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TARGET ARTICLE

Conscientious Objection to Aggressive Interventions for Patients in a Vegetative State

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ABSTRACT

Some physicians refuse to perform life-sustaining interventions, such as tracheostomy, on patients who are very likely to remain permanently unconscious. To explain their refusal, these clinicians often invoke the language of "futility", but this can be inaccurate and can mask problematic forms of clinical power. This paper explores whether such refusals should instead be framed as conscientious objections. We contend that the refusal to provide interventions for patients very likely to remain permanently unconscious meets widely recognized ethical standards for the exercise of conscience. We conclude that conscientious objection to tracheostomy and other life-sustaining interventions on such patients can be ethical because it does not necessarily constitute a form of invidious discrimination. Furthermore, when a physician frames their refusal as conscientious objection, it makes transparent the value-laden nature of their objection and can better facilitate patient access to the requested treatment.

KEYWORDS

Brain injury; chronic vegetative state; conscientious objection; disability; futility; persistent vegetative state

INTRODUCTION

Despite the promise of emerging consensus (Payne 1996; AAN 1994; 2018), there remains substantial disagreement in medicine and clinical ethics about providing life-sustaining interventions to patients who retain brain stem function and sleep-wake cycles, but who are very likely to remain permanently unconscious.[1] Depending on the type of injury (e.g. anoxic versus traumatic) and associated comorbidities, many such patients have an extremely low probability for substantive neurological recovery (Giacino et al. 2018; Multi-Society Task Force on PVS 1994). Well known recent work suggests that humility about prognosis is warranted, particularly in the early days and weeks following an injury, and therefore that physicians may be obligated to provide life-sustaining treatment during that time (Fins 2015; Giacino et al. 2014). But even in this era of prognostic caution, clinicians can reliably predict that a patient has very low odds of recovering consciousness when some factors are present: having an anoxic versus traumatic injury, greater time spent anoxic, ischemia, episodes and duration of myoclonic status epilepticus in the hours after injury, as well as higher age and the presence of various comorbidities (AAN 2018; Zandbergen 2008). Even when the etiology of the brain injury signals negligible odds of recovery, families sometimes still request long-term care, which often requires tracheostomy and percutaneous endoscopic gastrostomy (PEG) tube placement. Many clinicians can feel ethically conflicted about honoring such requests, particularly when the probabilities of recovering

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[1]Navigating the changing terminology surrounding brain injury can be difficult. In this paper, when referring to cases like the one that we use to motivate our arguments, or those that are similar, we use the descriptive phrase "very likely to remain unconscious." While cumbersome, this accurately captures not only the relevant state of consciousness, but the probabilistic nature of the prognosis in these cases, and it preserves a distinction between other kinds of cases where unconsciousness is not likely to be permanent (in light of its etiology and other influential factors, as discussed below). Where we refer to cases or the condition as it is portrayed in the literature, we follow the American Academy of Neurology nomenclature, using Vegetative State (VS) or Unresponsive Wakefulness Syndrome (UWS) for cases where injury was less than one month prior, and Persistent Vegetative State (PVS) for cases lasting more than one month; see AAN (2018).

consciousness are extremely low (Oropello, Mistry, Ullman 2015; Payne et al. 1996; Span-Sluyter et al. 2018).

In this paper, we consider whether it is ethically permissible for clinicians to conscientiously object to providing tracheostomies and other invasive interventions for patients who are very likely to remain unconscious. Conscientious objection is commonly used to protect clinicians' religious freedom (e.g., a refusal to prescribe contraceptives or provide abortions) (Dickens 2014; Rhodes 2019). However, we contend that physician refusal of life-sustaining interventions such as tracheostomy for patients very likely to remain unconscious can also meet widely accepted ethical criteria for conscientious objection, such as transparency, disclosure, and referral. More challenging is whether these conscience-based refusals violate the prohibition of conscientious objections based on "invidious discrimination" (Lewis-Newby et al. 2015). In particular, this question turns on whether patients who are very likely to remain unconscious should be considered disabled in such a way that warrants protection against conscience-based refusals of life-sustaining interventions.

We argue that it is not invidiously discriminatory for clinicians to conscientiously object to interventions such as tracheostomy for patients who are very likely to remain unconscious. To defend our thesis, we argue that conscience-based refusals of life-sustaining interventions for patients very likely to remain unconscious are not invidiously discriminatory because of reasonable disagreement in three important areas: 1) appropriate care for such patients vis-à-vis the goals of medicine, 2) tolerable levels of uncertainty regarding possible recovery of consciousness, and 3) whether such patients ought to be considered disabled. We conclude that refusals of life-sustaining interventions for patients very likely to remain unconscious is not only an ethically permissible form of conscientious objection, but it may actually *amplify* the voices of patients and families seeking such therapies, while at the same time mitigating clinician moral injury. Moreover, appeal to conscience can be an ethical solution in cases that are marked by tremendous empirical uncertainty, such that clinicians may feel stuck between evidence that motivates greater efforts at intervention and rehabilitation for neurologically devastated patients, and evidence that the odds of successful rehabilitation remain intolerably low. It would be dogmatic, as well as inconsistent with medical decision making in other contexts, to suggest that interventions for patients very likely to remain unconscious must be offered irrespective of the probabilities of recovery. Yet it is also true that bias and ableism have contributed to a history of unethical disregard for many of these patients. Conscience can steer individual clinicians through this ambiguity.

OBJECTION TO TRACHEOSTOMY: A CLINICAL CASE

Consider the following case on which we were consulted:

RNW was a 61-year-old man who experienced respiratory failure followed by cardiac arrest. He was anoxic for approximately 20 minutes before resuscitation. The patient was placed on a ventilator and a nasogastric tube was inserted. His neurological examination demonstrated unresponsiveness to verbal, tactile, and painful stimuli, as well as sluggish pupillary light responses bilaterally with reflexive eye opening. He had one episode of myoclonic status epilepticus lasting 27 minutes around the 12th hour post-admission.

The critical care team advised the patient's daughter, his next of kin, of the poor prognosis and recommended hospice care. However, the daughter requested that "everything be done." After several discussions over the following days, she remained firm in this request, demonstrating a good understanding of her father's likely prognosis, yet insisting he would have wanted to remain alive, citing his belief that all human life is valuable. By day ten, RNW developed significant tongue edema associated with oral bleeding. Given the prolonged anoxia and subsequent medical course, the ICU team recognized that the patient's odds of recovering consciousness were extremely low. However, given that the patient was only ten days post-injury, they agreed it was medically reasonable to pursue life sustaining interventions and requested surgical consults for tracheostomy and PEG tube placement. A gastroenterologist placed the PEG tube, but two days later an otorhinolaryngologist (ENT) documented in a consultation note that he could not "in good conscience" perform a tracheostomy because the intervention was "futile."

In response, ethics was consulted to evaluate whether placement of the tracheostomy indeed constituted a futile or medically inappropriate intervention. The ethics consultants opined that these interventions were ethically permissible because they offered several physiological benefits, despite the "guarded prognosis" and the extremely low likelihood that those interventions would reverse the underlying effects of the anoxic injury. In the process, the ethics consultants discussed the situation with the ENT and asked them to elaborate on their objection to the procedure. This

physician stated that they did not believe a "chronic vegetative state" was an existence "befitting the dignity of a human person," and that the procedure's performance would likely only prolong the patient's existence in this state.

The conflict in this case was resolved two days later when the ICU team identified another ENT surgeon who was willing to perform the procedure. However, the ethics question remained: Was the ENT surgeon's refusal ethically permissible or did it represent an abrogation of his professional responsibility to care for the patient? Relatedly, was the ENT correct to characterize their refusal as a response to a request for futile or inappropriate care, or were they engaging in a conscientious objection?

BACKGROUND CONSIDERATIONS: FUTILITY, CONSCIENCE, AND CLINICAL POWER

The physician in the case above made a familiar error: tracheostomy was not "futile." The concept of futility has a contentious history, but there is increasing agreement around its appropriate uses in clinical practice. For example, the Five Society Statement and the Kon et al. companion article have generated growing consensus that the term "futility" should be reserved for cases in which an intervention cannot possibly achieve its physiological goals (physiological futility) (Bosslet et al. 2015; Kon et al. 2016; Youngner 1988). In contrast, they suggest that clinicians should use the term "potentially inappropriate" to refer to interventions with slim chances of success (historically called "quantitative futility") or where the goals are not worth achieving (historically called "qualitative futility") (See Schneiderman, Jecker, and Jonsen 1990 regarding distinction among kinds of futility; see also Bosslet et al. 2015).

The term "potentially inappropriate" suggests that despite the physiological potential of an intervention, there may be countervailing ethical reasons to withdraw or withhold it. Perhaps more importantly, the use of "potentially" as a modifier holds open a space for discourse about competing values, and thereby recognizes how intensely value-laden the competing goals of patient, family, and provider can be.

We agree that it is important to limit the term "futility" to cases of physiological futility. Doing so helps clarify a potentially confusing conceptual terrain, and highlights often-obscured power dynamics in clinical medicine. For example, White and colleagues note that use of the term "futility" by physicians often equivocates between the three different meanings (physiological, quantitative, and qualitative) in ways that hide the kind of judgment that the physician is making (White et al. 2016). That is, in clinical practice, the term 'futility' seamlessly incorporates both judgments about the physiologic possibilities of an intervention (i.e. its odds of success) and judgments about whether its goals are worthwhile. Indeed, 79% of the physicians in the study by White and colleagues included notions of quality of life in their understanding of the concept of 'futility' (White et al. 2016).

In our opening case, the clinician wrongly masked his value judgment about the quality of the patient's life in the language of a seemingly objective clinical judgment about 'futility'. Of course, a family *can* dissent from a physician's determination of futility, but insofar as the notion of futility ostensibly relies on clinical facts about likely physiologic outcomes, such disagreement has limited standing and can easily be disregarded as the expression of "unrealistic expectations". In this way, the invocation of 'futility' can exacerbate problematic forms of clinical power (and more generally biopower), particularly of a medical perspective derived from a knowledge base generally not possessed by patients and families and against which their ability to dissent is severely limited (Foucault 1975[1963]; see also Youngner 1988).

It is widely recognized that the deeply held values of healthcare providers may influence which treatments they offer. However, recognizing forms of power inherent in the clinical space, bioethicists have identified ethical limits on a clinician's invocation of conscience. Previous analyses, however, have not addressed whether the refusal to provide interventions for patients who are very likely to remain permanently unconscious falls within those limits. Navigating this question involves interrogating whether refusals for such patients amount to invidious forms of disability discrimination.

The 2015 policy statement from the American Thoracic Society on "Managing Conscientious Objections in Intensive Care Management" states that conscience-based refusals cannot be "based on invidious discrimination" (Lewis-Newby et al. 2015, 220). However, this statement does not unpack the contours of invidious discrimination, other than to say that it involves objections based on clinically irrelevant characteristics of a patient. It also provides some comparatively uncontroversial examples:

> Some objections are based on medically irrelevant characteristics of the patient (e.g., the patient's race,

> sex, religion, ethnicity, or sexual orientation) rather than on the nature of the medical service. Such objections represent invidious discrimination, are condemned by most health care professionals' codes of ethics, are illegal, and should not be accommodated. (Lewis-Newby et al. 2015, 220)

The emphasis on medical irrelevance implies that there are cases when the characteristics of patients can be relevant for medical judgments and can therefore be the source of ethically permissible conscience-based refusal. However, this statement does not further specify which patient characteristics are relevant or the conditions under which they are relevant.[2] Below, we consider whether unconsciousness that is very likely to be permanent is a relevant kind of patient characteristic when physicians decide whether to provide life-sustaining interventions, and, therefore, whether refusal to perform life-sustaining interventions on such patients can avoid the charge of "invidious discrimination."

REFUSAL OF TRACHEOSTOMY AS AN EXERCISE OF CONSCIENCE

It is widely recognized that physicians have a moral right to object to participating in medical procedures or to providing medical goods or services that violate their moral integrity. Some have argued that professional commitments should outweigh personal conscience, such that there should be significant restrictions on conscientious objection in medicine. But even the more strident critics of conscientious objection have recognized at least some role for it in the professional landscape.[3] The AMA Code of Ethics notes that "physicians are not defined solely by their profession [but are] moral agents in their own right" (AMA 2016). There also have been recent efforts to provide greater legal protection for physician conscientious objection, especially highlighted by proposed revisions to the United States' Department of Health and Human Services rules (DHHS 2021). While these proposed federal regulations have not been implemented, they nonetheless illustrate that the ethical parameters of conscientious objection remain a controversial and often politicized issue. It is sometimes presumed that only clinicians with deeply held religious or socially conservative beliefs can invoke conscientious objections, especially because debates on the issue have traditionally centered on abortion services, contraception, physician-aid-in-dying, and sterilization (Dickens 2014; Rhodes 2019; Schuklenk 2019). However, there is no principled reason to constrain conscience protections to these contexts. In this section, we argue that the refusal to provide a tracheostomy for patients very likely to remain unconscious can satisfy standard ethical criteria for exercising a conscientious objection and, in turn, that such objections ought to be honored.

Tracheostomy and the Standard of Care for Permanently Unconscious Patients

Conscientious objection consists of refusal to perform or participate in procedures that are legal *and professionally accepted*, but which nonetheless violate one's deeply held beliefs. Thus, in order to determine whether a conscience-based refusal to provide interventions to patients like the one in the opening case can be considered an act of conscientious objection, we must first determine whether providing tracheostomy or other life-sustaining interventions for patients very likely to remain unconscious falls within the standard of care, that is, whether it is widely professionally accepted even if not endorsed as optimal.

Kon et al. (2016) suggest that providing life-prolonging interventions for at least some vegetative state (VS)/unresponsive wakefulness syndrome (UWS) patients typically should be deemed "potentially inappropriate," that is, outside the standard of care. They write, "physicians, nurses, and other healthcare staff appear to agree that life-prolonging interventions (or in some cases, interventions that merely prolong the dying process) are inappropriate when the patient will not survive outside the acute care setting or *when the patient has irreversible severe neurologic injury*" (Kon et al. 2016, 1770). In support, they cite guidance from the Canadian Medical Association (1995), Society for Critical Care Medicine (1997), American Medical Association (1999), and California Medical Association (2011), all of which suggest that interventions are futile or nonbeneficial when patients are in a PVS. (Notably, many of these statements no longer reflect the consensus terminology described in footnote 1.) Kon et al. (2016) further cite data suggesting that most clinicians and patients would not choose

[2]Appendix 2 of the American Thoracic Society statement offers some case analyses that helpfully clarify the positions of the main documents. However, none of the cases take up the question about whether the situation in our case constitutes invidious discrimination (Lewis-Newby et al. 2015).

[3]See for example, Julian Savulescu (2006, p. 296) who largely opposes physician exercises of conscience, but nonetheless concedes, "When a doctor's values can be accommodated without compromising the quality and efficiency of public medicine they should, of course, be accommodated."

life-sustaining interventions for themselves in such a situation.

However, there are good reasons to think that tracheostomy remains within the standard of care for patients like the one in our case. First, it is noteworthy that the patient had been hospitalized for only 10 days. Evidence from Fins and others, along with current recommendations from the American Academy of Neurology (AAN), promotes caution about prognostication, particularly immediately following injury (Fins 2015, 2019; Giacino et al. 2018). Indeed, the uncertainty of forecasts about a patient's potential to recover consciousness suggests that life-sustaining interventions for this patient are not *obviously* inappropriate (though there is room for reasonable disagreement, as we discuss below).

Additionally, some of the empirical data cited by Kon et al. (2016) identify kinds of interventions that clinicians *profess to want for themselves*, not what they *believe is ethically permissible to provide to patients*. The standard of care, however, is not limited to the kinds of interventions that physicians and nurses prefer for themselves.

Finally, the prevalence of life-sustaining interventions on VS/UWS patients provides robust evidence that such interventions remain within the standard of care, regardless of what some physician professional societies say. Some estimate that as many as 42,000 such patients remain medically supported, even when the probability of recovering consciousness is very low (Giacino et al. 2018; Wade 2018). Tracheostomy is often a necessary means for the possibility of the long-term supportive care such patients receive, and therefore is clearly accepted by a significant portion of the medical profession.

Tracheostomy for patients who are very likely to remain permanently unconscious appears to remain within the standard of care, even if a significant contingent of professionals and the general population feel that it is likely inappropriate. In fact, Recommendation 3 of the ATS statement on conscientious objections in the ICU further highlights that conscience-based refusals are not sufficient determinants of inappropriateness, something which involves a broader process of evaluation (Lewis-Newby et al. 2015). Therefore, other factors being equal (e.g. no convincing evidence that the patient would not have wanted such interventions) it remains ethically permissible to offer tracheostomy to such patients. Thus, if we want to support a physician's right to refuse to perform tracheostomy on a patient who is very likely to remain unconscious, then we cannot do so on the grounds that the intervention falls outside the standard of care. Instead, we must examine the ethical permissibility of the physician's refusal against the background of the fact that, other things being equal, doing so is ethically permissible (even if we would not recommend it, and even if some wish for a stronger consensus to emerge that would shift the standard of care). That is, we must consider whether refusal of tracheostomy and other life-sustaining interventions for patients very likely to remain unconscious meets ethical standards for conscientious objection.

The Ethical Exercise of Conscientious Objection

There is relatively wide agreement that ethically permissible conscientious objections usually should (see Wicclair 2011):

- be made transparently, such that the patient and/or family understands that the intervention is within the standard of care, but is being refused for reasons of clinician conscience
- not be invoked in emergencies
- be stated in advance (when possible)
- not unduly impede access to care or burden one's colleagues; and
- be accompanied by effective referral (this remains more widely disputed than the above conditions).

The physician in our case above did not meet all these conditions, but other physicians in similar cases could. Tracheostomy is rarely emergent in intubated patients. Furthermore, objecting clinicians could transparently state that the procedure violates their sincere moral belief. They can also provide referral and take steps to notify relevant stakeholders in advance, ensuring that patients are not abandoned by the clinician's refusal.

Several of these requirements of conscientious objection aim to promote patients' access to treatment in the face of an objecting clinician. Advanced notification, for example, allows families or patients to make informed decisions when they choose physicians. Perhaps more relevant to our case, advance notification allows healthcare institutions to schedule staff to provide adequate coverage of generally offered services (Wicclair 2011). For example, a hospital could ensure the availability of an ENT who does not object to providing the tracheostomy; indeed, the case above was resolved when another clinician stepped in. In contrast, when physicians suggest that an intervention

is futile, they do not have to ensure that the intervention is available to patients, nor do they need to transparently declare that their objection is based on a personal value judgment. Instead, claims of futility place the responsibility to find other care providers on patients or their families. The rights of a clinician's conscientious objection come with responsibilities to assist patients or families who disagree with the objector. For example, they are constrained (though perhaps not totally obviated) in situations where there is no alternative provider willing to perform the intervention (AMA 2016). In contrast to the common concern that conscientious objection might limit access to interventions, framing refusal as an exercise of conscience (as opposed to a declaration of futility) may instead facilitate a patient's access to those treatments.

We have argued that it is possible for clinicians to meet several core criteria for an ethical invocation of conscientious objection when they wish not to perform life-sustaining interventions on patients very likely to remain unconscious. However, a more challenging question is whether this kind of conscientious objection amounts to disability discrimination. As previously noted, the American Thoracic Society states that conscientious objection based on a patient's membership in a protected class constitutes a form of "invidious discrimination" and is therefore unethical (Lewis-Newby et al. 2015). Thus, we must consider whether persons who are very likely to remain unconscious are members of a 'protected class'. Recall that the ENT in our case did not object to providing tracheostomies *per se*, but to providing tracheostomies to *this kind of patient*. Is a patient who is very likely to remain unconscious the *kind* of patient who should be protected against discrimination when it comes to the provision of medical interventions? We argue that they are not.

REASONABLE DISAGREEMENT, THE GOALS OF MEDICAL TREATMENT, AND DISABILITY DISCRIMINATION

A common ethical concern about conscientious objection is that it may enable invidious discrimination (Brummett and Campo-Engelstein 2021). Some authors have addressed this concern by defending a 'people/procedure' distinction, which holds that a clinician may conscientiously object only to providing goods or services, but never to treating a type of person (Wicclair 2011). The people/procedure heuristic attempts to preserve the right of health care providers to exercise conscience, while preventing the exercise of that right from becoming unjustly discriminatory (Brummett and Campo-Engelstein 2021).

A broad interpretation of the people/procedure distinction holds that conscientious objections can never be based on refusing to treat *any* "type of person," but must be focused exclusively on types of goods or procedures. The issue with the broad interpretation is that any conscientious objection aimed at a medical good or service will simultaneously label a "type of person." For example, contraceptive services inherently involve "fertile patients," and abortion services inherently involve "pregnant patients." If we embraced the broad interpretation of the people/procedure distinction, the inevitable conclusion would be that conscientious objection can never be ethically permissible because it always discriminates against a type of person, (i.e., persons who are candidates for the relevant procedure).

Another problem with this broad interpretation of the people/procedure distinction is that it prohibits *all* kinds of discrimination, even though some kinds of discrimination may be medically relevant and ethically permissible. This is well understood, for example, in debates about resource scarcity. For example, during the COVID-19 pandemic, many agreed that persons with advanced dementia or cystic fibrosis should not, merely by virtue of belonging to a group with that diagnosis, be excluded from access to scarce resources. That would be unjustly discriminatory because their membership in those groups *per se* is medically irrelevant. Concurrently, many agreed that such persons could be denied access to resources if their medical conditions manifested in a way that was relevant to the assessment of the intervention's potential benefit. Building on the work of disability scholar Adrienne Asch, Fins argues that it would be "discriminating but *not* discriminatory" to hold a patient with a preexisting lung condition "to the same assessment as everyone else" when determining how to distribute scarce ventilators (Fins 2020). Resource allocation protocols—along the lines that Fins suggests—*did not* abandon clinically relevant criteria that are nonetheless *associated* with a variety of medical conditions and disabilities, even where they did abandon categorical exclusions based on merely having a condition or disability (see, for example, White and Lo 2020). Someone with a an extremely poor prognosis might still be fairly deprioritized in a rationing scheme, *even if* we can nominally identify a group to which they belong (e.g. persons with a PaO2/FiO2 ratio below a certain threshold) and *even if* that clinical condition was a function of their disease or disability. While not

related to conscientious objection per se, questions about invidious discrimination in other contexts, like resource allocation, highlight limits on the broad interpretation of the people/procedure distinction that are already widely recognized.

Moreover, it is not clear that all conscientious objections based on clinically irrelevant group characteristics necessarily constitute *invidious* discrimination. Ancell and Sinnott-Armstrong (2017) have argued that some conscientious objections to providing interventions or services to types of people are ethically defensible. For example, they claim that a Muslim clinician who conscientiously objects to performing intimate inspections on patients of the opposite sex should have their objection honored,[4] or that a clinician is ethically justified when refusing to treat the sexual dysfunction of known sex offenders on the basis that doing so would increase the likelihood that they will reoffend (Douglas 2017). These kinds of plausible exceptions to the people/procedure distinction further highlight the problematical nature of the broad interpretation, suggesting that not all objections based on the type of patient involved are unethical. Thus, *even if* one argued that likely permanent unconsciousness properly characterized a group of patients who deserved under other conditions to be a protected class, questions of some interventions under some conditions may represent a plausible exception to the people/procedure distinction. If so, refusal of interventions would not represent invidious discrimination.

A narrower and more reasonable interpretation of the people/procedure distinction rejects the idea that conscientious objection is rendered ethically impermissible whenever it involves a cohort of patients who can be named as a group. Instead, what matters is whether such an objection involves discrimination against groups that require special protection. This invites questions about which groups ought to be protected from conscientious objection. We will argue that patients very likely to remain unconscious do not constitute such a group.

Importantly, a decisive resolution to the questions regarding the clinical relevance of likely permanent unconsciousness or whether it constitutes a plausible exception to the people procedure distinction is not required. Instead, to create the necessary latitude for the ethically permissible exercise of conscience regarding interventions for these patients, *we only need to show that divergent or opposing views can each meet a standard of reasonability*. In the context of philosophical and religious pluralism, we often justify conscientious objection because of the presence of reasonable disagreement about the appropriate goals of medicine. As Eberl (2019, 571) notes, conscientious objections represent "claims [which] must be backed up by a supportive rationale that, while contestable, is defensible in the public square" (see also, Card 2020). Notably, this does not require reasons for refusal to be *sound*, let alone persuasive, but only that they contain arguments grounded in public reason (Eberl 2019, 574). Eberl (2019) uses this reasonableness standard to support conscientious objection to providing abortion, sterilization, contraception, or substances for physician-aid-in-dying. In such cases, both sides of these debates can give arguments that are defensible in the public sphere. For example, public reason arguments in favor of physician-aid-in-dying often appeal to patient autonomy rights (Lachs 1994), but secular arguments against physician-aid-in-dying can also be given, such as Daniel Callahan's (1992) view that the practice falls outside the proper goals of medicine, which is the healing of broken bodies.

We turn now to address whether conscientious objection to providing life-sustaining interventions for patients who are very likely to remain unconscious necessarily constitutes invidious discrimination. We identify three kinds of reasonable disagreement about life-sustaining interventions for patients who are very likely to remain permanently unconscious, and we show how these support the ethical permissibility of conscientious objection in such cases. First, there is reasonable disagreement about the moral relevance of clinical facts vis-à-vis the appropriate goals of medical care (or at least about how to balance competing goals). Second, there is reasonable disagreement related to tolerance of prognostic uncertainty in medical decision making. Third, there is reasonable disagreement about the metaphysics of disability and whether patients very likely to remain unconscious are disabled in ways that would require protections that would contravene conscience-based refusals of life-sustaining interventions for them. Importantly, we are not arguing in favor of any particular position on these issues. Instead, our goal is to show that disagreement on these questions is sufficiently reasonable and widespread (i.e. not merely represented by extremists) so as to offer latitude for clinicians to conscientiously object.

Reasonable Disagreement about the Goals of Medicine

The first area of reasonable disagreement that supports space for individual conscience concerns the

[4]One study found that 36% of Muslim medical students in the United Kingdom objected to performing intimate inspections on opposite sex patients (Strickland 2012).

appropriate goals of medicine. One traditional goal of medicine is to sustain life. On its own, this goal would favor life-sustaining interventions. But interventions can sometimes be ethically withheld even when they are life-prolonging because of countervailing medical goals, such as the pursuit of a good death (Gebhard et al. 1996).

Whether lack of consciousness makes life-sustaining interventions inappropriate is disputed. Recall that many medical associations endorse variations on the standard codified in the SCCM statement by Kon et al. (2016), according to which "sufficient cognitive ability to perceive the benefits of treatment" is a *pro tanto*, though defeasible, criterion for appropriate medical interventions. Histories of medical abuses provide good reason to be skeptical about appeals to quality of life in claims about withholding or withdrawing interventions. However, it is not unreasonable to insist that patients must have "some consciousness" to benefit from medical interventions. More importantly for our purposes here, "some consciousness" is a reasonable and publicly defensible standard, even if not everyone endorses it. As a result, cases where patients are very likely permanently unconscious may involve reasonable disagreement about whether the medical goal of sustaining life should be actively pursued in the context of unconsciousness. Latitude for the individual conscience of physicians in such cases is essential.

Reasonable Disagreement about Tolerable Uncertainty

The second clinical feature that engenders reasonable disagreement concerns the nature of prognosis and what counts as sufficient probability for the recovery of some consciousness. Since Fins (2015, 2019) landmark work highlighting the ethical implications of instability of CVS diagnoses, there has been increased concern about the rights of patients with disorders of consciousness. Indeed, one systematic review reveals that among patients with disorders of consciousness lasting longer than 28 days, the cumulative recovery of consciousness by 6 months is 67% for those with traumatic injury and 17% for those with nontraumatic injury (Giacino et al. 2018). This suggests that commonplace declarations of "guarded" or "grim" prognosis for some patients, particularly in the early days and weeks following brain injury, may need to be reconsidered.

General instability in prognosis notwithstanding, there are some factors that can increase confidence in the prognosis of permanent unconsciousness. The same systematic review cited above also highlights how type of injury is especially relevant, with anoxic injury suggesting a much worse prognosis (Giacino et al. 2018). Indeed, in a study commonly used to highlight the potential for misdiagnosis, *all* instances of misdiagnosis came from TBI patients while *none* came from patients with anoxic injuries (Monti et al. 2010). Other recent work has highlighted that, even while current evidence suggests the need for greater humility, factors such as diffuse and anoxic injury, status myoclonus, no pupillary or corneal reflexes after 72 hours, and a highly malignant EEG after 24 hours are all reliable early indicators associated with decreased probabilities of improvement (Nolan et al. 2021).

Insofar as numerous clinical events and comorbidities can influence prognosis, there will always be cases in which permanent unconsciousness is highly likely. In our case above, for example, there are other relevant factors beyond the etiology of the injury. These include the prolonged nature of the anoxic episode, comorbidities, and post-injury events (such as seizures). Just as it is reasonable to demand humility about the odds of recovery of consciousness for some unconscious patients, it is also reasonable to suggest that there is a threshold of probability below which it can be reasonable to conclude that the odds of recovery of consciousness are too low to justify interventions. In the context of patients who are very likely to remain unconscious, there is substantial room for reasonable disagreement about those probability thresholds. That space must be navigated by a clinician's individual conscience.

Reasonable Disagreement about the Metaphysics of Disability

As we highlight above, the history of disability discrimination should motivate vigilance about medical power and patient vulnerability. The Americans with Disabilities Act (ADA) confers important protections for people with disabilities and it guarantees their access to valuable social resources. However, the ADA also has been criticized for embracing an overly broad conception of disability as "a physical or mental impairment that substantially limits one or more major life activity."[5] This definition can present challenges in the medical context, particularly for decisions involving patients who are very likely to remain unconscious. Indeed, there has been intense debate about whether to consider such patients disabled and

[5]Court decisions narrowed its interpretation in the years after its passage until congressional amendments re-expanded its scope (see Gostin 2015).

even some staunch advocates for disability protections argue that they are not disabled in the metaphysical sense. The reasonable disagreement surrounding the metaphysics of disability, as described in this section, provides a further reason to support conscientious objector rights for clinicians to refuse to provide life-sustaining interventions to patients who are very likely to remain unconscious.

Some have argued that severely brain injured people qualify for protections under the ADA and that refusal to perform life-sustaining interventions to these patients is an illicit form of disability discrimination. Fins, Wright, and Bagenstos (2020, 1736) contend that, "Individuals with DoC, (disorders of consciousness), clearly count as having a 'disability' under [the ADA] because they have a physical or mental 'impairment' that 'substantially limits' consciousness, a 'major bodily function'." They further note that rehabilitative services are precisely the kinds of resources that the ADA requires be provided to disabled persons, particularly in the context of the underappreciated rehabilitative potential of individuals with DoC diagnoses. Ezer, Wright, and Fins (2020) leverage international human rights doctrines to run similar arguments for the same conclusion.

However, Fins and colleagues also appear to acknowledge that there are different levels and types of injury that bear on both the certainty of prognosis and the status of patients vis-à-vis consciousness. For example, they write, "We believe that the ineffectuality of treatment found in cases where the patient is indisputably and chronically vegetative has been generalized to other similar but distinct brain states where there may be benefit in ongoing treatment and rehabilitation." (Fins, Wright, and Bagenstos 2020, 1734). Here, the authors appear to consider the relevance of prognostic probabilities, as well as the difference between patients who are "indisputably and chronically vegetative" and those with greater odds of recovering consciousness.

Others have more straightforwardly suggested that consciousness is a prerequisite for being considered metaphysically disabled. Andrew Batavia, who participated in drafting of ADA, argues that the broad definition of disability contained in that law likely includes permanently unconscious patients, but perhaps only by technicality. He notes that the authors of the ADA had not considered and were not intending to include "permanently unconscious people" (Batavia 2002). He concludes, "I would argue that when a person is permanently unconscious and therefore has no capacity to interact with the environment, he or she is not disabled in a metaphysical sense … " (Batavia 2002, 229).

L. Syd Johnson (2022) notes that we do not have to label unconscious patients disabled in order to treat them as persons who deserve moral consideration. However, while this may lower the stakes of resolving the metaphysical debate, the ambiguous question about what constitutes "moral consideration" further underscores the extent of reasonable disagreement. In our situation, the physician who objected to providing tracheostomy would likely argue that he was showing moral consideration for his patient by *not* performing this procedure. However, Johnson (2022) suggests that known preferences or values should be the guide, which can be helpful in many cases. In our case, this further supports the ethical permissibility of tracheostomy insofar as the patient's daughter has a coherent and believable account of her father's values that suffices as an expression of substituted judgment on his behalf. But even the best forms of patient autonomy, (e.g., well-written advance care planning documents), do not obviate the conscience rights of physicians. If a physician has a right to conscientiously object, then they have that right even when a capacitated patient requests the intervention the physician refuses to provide.

As further evidence of this reasonable disagreement, Batavia (2002) notes that courts have been split in such cases. He writes, "Some courts have insulated providers from liability while others have found that providers can be held liable if the disability *is not relevant to the treatment decision*" (Batavia 2002, 227, italics added). Importantly, many such legal cases have involved disputes about whether the interventions in question were futile. But, as we have stressed, conscience-based refusals can sidestep these kinds of claims. Instead, we have argued that it is the personal conscience of a clinician in the context of reasonable disagreement that tells in favor of protecting the right of clinicians to refuse interventions in such cases. This variability in the courts only further underscores the reasonable disagreement surrounding the inclusion of patients very likely to remain unconscious as a protected class vis-à-vis disability.

Here again, it is not necessary for our thesis to resolve the metaphysical debate about permanent unconsciousness as a form of disability. As in the case of debates about the appropriate goals of medicine and tolerable levels of uncertainty, all that is necessary is that one recognize the existence of reasonable disagreement. If one acknowledges that there is reasonable disagreement about whether patients very likely to remain unconscious should be considered disabled, then one's personal beliefs on the matter cannot suffice to show that it is wrongfully discriminatory to refuse to provide

tracheostomy to those patients. Instead, such reasonable disagreement permits individual clinicians to navigate that question by appeal to their own conscience.

Reasonable Disagreement as a Constraint

One objection to our argument is that it might lead to a slippery slope in which justifications for conscientious objections to performing interventions on other kinds of cognitively impaired patients might gain standing. This might seem to link our position to physician complicity in eugenics and genocide. In light of the troubling history of disability discrimination, we take such concerns seriously. Recently, the case of Michael Hickson involved a patient in a minimally conscious state whose physician refused to provide him with ventilator support (Shapiro 2020). Hickson's wife recorded a conversation in which the physician stated, "…the big question of futility is one we always question. And the issue is, will this help him improve his quality of life? Will this help him improve anything? Will it ultimately change the outcome? And the thought is, the answer is no to all of those."

We are concerned about cases like this, but our arguments do not support the actions of Hickson's physician, much less eugenics or genocide. First, Hickson was not likely to remain unconscious, but indeed had periods of responsiveness and appeared to have some subjective quality of life. Moreover, there is no indication that his surrogate was failing to represent his own preferences and values properly. Finally, there was no extant scarcity of resources that might have affected the decision to offer ventilator support. Thus, interventions to support his life were clearly neither futile nor inappropriate. In fact, the Hickson case underscores our concerns about the misuse of futility and its attendant exacerbation of clinical power, *which are mitigated*, *not exacerbated*, by a reframing of such refusals as a form of conscientious objection that lays bare the value judgments involved. The physician in the Hickson case was incorrectly invoking the idea of 'futility' and leveraging his medical authority, thereby obscuring how his own values led him to conclude that Hickson's life was no longer worth living. Alternatively, if framed explicitly as an exercise of conscience, this physician's value judgments would have been exposed. Secondly, and more importantly, there is no reasonable disagreement about whether Hickson was disabled or whether he could benefit from continued ventilator support. In similar cases, the condition of reasonable disagreement acts as an important constraint for physician conscientious objection.

CONCLUSION

Many clinicians express moral consternation about performing life-sustaining interventions on patients who are very likely to remain permanently unconscious. Debates over the appropriateness of life-sustaining interventions for these patients will likely continue, but they currently remain within the standard of care. Nonetheless, we argue that physicians who object to these procedures based on sincere moral commitments should express their objection as an exercise of conscience, accompanied by all its relevant rights and responsibilities.

While debates about the appropriate latitude for conscientious objection remain important, conscientious objections to life-sustaining interventions for patients very likely to remain unconscious accord with current ethical consensus surrounding notification, transparency, and disclosure, and are not invidiously discriminatory. Amplifying the role of individual conscience in related policies represents an important and practical step toward mitigating the moral distress that many experience in these cases, while simultaneously demonstrating appropriate humility around prognostic certainty and differing views about sufficient quality of life. Furthermore, there are policy implications, particularly when adding explicit references to conscience exceptions in institutional futility policies. Such policies should offer individual practitioners options designed to help them navigate their own value judgments in cases where a proposed intervention does not meet criteria as being futile or inappropriate. Finally, the implications of institutional conscience claims in the context of interventions for patients very likely to remain unconscious will need to be further explored.

Our arguments here are also an opportunity to test whether those who support or oppose conscience rights for health care workers have a principled commitment to those rights. Conscientious objections in healthcare have largely involved protecting the rights of clinicians with "pro-life" views and other derivatives of politically and morally conservative commitments. The situation above represents a case where the political stance is likely to the contrary. Will those who support conscientious objection in traditional contexts (e.g., abortion, contraception) also support the objection in our case and cases like it? Conversely, will those opposed to conscientious objection in

traditional contexts also oppose the physician's objection in cases like the one we discuss? We believe that the case for conscience rights is and should be neutral between different conceptions of ethical behavior and religious commitments. It can be endorsed by people with diverse religious and philosophical beliefs, particularly where there is reasonable disagreement about such matters.

Importantly, our arguments for the ethical *permissibility* of a physician's objection to performing tracheostomy for patients very likely to remain unconscious are not grounded in the claim that such an objection is ethically *required*. Indeed, in the case we previously discussed, *we* were the ethics consultants and we stipulated at the outset that it was ethically permissible to perform the tracheostomy. However, if we are to take conscience protections seriously, and if we recognize that spaces of reasonable disagreement exist within the moral terrain of medicine, then we should afford physicians the right to object in such cases. Otherwise, we either are effectively mandating the provision of care in situations where it violates the conscience of the physician, or we are inadvertently encouraging physicians to engage in inaccurate or even deceptive invocations of 'futility'.

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