinguishes it from the vegetative state. Through various neuroimaging techniques, we know that MCS patients show neuroanatomical activity strongly indicating conscious awareness and higher-order cognition including semantic and emotional processing (Laureys, Perrin, Schnakers, et al., 2005; Schiff, Rodriguez-Moreno, Kamal, et al., 2005). Specifically, Laureys et al. observed that "cortico-cortical functional

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[1] The epistemology literature has blossomed in regard to whether there is a pragmatic aspect of justification or knowledge. See Fantl and Fantl and McGrath (2009), and Stanley (2005). With application to ethical cases, see Moller (2011) and Lockhart (2000).

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connectivity between auditory cortex and a large network of temporal and prefrontal cortices was more efficient in 15 MCS patients than in 15 vegetative state patients" (Laureys, Perrin, and Schnakers, 2005, 730–731). The importance of these findings is that MCS patients evince functional *integration* between different processing centers which suggests higher-order cognition, but they lack the ability to *express* such processing fully or consistently. These results were confirmed via metabolic studies using FDG-PET (fluorodeoxyglucose with positron emission tomography) in which brain regions associated with language processing and possibly volition were notably active (Bruno, et al., 2012, 1096). On the basis of these studies and in particular imaging studies of cortical activity, MCS patients should not be viewed as lacking a "self," they are conscious, by behavioral criteria, and *likely* retain reasoning abilities on the basis of neuroimaging data (Braddock, 2017).

I emphasize "likely" here because of a legitimate concern about the reverse inference fallacy (Nachev & Hacker, 2010).[2] The first point to note is that fallacies are typically distortions or deviations from good forms of reasoning (Pruss, 2016). The *ad hominem* fallacy is typically a distortion of a legitimate concern about someone's reliability in assessing the evidence, and reliability *is* evidentially relevant. The fallacy of composition (i.e., inferring from the fact that a part has a property to the whole has that property) is a deviation from a legitimate inference from part to whole, for example, if my toe is injured, I am injured; if my digestive system digests food, I digest food. Likewise, the reverse inference fallacy is a deviation from a legitimate kind of inference. Before addressing the legitimate inference, a brief recapitulation of the reverse inference is required.

The reverse inference fallacy occurs when one reasons as follows: if subject S is given a task T under fMRI, for example, we may see that brain region r shows activity. From this observation, one may infer that brain region r grounds/causes cognitive function for task T, namely, if brain region r shows activity, then S is engaged in task T. Reverse inference is a fallacy because it is an instance of affirming the consequent according to which one affirms the consequent of a conditional to infer the antecedent. If I am in Chicago, then I am in Illinois. But, if I am in Illinois, it is not necessarily the case that I am in Chicago, I could be in East St. Louis. So, the reverse inference fallacy is a fallacy if one is constructing a deductive argument. As noted in the previous paragraph, however, a fallacy is a deviation from legitimate reasoning. If one understands the consequent as *evidence* for the antecedent being true, there is no fallacy (Nachev and Hacker (2010, 71) acknowledge this). Being in Illinois is evidence for being in Chicago, even if it is not strong evidence. Maybe a better example is to contrast the following inferences. If I am in Chicago, then I am in Cook County. I am in Chicago. Therefore I am in Cook County. This much is deductively valid. Conversely, if I am in Cook County, that *is evidence* – stronger evidence than simply being in Illinois – that I am in Chicago. I interpret neuroimaging studies to say that certain brain region activation is evidence for certain cognitive functioning. Therefore, I am not committing the reverse inference fallacy.

Several therapeutic modalities are effective for improving MCS patients' cognitive abilities. Deep-brain stimulation (DBS) has been effective for increasing arousal, limb control, and oral feeding (Chudy et al., 2017; Giacino, Fins, Machado, & Schiff, 2012). Notably, the subjects in Giacino's study were chronic MCS patients with no signs of improvement in two months preceding enrollment. Dopaminergic agents, specifically amantadine, have improved acute MCS patients significantly (Whyte, Katz, Long, et al., 2005). Recently, transcranial direct current stimulation (tDCS) has been used with some evidence of benefit (Bai et al., 2017). Bai et al., only measured cortical excitability and not behavioral effects. Clinical response to tDCS was noted in a subgroup of MCS patients who had grey matter preservation and metabolic activity in the dorsal-lateral and medial pre-frontal cortexes, precuneus, and the thalamus (Thibaut et al., 2015). Additionally, the following modalities have shown some benefit in subjects satisfying the vegetative state criteria: Zolpidem, median nerve stimulation, extradural cortical stimulation, spinal cord stimulation, and intrathecal baclofen (Georgiopoulos et al., 2010). Lastly, outcomes of patients in MCS show a positive trend and are not temporally restrained – meaning, the length of time being minimally conscious is not correlated with lower outcomes (Voss, Uluç, Dyke, & al, 2006). Nakase-Richardson et al. (2012) followed traumatic brain injury patients who had a Glasgow Coma Score (GCS) of 3 on ED admission (3 is the lowest score compatible with life). 68% regained consciousness, 19.6% achieved functional independence, and 18.7% demonstrated employment potential. It is important to emphasize that the inclusion criteria were unconsciousness and a GCS of less than 6 (worse than MCS) upon admission to a rehabilitation center. Of course, more evidence and research would be nice, but part of the tendency my argument aims to resist is what Joseph Fins refers to as the societal neglect syndrome (Fins, 2015). The point is to resist the urge to assume a static picture of the patients on whom one provides ethical commentary. Any ethical commentary on a specific MCS patient should *at least* tell us whether therapeutic interventions were attempted.

Lastly, most MCS patients require artificially delivered nutrition and hydration – typically, PEG tube feeding. The clinical circumstances to which my argument applies includes MCS patients who require PEG feeding to survive. I focus on tube feeding since its purpose is merely to nourish and hydrate, i.e., to provide basic necessities.[3] Whether one is sick or healthy, we need nutrition and hydration. Furthermore, tube feeding (via PEG) is typically quite easy to administer. Further acuminating the scope of my argument, I focus on MCS patients whose refusals of PEG feeding are based on a judgment that MCS involves a low quality of life (QoL).[4] My argument assumes these features of a patient's setting. If the critic imports into this setting other complicating features such as other pathologies, that would not be a criticism of my argument.

3. Undercutting the argument from advance directives

End-of-life decision-making should focus on the question whether *a clinician* is morally justified to withdraw a means of sustaining life from the patient in the actual clinical circumstances the clinician faces. The reason for this emphasis is that the clinician is the agent of the action. The key question I answer in this section is whether a clinician is morally justified in withdrawing tube feeding from a patient who is in MCS. Broadly construed, there are two ways in which this judgment can be justified. The first is if the clinician is justified in believing that S *would want* PEG feeding withheld or withdrawn in the present circumstances. The second is if the clinician is justified in believing that it would be in S's *best interest* to have PEG feeding withheld in the present circumstances. I address only the former justification in what follows.

Consider the following train of thought. Suppose S decides at some point in the past that she would not want PEG feeding if she were in MCS because that would involve what in her assessment is a low quality of life. Suppose also that S is no longer competent to make decisions for herself. Advance directives are morally sufficient to act upon only if[5] those directives are applicable; and to count as applicable, there must be justification for moving from 'S decided to refuse PEG feeding,' to 'S would decide to refuse PEG feeding.' The argument from advance directives would hold, then, that a clinician is justified in withdrawing PEG

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[2] I thank an anonymous reviewer for prompting me to address this issue in more detail.

[3] See Meilaender (1984).

[4] The author disagrees with the language of "quality of life" judgment for the simple reason that it is not theory neutral. It invites the idea that one's value is determined solely by how that person sees her value. This language endorses subjectivism without arguing for it. A second reason is that even proponents of this language really do not mean quality of someone's *life*. They mean quality of one's experiences or circumstances. With these confusions in mind, I capitulate and use such language throughout.

[5] Of course there are other necessary and jointly sufficient conditions. My argument, however, is to challenge whether this one necessary condition is satisfied.

feeding from S only if the clinician is justified in believing that S *would* not want it. And the clinician's evidence for believing this comes from what S had decided in the past (when she was competent).

The task in this section is to argue that this line of reasoning suffers from an undercutting defeater.[6] In particular, I argue that one cannot move from;

> (Past) S decides at some time in the past to refuse PEG feeding in MCS because this would involve a low quality of life.
> to,
>
> (Present) S *would* decide to refuse PEG feeding in MCS because this involves a low quality of life.

In a typical clinical scenario, (Past) supplies sufficient evidence for (Present).[7] I shall argue that it does not for patients in MCS. Evidence for the disability bias blocks the inference from (Past) to (Present). The disability bias is the trend by third parties to devalue or rate the quality of life of those who are disabled as being significantly lower than how the disabled themselves judge their lives. I argue that the evidence for the disability bias applies as well to MCS patients.

3.1. The disability bias

The present task is to argue that third person QoL judgments are unreliable. The reason for focusing on third person judgments is because we issue *advance* directives from that very standpoint. The *future* patient does not know what it *is* like to be disabled. The argument herein does not argue that being minimally conscious is a quality way to live. I do not know whether it is or is not. Thus, my argument aims only to block the inference from a third person QoL judgment to one's actual first person QoL judgment.

Quality of life studies performed on those with severe motor disabilities show that the patient's own assessment is at or slightly below the quality of life scores of normal controls. What is more, when non-disabled controls are asked what the disabled think of their own quality of life, the non-disabled rate it significantly lower than the disabled actually do. This serves as evidence for a disability bias. The disability bias is a judgment about a disabled person's quality of life and it counts as a *bias* because it does not reflect what such persons actually judge about their own quality of life. After presenting this evidence, I address why the evidence, which focuses on those with severe motor disabilities, is applicable also to those with cognitive disabilities – as is the case with MCS.

Consider first patients with Locked-in syndrome (LIS). LIS is a disorder typically caused by a stroke to a portion of the brainstem, commonly the pons. We can think of the brainstem like a two-way highway with multiple lanes. For LIS patients, all lanes are open going *into* the brain; they can see, think, hear, and understand. All lanes going *from* the brain are closed. They are completely paralyzed but in classical LIS retain voluntary control over blinking and eye-movement.

What is it like to be fully conscious and fully paralyzed? Apparently, it is not as bad as one might think. Laureys, Pellas, van Eeckhout, et al. (2005) summarizes much of the literature on this topic considering quality of life measures, end of life decision making, and suicidal ideation. In all three areas, the conclusions may strike some as surprising. Ghorbel (2002), (see also Doble, Haig, Anderson, & Katz, 2003) administered self-reports on mental and physical well-being. Self-scored perception of mental and physical health were not significantly different than age-matched normal controls. Leon-Carrion, van Eeckhout, and Dominguez-Morales Mdel (2002) discovered that of 44 subjects, 48% regarded their mood as good whereas only 5% regarded it as bad. 13% noted that they were depressed, 73% enjoyed going out and 81% met with friends at least two times a month. Of note, suicidal ideation was correlated with perception of pain, indicating that proper pain management might decrease the incidence of depression generally and suicidal ideation specifically. A subset of patients in the Ghorbel (2002) study suffered total LIS, but very few had suicidal ideation even after being locked-in for 6 years. On a scale from 0 to 10 (never to constantly), only 4 patients experienced suicidal ideation more than 3 on the scale, compared to 8 who *never* had suicidal ideation and only 4 who rarely had it. Regarding treatment choice, 80% wished to receive anti-biotics if they were to contract pneumonia and 62% elected to be full codes.

Bruno, Bernheim, Ledoux, et al. (2011) explored QoL assessments with 91 LIS patients. 47 patients expressed happiness, with only 18 expressing unhappiness. Unhappiness was associated with lack of integration into social life, anarthrea, and lack of recreational activities. Bruno et al., conclude that.

> Our data stress the need for extra palliative efforts directed at mobility and recreational activities in LIS and the importance of anxiolytic therapy. *Recently affected LIS patients who wish to die should be assured that there is a high chance they will regain a happy meaningful life* (Bruno et al., 2011, 1, emphasis added).

Lule, Zickler, Hacker, et al. (2009) discuss the “disability paradox” that this evidence suggests. Severely disabled patients, like those in LIS, and amyotrophic lateral sclerosis (ALS), adapt to their disabilities as indicated in higher QoL scores the longer they have experienced the disability. Important for my purposes is the following observation, “Preliminary results from our study on clinicians' perception of LIS show that in 97 interviewed health-care workers the majority (66%) considered that “being LIS is worse than being in a vegetative or minimally conscious state”” (Lule et al. 2009, 347). This assessment is clearly incongruent with what LIS patients themselves think.

Regarding research on ALS patients, a motor degenerative disease leading to progressive paralysis, shows the same mismatch between clinician judgment and patient judgment. A common sequelae of ALS is ventilator dependence. On the Life Satisfaction Index (using a Likert scale 1–7), ventilator users reported a mean score of 4.98. For perspective, normal controls reported a mean LSI of 5.33. The remarkable finding in this study was not only that ventilator users had near equivalent LSI scores as normal controls but also that health care professionals' assessment *of the ventilator users'* life satisfaction was 2.42 – far below the patients' own assessment of their life satisfaction (Bach, 2003, S25).

Similar findings on quadriplegics secondary to high-spinal cord injury (SCI) were reported by Gerhart, Koziol-McLain, Lowenstein, and Whiteneck (1994). QoL measures were administered to SCI patients and their health providers for comparison. 92% of patients reported that they were glad to be alive whereas only 18% of the health professionals imagined that they would be glad to be alive. 86% of the patients rated their QoL as average or better (than pre-SCI). Only 17% of their medical staff thought that SCI patients could have an average or better QoL.

ALS patients themselves seem to experience the same mismatch between their pre-paralysis/vent dependence period and when they need respiratory support on a regular basis. Again, Bach notes that when queried early on in the development of ALS, patients refuse respiratory support if they were in need of it. However, their minds change when they become dyspneic and non-invasive respiratory aids prove effective. (In many cases, general QoL judgments by ALS patients match normal controls *throughout* the illness. This again, illustrates adaptation, see Lulé, Pauli, Altintas, & et al., 2012). Notably the “patient's

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[6] As explained in more detail below, an undercutting defeater is a belief that if true would undermine the reasons upon which I base another belief. A related concept in scientific research is a confounder.

[7] This assumption is problematic mainly because patients for whom advance directives are needed typically do not have present wishes since they might be unconscious or unable to process any relevant information. But this is a problem for all advance directives no matter what their content is. For a host of other philosophical problems affecting advance directives, see Vogelstein (2017). I assume in this paper that advance directives are morally relevant without explaining why.

attitude toward the use of ventilatory aids seems *to reflect his/her physician's attitude and the nature of the treatment options being presented rather than his/her own informed rational decision*" (Bach, 2003, S26-S27, emphasis mine). Bach's research on ALS patients shows rather vividly the mismatch between clinician and patient QoL judgments and even QoL judgments between healthy patient and disabled patient.

Laureys, Pellas, et al. (2005) comment that the results here run contrary to what many health professionals think. Many clinicians are involved with the patient populations discussed here only on a short-term basis when the patient is at his or her worst. Because of this, clinicians may simply assume that the patient would refuse further support and would want to die.

> As a result, debates about cost, daily management, quality of life, withdrawal or withholding of care, end-of-life decisions and euthanasia often go on with prejudice and without input from the conscious but mute and immobile patient….Clinicians should realize that quality of life often equates with social rather than physical interaction and that the will to live is strong when struck by an acute devastating disease (Laureys, Pellas, et al., 2005, 506–507).

In each of these studies several themes emerge. First, clinicians' assessment of their patients' quality of life are typically *much lower* than what the patients themselves judge. Second, lower QoL assessments by the patients do *not* correlate with the level of disability, and higher QoL assessments are associated with higher integration into the patient's social network. They are taken on walks, read to, etc. Third, there is usually a period in the early stages of severe disability with acute onset that patients report unhappiness. After a period of adaptation and re-integration, patients return to QoL judgments on par with or slightly below normal controls. Because of this, Bach (2003, S23) notes that for ALS patients, advance directives are inappropriate because such patients are typically ill-informed about non-invasive respiratory aids, and they suffer from a bias against being disabled inherited from their physician.

The conclusion I wish to draw from these studies is that our assessment of what it is like to be disabled are radically incongruent with those who experience the disability first hand.[8] Consequently, we should be skeptical of our quality of life judgments from the third person standpoint. But it is just from this standpoint that we issue *advance* directives. So the distortion that infects the third person standpoint applies to the future patient issuing an advance directive. *We* think LIS would be a bad way to live, LIS patients do not think so. *We* think MCS would be a bad way to live. It may be the case that they do not think so, (to the extent that they can understand).

3.2. What follows from this evidence?

It is important to say why the disability bias for motor disabilities applies to those suffering a disorder of consciousness. The inference from 'the disability bias infects QoL judgments for patients with motor disabilities' to 'the disability bias infects QoL judgments for those with disordered consciousness' is mediated by three interrelated points.

(a) We do not know what it's like to be compromised in the way MCS patients are. This lack of knowing what-it's-like is present in any third party assessment of a disabled person's quality of life. Certainly, one reason why the QoL judgments by the non-disabled and the disabled diverge is because the non-disabled lack the "what-it's-like" aspect about living with a disability. The source of skepticism is the same for both types of disability - viewed from the third-person standpoint.

(b) Another feature of third party QoL judgments about the disabled is that they likely issue from an "I-wouldn't-want-to-live-like-that" sentiment.[9] But this sentiment is not indexed to a type of disability. Any severe disability falls under the sentiment when issued from a third-person standpoint. The evidence canvassed in this section indicates that such a sentiment changes in the case of motor disability, and there is no positive reason to think that it does not change for cognitive disabilities.

(c) The functional abilities of MCS patients may be underestimated since it is likely that treatment modalities (amantadine or DBS)[10] are not even tried before withdrawal decisions are made. Neuroimaging studies have taught us at least one thing about MCS patients, they are more cognitively active than what can be demonstrated through spoken communication (see Section 3). A general epistemological dictum is apropos here: Absence of evidence does not entail evidence of absence. In general, whether someone is conscious and to what degree of consciousness the person attains is a different question from whether he can *demonstrate* that he is conscious or the degree to which he is conscious. We cannot infer from 'patient M cannot *demonstrate* that she is conscious and aware through spoken communication' to 'patient M is not conscious or aware'. Consequently, the inference from 'the disability bias infects QoL judgments for motor disabilities' to 'it infects QoL judgments for cognitive disabilities' is more continuous if we take seriously the neuro-biological evidence that minimally conscious patients retain cognitive function.

In concluding the previous two subsections, it is important to understand the epistemic work this evidence is meant to do. Suppose we want to know whether a particular drug is toxic and that there is a theoretical reason for thinking that it is lethal (for example, it has a molecular composition similar to known lethal drugs). So, we perform experiments on some macaque monkeys and they all survive. That all the monkeys survive is evidence (though not sufficient evidence) that the drug is safe for humans. But suppose also that the monkeys all survived high doses of other drugs known to be lethal to humans. This evidence clearly undercuts the initial, albeit paucious, evidence we had for thinking that the drug is safe for humans. If we bring the drug to market anyway, we would be doing something careless and irresponsible – even if, by luck, no one dies from the drug. Why? The cost of being wrong is high (numerous human lives might be killed by the drug), and our original reason is no longer a reason (the drug may be lethal and our evidence base would look just the same).

The cost in being wrong in thinking that (Past) provides sufficient evidence for (Present) in an MCS patient, is that one lets a conscious patient dehydrate to death, plausibly going against what the patient's actual wishes may be, and withholding an easy means of sustaining his or her life. The burden of proof is on those who would argue to remove PEG feeding. To say that the disability bias is not ubiquitous, is not sufficient to override the burden. The evidence for the disability bias is strong enough to undercut the inference from (Past) to (Present) in any given case.

4. Objections

Because my argument says that it is impermissible to act on a patient's previous refusal when she/he was decisional, an obvious moral concern is that I am ignoring the presumption in favor of advance

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[8] See Goering (2008) for a good response to those who wish to contest the veracity of these QoL judgments by the disabled.

[9] On this point, Michael Wreen is entirely correct when he says, "a clear-thinking and rational person…realizes that, however certain he may be of his values and desires now, they could change radically under desperate, life-threatening circumstances, and some provision should be made for the possibility of such a change" (2004, 328).

[10] For an extended discussion of how functional MCS patients can be, see Fins (2015) and Chudy et al. (2017).

directives having moral authority. The purpose of this section is to deflect this and related concerns.

One practical consequence of my argument may be that a minority of MCS patients would have their wishes not fulfilled.[11] Some commentators might take that to be a symmetrical cost. But again, this would ignore the clinical scenario my argument is indexed to, namely, PEG feeding is a fairly easy means to deliver and receive, and – per lesson learned from QoL studies on LIS patients – treating disabled patients as the persons they (still) are is imperative (see my concluding remarks below). In point of fact, far from ignoring a minority of patient's wishes, my argument is that in the absence of evidence to the contrary, the evidence from the disability bias is strong enough to undercut the inference from (Past) to (Present) in most cases. All of what I have argued for is to act *in accordance with* what the patient *presently* wants. A patient's actual wishes retain moral authority on my view. Here is how to see the point. In a majority of cases, a patient's past wishes do not provide evidence for their present wishes. This fact is normatively relevant. To think it is normatively relevant, one must hold in view the moral authority of a patient's actual wishes.

A concern with paternalism is also misplaced. The first reason is that the conclusion of my argument is technically not paternalistic at all. The really bad kind of paternalism requires one agent A going against another *fully autonomous* agent's choice and A justifies the act on the basis that the agent is benefited (Wreen, 2004). Since MCS patients are likely not fully autonomous, the really bad form of paternalism does not even apply.

Is going against a *precedent* fully autonomous choice so bad? The badness of paternalism correlates with the goodness of the choice being impugned. And it is unclear what normative weight a precedent autonomous choice bears especially when it may be subject to a bias. That I have chosen X does not by itself justify doing X. To justify a choice, one needs to site the goods realized by the choice. And in the case at hand, one of the goods at stake is keeping a conscious patient alive through simple means and the choice might be biased anyway. Autonomy considered qua ability strikes me as extremely valuable. Autonomy qua discrete choice is valuable only as a function of the goods such a choice realizes.

Some other important objections may now be addressed. Walter Glannon (2013) takes the position that tube feeding should not be given to MCS patients. Specifically, he discusses patient M who was minimally conscious and the English Court of Protection ruled that it would be impermissible to withhold tube feeding from her. Glannon thinks that the English court erred in its reasoning and in its conclusion. Glannon summarizes his reasoning as follows, "[t]he poor prognosis for MCS patients, the fact that M was regularly in pain and likely suffering from it, her complete dependence on others, and the lack of restorative therapies made the burdens outweigh the benefits for her" (Glannon, 2013, 2). Glannon seems to think that tube feeding would *only* be worthwhile in conjunction with effective therapies aimed to restore cognition and physical mobility "to beneficial levels" (Glannon, 2013, 2). On some points, I tentatively agree with Glannon, and so properly understanding the borders of my argument requires limning where Glannon and I agree and where it appears we disagree.

I tentatively agree on the following items: (1) Glannon notes that patient M was in pain that the pain was intractable. If true, this might be a reason for withholding tube feeding. My agreement is cautious since it is unclear what kind of palliative care the patient was receiving. If it were known that the patient was in pain, proper pain management should address the issue. In any case, truly *intractable* pain is typically a sign that some other pathology is inflicting the patient (e.g., stomach cancer), in which case my argument does not apply. (2) Glannon notes that death does not always harm the one who dies. Technically speaking, if harm is understood as violating someone's interests and it is not in someone's interest to continue living, then death is not a harm – on this definition of harm.[12] My agreement is cautious since it would be a mistake to think that the category of harm *exhausts* the category of wrongdoing. It would be wrong, for instance, to push a suicidal teenager off a tall bridge but that would not be violating his interests. Consider raping a patient in a persistent vegetative state (PVS), or using PVS patients for car safety testing (Watt, 2000) or for orthopedic surgical practice. All of these actions would be seriously wronging the patient, but arguably not harming the patient (on the view of harm noted). (3) Glannon notes that if the clinicians improve the conscious awareness of an MCS patient "without a corresponding improvement in pain management" (2013, 2), one would be doing more harm than good. My agreement is cautious because it hardly seems relevant. No one would argue for improving cognition without improving pain control. In fact, improving cognitive function could improve pain management because we could then ask the patient if she or he were comfortable.

As for the likely disagreements, Glannon notes that "a reasonable level of quality of life implies a sufficient degree of pain control and a sufficient degree of functional recovery, such that the patient is not *completely dependent on others*." And he repeats the point a few lines later claiming that a source of suffering is not only from physical pain but "[t]hey could also suffer from the experience of being completely dependent on others" (Glannon, 2013, 2, emphasis mine). These comments clearly demonstrate the disability bias articulated above. On Glannon's reasoning, LIS patients, quadriplegics, and advanced ALS patients do not have a "reasonable level of quality of life" since they are completely dependent upon others and they lack a "sufficient degree" of functional recovery – whatever that can mean. Would Glannon hold that we should dehydrate them to death even if they indicate that they want to live (as most do)? If he answers "no" then what exactly is this notion of a "reasonable level of quality of life" doing in his argument? Is not such a notion endorsing a particular conception of the good which might not be congruent with the patient's own conception? Furthermore, what is to count as a "sufficient degree" of functional recovery? Answering these questions appears difficult if one wants to avoid the disability bias.

5. Conclusion

In their work on deep brain stimulation, Giacino et al. (2012) have received criticisms, not for the fact that they are doing neurosurgery on the non-consenting, but that they are even trying to develop therapeutic interventions for MCS patients. Their colleagues complain that MCS would be a state worse than death. To which they reply that such comments.

> [r]eflect… the aforementioned biases that…nothing can or should be done to them. However, this stance immediately becomes problematic if one considers that these patients are conscious and that some of them might have degrees of awareness that suggests that they are cognizant of the isolation that our collective societal neglect has imposed upon them. In our view, there are moral and fiduciary obligations to intercede and attempt to remediate their potential sense of isolation….(Giacino et al., 2012, 346).

The proper response to severe disability and dependency is a deeper and more involved care, i.e., we need to love this patient population without condescension. A state that would be worse than death is to be disabled, dependent *and* ignored or treated with the disability bias.[13]

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[11] I thank an anonymous referee for pointing out this objection.

[12] Beauchamp and Childress appear to hold such a view. "These arguments [for what counts as wrongdoing] suggest that causing a person's death is morally wrong, when it is wrong, because an unauthorized intervention thwarted or set back a person's interests" (2001, 148).

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