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REVIEW PAPER

The Case of Hannah Capes: How Much Does Consciousness Matter?

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Abstract A recent legal case involving an ambiguous diagnosis in a woman with a severe disorder of consciousness raises pressing questions about treatment withdrawal in a time when much of what experts know about disorders of consciousness is undergoing revision and refinement. How much should diagnostic certainty about consciousness matter? For the judge who refused to allow withdrawal of artificial nutrition and hydration, it was dispositive. Rather than relying on substituted judgment or best interests to determine treatment decisions, he ruled that withdrawal was categorically prohibited, even as he concluded that Hannah Capes was *more likely than not* in a permanent vegetative state. In many jurisdictions, his decision would likely be consistent with existing law. Evolving technological advances have demonstrated that biologically distinct diagnoses incorporated into state laws may be difficult to establish even under ideal conditions. We offer the *Capes* case for purposes of examining the consequences of enshrined legal distinctions between permanent vegetative state and other severe disorders of consciousness. Insistence on proof of the permanent absence of consciousness before treatment withdrawal is allowed fails to respect the rights of persons with disorders of consciousness. Even the well-established rights to treatment withdrawal for those in a permanent vegetative state may be in jeopardy if reform is not undertaken.

Keywords Law · End-of-life decisions · Patient autonomy · Disorders of consciousness · Vegetative state

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Introduction

A recent legal case in Virginia—*Capes v. Kim*[1]—raises pressing questions about withdrawal of life-sustaining treatment from patients with severe, chronic disorders of consciousness [1]. The case of Hannah Capes, like that of Terri Schiavo in the early 2000s, involved a dispute between family members about withdrawing artificial nutrition and hydration amid disagreement over their loved one's condition. At the time of trial in 2016, Ms. Capes' mother believed that she exhibited signs of minimal consciousness,

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[1] Information about Hannah Capes' medical history was obtained from public testimony at trial and documents that have been made part of the public record.

while her husband attempted to prove that she was in a vegetative state. Medical experts called to testify equivocated or gave inconsistent testimony. Because her medical condition could not be clearly established to be that of a vegetative state, the state court judge refused to allow removal of artificial nutrition and hydration. He determined that Virginia law categorically prohibited the withdrawal of life-sustaining treatment from someone in a minimally conscious state. As this paper will explain, that decision was not required under existing Virginia statutes and case law and, in fact, deviates from the provisions of the Virginia Health Care Decisions Act (HCDA), which does not distinguish among medical conditions in its rules relating to withdrawal of life-sustaining treatment.

The judge's decision in the *Capes* case reveals legal uncertainty surrounding withdrawal of life-sustaining treatment for persons with severe disorders of consciousness. This legal uncertainty goes beyond this case and beyond Virginia. Many of the state statutes that specify when life-sustaining treatment may be withdrawn or withheld address only patients with certain medical conditions, usually terminal illness or permanent unconsciousness or permanent vegetative state. They are silent on whether life-sustaining treatment can be refused in advance directives or withheld or withdrawn by appointed health care agents or surrogate decision-makers for patients in other conditions, such as the minimally conscious state, on the basis of substituted judgment or the patient's best interests.

There is also little judicial precedent on withdrawal of life-sustaining treatment for people in a minimally conscious state. The well-known cases of Karen Ann Quinlan in 1976 (New Jersey Supreme Court) and Nancy Cruzan in 1990 (U.S. Supreme Court), which were instrumental in establishing the constitutional and common law rights of incompetent patients to withdraw life-sustaining treatment, spoke to withdrawal decisions for patients who were in a vegetative state with no reasonable probability of recovering consciousness [2, 3]. In any event, the minimally conscious state was not delineated as a clinical syndrome until 2002 [4].

Two recent appellate cases involved profoundly disabled patients with some, albeit limited, consciousness [5, 6]. Those patients outwardly exhibited much more awareness of themselves and their surroundings than did Hannah Capes. Neither court categorically barred withdrawal of life-sustaining treatment, but each refused to permit withdrawal of artificial and nutrition without evidence that the patients had previously expressed wishes about refusing such treatment in their current condition.

In contrast to these cases, Ms. Capes had completed an advance directive that appointed a health care agent (her husband, Clifton Capes) and provided written, if vague, instructions about terminating life-sustaining treatment. In Virginia, surrogate decision-makers (whether appointed by patients in an advance directive or identified from a statutory hierarchy of family members) are permitted to withhold or withdraw life-sustaining treatment if that decision is based on the patient's "beliefs, values, and preferences." [7] The judge in the *Capes* case did not deny Mr. Capes' request to withdraw life-sustaining treatment because that decision was based on inadequate evidence about what his wife would have wanted if she was in a minimally conscious state. The judge's categorical bar against withdrawal of life-sustaining treatment in anything but terminal illness or permanent vegetative state made that inquiry moot. In fact, he ultimately believed that Ms. Capes *was* in a vegetative state, but determined—without any existing legal requirement to do so, and in apparent conflict with Virginia's Health Care Decisions Act—that a permanent and complete lack of consciousness would have to be proved by the very high standard of evidence known as "clear and convincing." This burden was not met at trial, an outcome we may begin to see more frequently in contested cases about withdrawal of life-sustaining treatment from patients in a permanent vegetative state.

Much of what experts know about disorders of consciousness is undergoing revision and refinement. With better diagnostic tools, rehabilitation efforts, and therapies, physicians are discovering that some patients with severe brain injury may experience better prospects for some level of recovery than previously believed. Scientific discoveries combined with advocacy offer a corrective to the "pervasive nihilism" toward patients with disorders of consciousness and have the potential to improve their lives [8].

At the same time, applying scientific diagnostic advances in contested cases, in or out of courtrooms, is challenging given the evolving state of the science, as well as limited availability of experts, technology, and funds. In the *Capes* case, two experts appeared unwilling to speak to the exact nature of Ms. Capes' condition (no consciousness vs. minimal consciousness) without the use of advanced imaging techniques—like functional MRIs—even though they are not standard of care and their use is largely investigational.

All persons, whether minimally conscious or permanently unconscious, deserve respect and care. At the same time, existing laws—and ethical norms—that have the effect of categorically barring decisions to withdraw life-sustaining treatment from a person diagnosed as being in a minimally conscious state can have the effect of denying those patients' rights to self-determination and bodily integrity. Moreover, prohibitions on withdrawal of life-sustaining treatment from patients in a minimally conscious state affect not only their rights, but also, when certain proof in diagnosis is required—a challenging task when the science behind diagnosis and prognosis involves fine gradations and is a moving target—threaten to erode the more clearly-established rights of patients in a vegetative state. This latter consequence has not been adequately recognized or explored in the existing literature.

In the *Capes* case, the Virginia Supreme Court declined a petition for review, another failure of the legal system to attend to Hannah Capes' rights. Appellate courts, not trial courts, set precedent, and thus the decision in Hannah Capes' case only affects her situation; it was not precedent setting. It illustrates well, however, the problems encountered by patients and those responsible for making decisions on their behalf when the legal rules are complex, indeterminate, and arguably outdated.

We offer the *Capes* case for purposes of examining that body of law and, in particular, the consequences of enshrined legal distinctions between permanent vegetative state and other severe disorders of consciousness. These distinctions can be found in many statutes governing surrogate decision-making or may be imposed by courts. They can be found in advance directive forms, limiting the choices that surrogate decision makers can make or that health care providers will honor in ways that the persons who executed them may not have understood or desired. Rather than determining whether withdrawal of life-sustaining treatment is or is not allowed based on whether the patient fits into a category of patients, we argue that the law should allow for and require an individualized assessment of a particular patient's preferences, values, and best interests in light of their medical condition. Certainly, consciousness or the capacity for future consciousness does matter. The developing diagnostic and therapeutic tools for severe disorders of consciousness represent progress for these patients. But these tools should not be put in service of creating or maintaining rigid legal categories that deny patient autonomy.

Vegetative State/Unresponsive Wakefulness Syndrome and Minimally Conscious State: Definitions

Disorders of consciousness are complex, and the terms used to describe these conditions are often misused. The term "persistent vegetative state" was coined by Jennett and Plum in 1972 to denote a person with a prolonged (i.e., more than one month) absence of awareness, or consciousness, but who retains the capacity for sleep–wake cycles and reflexive movements [9]. In the early 1990s, when The Multi-Society Task Force on PVS determined that the persistent vegetative state could be considered irreversible three months following anoxic injury and 12 months following traumatic injury, the term "permanent vegetative state" became widely used in ethical and legal cases concerning withdrawal of life-sustaining treatment [10, 11].

For both clinical and social reasons, the term "unresponsive wakefulness syndrome" was proposed in 2010 by the European Taskforce on Disorders of Consciousness [11]. This proposed change in terminology remains controversial, in particular whether the focus on "unresponsiveness," which may be the result of a cognitive-motor dissociation preventing movement, directs attention away from consciousness, which may be covert [12, 13]. Statutes and legal opinions in the U.S. have not adopted this change in terminology.

In August 2018, the American Academy of Neurology released new practice guidelines for patients with disorders of consciousness, which use the terms vegetative state (VS) and unresponsive wakefulness syndrome (UWS) interchangeably, and often in conjunction (VS/UWS) [14]. The guidelines hold that references to permanency of the patient's condition are no longer justified since some patients, though still a minority, recover some degree of consciousness well past three months after an anoxic insult, and twelve months after a traumatic injury (the earlier markers for "permanency" determined by the Multi-Society Task Force) [10]. Rather, after these time periods have elapsed, the term "chronic" is now employed, qualified by the duration of the state; for example, a patient may be in a "chronic VS/UWS, 24 months in duration." The discussion regarding change in nomenclature is ongoing, and there are limitations to all current terminology [12].

In this article, we will employ the term VS/UWS in medical contexts; when citing statutes and case law, we will use the term vegetative state or PVS, denoting the expected permanency of the condition upon which the law was based. In Virginia, as in many states, the law refers to a "persistent vegetative state" although identifies it as a condition "from which, to a reasonable degree of medical probability, there can be no recovery" [15].

In contrast to patients with VS/UWS, those in a minimally conscious state (MCS), have some degree of environmental or self-awareness. MCS is defined as a "condition of severely altered consciousness in which minimal but definite behavioral evidence of self or environmental awareness is demonstrated" [4; p.350–351]. The state can be further divided into subcategories, MCS + and MCS-, where people in MCS + demonstrate evidence of intact receptive language as evidenced by their ability to follow commands or speak intelligibly, and people with MCS- demonstrate only nonlinguistic evidence of consciousness—for example, limb and eye movements in relation to external stimuli [16].

Due to motor, sensory and language impairments, up to 37–43% of patients reported to be in a vegetative state have been misdiagnosed and ultimately found to have an alternative diagnosis, including minimally conscious state and locked-in syndrome [17, 18]. The new guidelines were generated with this contingency in mind as a means of improving diagnostic certainty and, accordingly, therapeutic options for those who might have something to gain.

Although significant technological resources exist for evaluating disorders of consciousness, the new guidelines continue to support the clinical neurologic exam as the best method for determining a patient's condition [14]. Serial evaluations with the validated coma recovery scale-revised rather than a single exam are essential due to the variability of arousal in patients with disorders of consciousness, who often have comorbid medical illnesses and medication regimens that can decrease their level of arousal [19]. Skilled clinicians trained in the application of the neurobehavioral assessment instrument should perform such examinations. Other tests, including magnetic resonance imaging (MRI), positron emission tomography (PET), single-photon emission computed tomography (SPECT), somatosensory evoked potentials, and electroencephalography (EEG), may be helpful for prognostication [14].

For at least 15 years there have also been research studies of functional MRI (fMRI) designed to evaluate for the presence of awareness in patients without sufficient motor function to meet standard criteria for the minimally conscious state [13, 20]. One of the earliest of these studies was reported in *Science* over a decade ago [21]. A woman diagnosed as being in a vegetative state was asked to imagine playing tennis and then to imagine visiting the rooms of her house as her neural responses were captured using fMRI, to investigate what researchers called "willful modulation"; the imaging revealed neural responses indistinguishable from healthy volunteers performing the same mental imagery tasks. These findings have since been more widely reproduced [20–22].

In the largest functional neuroimaging study published to date on patients with disorders of consciousness, researchers employing a similar mental imagery task found that 11% of patient-subjects believed to be VS/UWS by clinical consensus were likely to have some minimal consciousness [20]. In response to requests to perform the tasks, these patient-subjects demonstrated activation on fMRI in regions of the brain consistent with minimally conscious patients who exhibited clinically observable behavioral responses [20]. Accordingly, these people seem to be *conscious*, but are limited in their ability to visibly demonstrate a response.

The authors of the disorders of consciousness guidelines recommend that imaging, including fMRI, may be considered in ambiguous clinical scenarios. This recommendation, which uses the word "may" rather than "must" or "should," is "the lowest allowable recommendation level that the American Academy of Neurology considers useful within the scope of clinical practice and can accommodate the highest degree of practice variation" [14; p.452]. The authors point out that the use of neuroimaging modalities yield largely negative results and are "unlikely to change the diagnosis in most patients diagnosed with VS/UWS" [14; p.453]. They further note that "functional imaging is not widely available and may not be clinically feasible in large numbers of patients" [14; p.452].

Hannah Capes

Hannah Capes was 22 years old in June 2007 when she lost consciousness while driving. She was urgently evaluated by her primary care physician to whom she reported seven months of headaches. On exam, she was found to have left-sided weakness and an MRI of her brain showed a large mass. She was referred to a tertiary care center for prompt surgical resection. Post-surgery complications caused a prolonged period of high intracranial pressure, limiting cerebral perfusion and resulting in an anoxic brain injury. Clinically she was largely unresponsive. A percutaneous gastrostomy (PEG) tube was placed for nutrition and hydration. By the time of her discharge in early August 2007, more than a month after her initial surgery, she had intermittent eye opening and would localize to pain in her upper extremities but she did not follow commands. She was discharged to her mother's house where an attached apartment was built to enable her husband and her mother to care for her.

Over the next several years, no major changes regarding her level of consciousness were observed. Periodic MRI scans were performed to monitor her tumor, and when it again showed growth in 2013, Ms. Capes underwent gamma knife radiosurgery to shrink its size. The surgery to improve tumor burden did not result in any clinical improvement, which was not unexpected given the underlying anoxic brain injury.

Dispute over Continued Life-Sustaining Treatment

In 2015, eight years after Hannah Capes' initial surgery, her husband, Clifton Capes, sought a court order for Hannah's custody and authorization to remove her artificial nutrition and hydration to allow her to die. Mr. Capes had been named his wife's health care agent in her advance directive, which also provided, "I do not want my life prolonged if, to a reasonable degree of medical certainty, my situation is hopeless." (The other option to choose on the form was "I want my life to be prolonged as long as possible within the limits of generally accepted medical standards, even if this means that I might be kept alive on machines for years.") The advance directive specifically gave her health care agent "full power and authority to consent to or to refuse life-sustaining treatment (including artificial nutrition and hydration) on my behalf," and "to take legal action to ensure that my wishes are honored." Testimony at trial revealed that, in the hospital awaiting her surgery, she had discussed the possibility of a poor neurological outcome with her husband and her faith leader. She told them that should this ensue she (in her words) would "not want to be a vegetable" [23; p.176]. Objecting to the withdrawal of life-sustaining treatment, Hannah's mother, Ms. Sharon Kim, asked the court to appoint her as Hannah's guardian in order to allow her to continue caring for Hannah.

This was not the first disagreement between Ms. Kim and Mr. Capes since Hannah's discharge from the hospital. Mr. Capes, who had been living in a tiny room that also functioned as a hallway between Ms. Kim's house and Hannah's apartment, moved out within a year of his wife's hospital discharge, citing issues of privacy and difficulty finding work nearby. He relocated to northern Virginia with plans to move his wife to a nursing facility near his new home, but yielded to Ms. Kim's wishes that Hannah remain under her care in the attached apartment with visits from Mr. Capes on weekends. Through the years, despite not being named the health care agent in her daughter's advance directive, Ms. Kim took Hannah to all medical appointments and signed all consent forms for procedures and surgeries.

When Mr. Capes initially began gathering information in preparation for a decision to remove artificial nutrition and hydration, he requested an ethics consultation at the health system that provided Ms. Capes' care. Attempts at arriving at an out-of-court resolution with Ms. Kim were unsuccessful.

Evidence of Hannah Capes' Current Condition

Multiple physicians had evaluated Ms. Capes over the years following her initial surgery and its sequelae. The opinions that they had expressed, in her medical record and to family, were often ambiguous and changed over time despite no appreciable clinical change in her condition. This wavering and inconsistency was also on display in testimony heard at trial. Two of Ms. Capes' physicians testified—her primary care physician (an internal medicine specialist) and her neuro-oncologist. Mr. Capes additionally had his wife evaluated by an independent neurologist with expertise in disorders of consciousness. Portions of this expert's opinion were discussed at trial and his report was submitted into evidence although, unfortunately, he did not testify.

In a pre-trial deposition, the primary care physician, who had cared for Ms. Capes for many years, including making visits to her home, stated that it was "possible" that Ms. Capes was in a vegetative state but that she "did not feel that [she] could make that final determination" because she was not a neurologist [23; p.248]. However, by the time of the trial, she had become more certain and felt it was "probable" that Ms. Capes was in a vegetative state. Pressed by Ms. Kim's lawyer on this discrepancy, the physician explained that her diagnosis changed after "10 months reviewing the records" [23; p.249].

In contrast to the primary care physician's increasingly firm declaration that Ms. Capes was in a vegetative state, her neuro-oncologist became less certain about her diagnosis. In April 2015, seventeen months prior to the trial, he had written in a letter (requested by Mr. Capes for clarification of her condition) that complications following her original surgery "left Ms. Capes debilitated in a permanent vegetative state" [23; p.186]. At the trial, however, he explained "my opinions, I think, have become somewhat more nuanced on what entails a permanent vegetative state and … how to try to make that diagnosis more definitively" [23; p.187]. The judge responded with exasperation: "I'm not interested in the medical field. I'm interested in this lady who's been in this condition for nine years" [23; p.188]. But the neuro-oncologist insisted that with current technology, he would want "more testing to make a diagnosis," specifically referencing functional magnetic resonance imaging testing by an expert in disorders of consciousness. Although he deferred to others with more expertise in neuroradiology, he acknowledged that meaningful imaging might not be possible in Ms. Capes' case because of her ventriculoperitoneal shunts and intermittent movements. Even though imaging was not the standard of care, the neuro-oncologist was unwilling to give an opinion.

Lastly, the expert in disorders of consciousness concluded in his report that, on the basis of his June 2016 examination of Ms. Capes and a subsequent EEG, "it [was] not possible to determine a vegetative state within a reasonable degree of medical certainty" [23; p.205–206]. The clinical indication he observed most indicative of consciousness was that she "spontaneously would lift her head up and arch her neck backwards almost as if she was listening. There was a sense that she was to some slight degree awake and somewhat aware." He also reported that "[s]he is not tracking spontaneously. She makes a sound but is unable to talk." He too had interest in an fMRI study for further evaluation, and although imaging had been scheduled, it did not occur due to concerns about her implanted shunts and difficulty contacting her neuro-oncologist.

The judge paid careful attention to the evidence about Hannah Capes' medical condition and did not hide his struggle in determining whether her artificial nutrition and hydration should be withdrawn. Near the end of the several days' trial, the judge remarked that, "it goes without saying, again, being the master of the understatement, this is probably the most difficult case I've had in my 20 years on the bench, and I dare say it's probably one of the most difficult cases I've ever been involved in" [23; p.467].

The judge denied the request to remove artificial nutrition and hydration because, as he explained, he did not believe that Mr. Capes had met the burden of proving by clear and convincing evidence that Hannah Capes was permanently unconscious. The judge stated that had the standard of evidence simply been a "preponderance of the evidence"—the usual standard in a civil trial—he would have ordered withdrawal of life-sustaining treatment [23; p.467]. In other words, the judge found that there was strong evidence that Ms. Capes was in a permanent vegetative state —it was in fact, "more likely than not" that she was—but he believed that (1) artificial nutrition and hydration could only be removed if Ms. Capes was in a permanent vegetative state *and* (2) that the condition had to be proven by clear and convincing evidence.

Virginia's Health Care Decisions Act (HCDA), however, does not limit withdrawal of life-sustaining treatment to certain medical conditions. The trial judge was either mistaken about Virginia's statutory requirements and its limited case law, discussed below, or he decided to impose this prohibition on withdrawal of life-sustaining treatment of his own accord. If the latter, however, he did not indicate that he was doing so.

Virginia Law

Based on our experience working in a Virginia health system and consulting with other ethics professionals around the state, the sharp distinction between PVS and MCS that the judge recognized in the *Capes* case has not informed or governed practice relating to withdrawal of life-sustaining treatment in Virginia for many years. The Virginia Health Care Decisions Act makes clear that patients may, through an advance directive, refuse any life-sustaining treatment, including artificial nutrition and hydration, regardless of their condition [24]. It reads: "Any adult capable of making an informed decision may, at any time, make a written advance directive to address any or all forms of health care in the event the declarant is later determined to be incapable of making an informed decision [24].

The Virginia HCDA is modeled, in this respect, on the Uniform Health Care Decisions Act drafted by the Uniform Law Commissioners and endorsed by the American Bar Association in the early 1990s [25]. As Charles Sabatino, an observer and advisor during that process explained, the model law discarded preconditions such as the diagnosis of a terminal condition or permanent unconsciousness [26]. "This unencumbered approach," he wrote, "keeps the focus of decisionmaking where it should be—on discerning what the patient meant by his or her words and instructions, even if they are less than clear, rather than on what the legislature meant by its terms and instructions." [26].

Under the Virginia HCDA, the primary question in making medical treatment decisions for someone who has lost decision making capacity is what the patient would want, to the extent that can be determined. If a patient's wishes have been expressed in an advance directive, a surrogate decision-maker must follow those instructions. Otherwise, a surrogate decision-maker must make decisions based "on the beliefs, values, and preferences of the patient, or if they are unknown, on the patient's best interests" [7]. Out-of-court decisions by health care agents are judged by whether they are made in good faith [28]. If court review is sought, a court may enjoin the provision, continuation, withholding, or withdrawing of health care "upon finding by a preponderance of the evidence that the action is not lawfully authorized by this article or by other state or federal law." [29].

It is not clear why the trial judge was under the impression that in Virginia withdrawal of life-sustaining treatment could only be permitted if Ms. Capes was in a permanent vegetative state and, further, that the condition must be proved by clear and convincing evidence. This is what Ms. Kim's attorney argued, but he cited no clear authority for the limitation. Like many states, earlier Virginia law *had* limited advance directives to people in a "terminal condition"—defined by imminent death or permanent vegetative state—but the law underwent a major revision in 2009 that removed that limitation.[2] The same was true with respect to the authority of surrogate decision-makers; earlier versions of the statute had limited the withholding and withdrawal of life-sustaining treatment to "terminal conditions." These limitations were removed in 1992.[3]

"Terminal condition," which includes the "persistent vegetative state," is still a term found in Virginia's Health Care Decisions Act, which may have contributed to the confusion. Terminal condition is

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[2] In 1983, Virginia followed many states in passing an end-of-life decision-making statute. See the Natural Death Act, V.A. H.D. REP. No. 32 (1983). The initial legislation limited advance directives to "terminal conditions." See Va. Code Ann § 54–325.8:3 (1983) (recodified as § 54.1–2983). A 1991 amendment altered the definition of "terminal condition" to include PVS. See H.B. 1615, 1991 Leg., Reg. Sess (VA. 1991). The provision was largely unchanged until 2009 when a major overhaul of Virginia's law was undertaken. See H.B. 2396, 2009 Leg., Reg. Sess (Va. 2009). Any language limiting advance directives to terminals conditions was removed. See Va. Code Ann. § 54.1–2983.

[3] From 1983 to 1992, Virginia law provided authority to surrogates to withdraw life-prolonging procedures only from patients with terminal conditions without addressing surrogates' authority to refuse other unwanted treatment. See Va. Code Ann. § 54.1–2986 (1983) and Va Code Ann. § 54.1–2986 (1991). In 1992, this authority was expanded to allow surrogates to provide, withhold, or withdraw any "medical or surgical care or treatment" on behalf of patients. See S.B. 254, 1992 Leg., Reg. Sess. (Va. 1992). Under the 1992 bill, the only articulated restrictions on the surrogate's power were that the surrogate could not authorize nontherapeutic sterilization, abortion, psychosurgery, admission to a psychiatric hospital, and could not act knowing that such action was protested by the patient.

referenced for the limited purposes of specifying: (a) when a patient may make an oral advance directive [24]; (b) certain limitations on removing life support when a patient does not have an advance directive and has no appointed agent or next-of-kin [27]; and (c) conditions for withdrawal of life-sustaining treatment in the optional statutory advance directive form [30]. Ms. Kim's attorney repeatedly stated that life-sustaining treatment could only be withdrawn if Ms. Capes' condition were terminal [23; p.10 and 442] and that interpretation of the advance directive's instructions was "irrelevant" [23; p. 29–30]. A guardian ad litem, an attorney appointed by the judge to represent Hannah Capes' interests, also submitted a report that stated, without citing any authority, that Hannah Capes must be terminally ill or in a vegetative state before life-sustaining treatment could be withdrawn [31; p.5].

Ms. Kim's attorney and the guardian ad litem further asserted that Mr. Capes had to prove that Hannah Capes was in a PVS by "clear and convincing" evidence [23; pp. 442–45], and indicated that this standard of evidence was determined by the Supreme Court in *Cruzan* to be appropriate for cases of this kind. *Cruzan*, however, did not adopt any standard of evidence for withdrawal of life-sustaining treatment for the states [3]. Instead, the U.S. Supreme Court considered whether the state of Missouri was allowed to require clear and convincing evidence that Nancy Cruzan, while competent, had expressed the desire to refuse artificial nutrition and hydration in a PVS before its removal would be permitted. The Supreme Court determined that Missouri's standard of evidence as to a patient's wishes did not violate the Constitution. Most importantly, the Court did not impose any requirement—much less any standard of evidence by which it should be met—that a patient must be in a *particular medical condition* before life-sustaining treatment could be withheld or withdrawn.[4]

The judge appeared to accept without question that "clear and convincing" evidence of a PVS was required and, according to his own statement, this determination about the evidentiary standard was dispositive in his ruling against withdrawal of life-sustaining treatment.

A final source of confusion appears to have been a boilerplate provision of Virginia law that is also found in many other states' law. This provision distinguishes the withdrawal and withholding of life-sustaining treatment from "mercy killing or euthanasia" [32]. It provides that nothing in the Virginia Health Care Decisions Act "permit[s] any affirmative or deliberate act or omission to end life other than to permit the natural process of dying" [32]. Ms. Kim's lawyer argued that this statute limited the withdrawal of artificial nutrition and hydration from someone who is not either terminally ill or in a permanent vegetative state. He cited *Gilmore v. Finn*, the single Virginia appellate case relating to the removal of artificial nutrition and hydration [33]. In that case, the Virginia Supreme Court considered whether Governor Gilmore's lawsuit to prevent the removal of Hugh Finn's artificial nutrition and hydration was "grounded in fact," and a "good faith argument" for purposes of assessing whether the state must pay the attorney fees of Finn's health care agent. Although the dispute in the *Finn* case involved attorneys' fees, the Virginia Supreme Court made clear that the "euthanasia" provision did not bar the removal of artificial nutrition and hydration from someone in a PVS, stating that withdrawal "merely permit[ted] the natural process of dying." Logic dictates that the same would hold true for someone in an irreversible minimally conscious state whose life is also being sustained by the medical intervention of a permanent feeding tube. For both such patients, neither is in the process of dying while being maintained by artificial nutrition and hydration.

In truth, it appears that none of the attorneys or court officials in the *Capes* case had carefully reviewed the Virginia HCDA, the *Finn* case, or the *Cruzan* case. Mistaken characterizations of the law were introduced, never corrected, and ultimately controlled the decision. The statute and the case law are admittedly complex—as they are in many states.

But what they required, quite clearly, was a focus on whether discontinuing artificial nutrition and hydration was consistent with Ms. Capes' written advance directive and other evidence of her wishes

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[4] The guardian ad litem acknowledged in his report that "no authority could be located" in Virginia adopting the "clear and convincing" evidentiary standard for these decisions, but nevertheless "contend[ed]" that §54.1–-2985.1, the Virginia provision that sets the evidentiary standard for reviewing decisions made under the Health Care Decisions Act, "establishes a 'preponderance of evidence' standard only for initial proceedings, a temporary injunction for example, and not for a final determination on the merits." [32, p. 6]).

as they related to her current medical condition. Particular attention should have been paid to whether her condition should be understood as "hopeless"—as she understood that term in her advance directive, as it has no particular legal meaning despite being the term used by the New Jersey Supreme Court to describe Karen Ann Quinlan's condition. Mr. Capes testified at trial that "Hannah was terrified of being in a position where she would be kept alive in a hopeless condition. She was very afraid of just being trapped in her body and with no hope of recovery. So she told me several times, 'don't let that happen to me'" [23; p.57]. Whether this and other testimony that was offered at trial regarding statements Hannah Capes had made or about her beliefs and values would be sufficient to support withdrawal of life-sustaining treatment may be a source of reasonable disagreement. For some fact-finders, it may depend on the standard of evidence or on the deference to be given the decisions of an appointed health care agent. The 2001 California case of Robert Wendland provides the closest precedent case and contains extended analysis of the many legal considerations involved [5].

Robert Wendland had suffered severe brain injuries following a vehicular accident. His wife, Rose, was named his conservator to make health care decisions for him and, after two years, requested removal of the artificial nutrition and hydration that was keeping him alive. Other family members objected. Robert Wendland was clearly more than minimally conscious. For example, "[a]t his highest level of function … Robert was able to do such things as throw and catch a ball, operate an electric wheelchair with assistance, turn pages, draw circles, draw an "R' and perform two-step commands" [5]. But he "remained severely disabled, both mentally and physically" and exhibited agitation, aggressiveness, and "general dysphoria." Testifying physicians agreed that further improvement was unlikely.

California's legislature, like Virginia's, had followed the Uniform Health Care Decisions Act in repealing earlier statutory provisions that limited withdrawal of life-sustaining treatment to patients who were terminally ill or in a PVS and replacing them with provisions that gave "competent adults extremely broad power to direct all aspects of their health care in the event they become incompetent" [5]. Appointed agents and surrogates under the new law were required "to make health care decisions 'in accordance with the principal's individual health care instructions, if any, and other wishes to the extent known to the agent'" [5]. Like Virginia's HCDA, California's Health Care Decisions Law also explicitly adopted a "preponderance of the evidence" standard by which to judge the appropriateness of a surrogate's decision to withdraw life-sustaining treatment [5].

In *Wendland*, however, the California Supreme Court decided to impose a higher burden of proof to Mr. Wendland's preferences because he was conscious. It was concerned that the legislature had not fully appreciated the changes it had made to the law in adopting the Health Care Decisions Law. It was also concerned that patents' constitutional rights to life and privacy were not adequately protected by these changes when health care decisions were made by court-appointed conservators. The court determined that in the absence of an appointed health care agent or clear formal instructions in an advance directive, there must be evidence of prior conversations "in which the patient expresses a desire to have his life-sustaining medical treatment terminated under the circumstances in which he now finds himself" [5]. To satisfy this standard, the conversations should reflect "an exact 'on all-fours' description of the conservatee's present medical condition." Reviewing the trial court's assessment of the evidence presented at trial, the California Supreme Court determined that Rose Wendland had not met this burden, and life-sustaining treatment could not be withdrawn.

There are two important lessons to draw from *Wendland*. First, a court may decide to impose a higher standard of evidence than the state legislature has required regarding proof of patient preferences and interests if the court determines that doing so is necessary to protect the patient's constitutional rights. This is not, however, what the judge in the *Capes* case did. His prohibition against withdrawal of life-sustaining treatment in any condition but terminal illness or PVS was wholesale, not a matter of requiring more exacting proof of Hannah Capes' preferences or wishes.

Second, central to the *Wendland* court's decision was the fact that Rose Wendland was a conservator, appointed by the court to make health care decisions for Robert Wendland, rather than appointed by him. The court wrote: "A reasonable person presumably will designate for such purposes only a person in whom the former reposes the highest degree of confidence. A conservator, in contrast, is *not* an agent of the conservatee, and unlike a freely designated agent cannot be presumed to have special knowledge of the conservatee's health care wishes" [5]. The court made clear that its imposition of a higher burden of proof regarding the patient's preferences and interests did not apply to decisions to withdraw life-sustaining treatment from persons in a PVS. Nor did it apply to persons who had designated agents for health care. Unlike Robert Wendland, Hannah Capes had executed an advance directive. It named her husband, Clifton Capes, as her health care agent and her brother as the alternate agent.

Reasonable people can disagree about whether the *Wendland* case was correctly decided. We appreciate that the court was committed to determining what the patient would have wanted—rather than categorically barring withdrawal of life-sustaining treatment, but the kind of evidence that likely would have satisfied the court does not reflect the realities of how people think about, talk about, and document (or not) their wishes regarding life-sustaining treatment in the event of illness or injury [34]. Among the evidence offered at trial was testimony about statements Robert had made about not wanting "to live like a vegetable." His daughter recalled him saying "if he could not be a provider for his family, if he could not do all the things that he enjoyed doing, just enjoying the outdoors, just basic things, feeding himself, talking, communicating, if he could not do those things, he would not want to live." [5]

In our view, establishing a different set of rules according to the diagnostic category in which the patient fits is unwise and unjustified. Unreasonably high evidentiary burdens erect a barrier to refusal of life-sustaining treatment similar to triggering conditions found in many state statutes, to which we now turn.

Other States' Laws

So far, we have reviewed the application of Virginia law on questions of withdrawal of life-sustaining treatment for patients in a PVS or MCS. Other states have a similarly complex web of statutes and cases. Many of them, however, in contrast to Virginia's HCDA, continue to designate certain conditions in rules specifying when life-sustaining treatment can be withheld or withdrawn. These conditions are sometimes referred to by legal scholars as "triggering conditions" [35]. State statutes generally recognize the use of advance directives to withhold or withdraw life-sustaining treatment in terminal illness or a permanent vegetative state. In the absence of an advance directive they also authorize surrogate decision-makers to withhold or withdraw life-sustaining treatment when the patient is in one of these two conditions, as long as doing so is consistent with the patient's preferences or best interests [36]. Some states, like Florida, specifically authorize withdrawal of life-sustaining treatment in an "end-stage condition" (such as end-stage renal disease) as well [37].

These statutes are typically drafted in the form of "safe harbors" [38]. They specify those situations in which people involved in decisions to withhold or withdraw life-sustaining treatment —physicians, surrogate decision-makers, and so on—are immune from civil or criminal liability. The statutes also specify the kinds of life-sustaining treatment that can be withheld or withdrawn; earlier statutes included ventilators on this list, but excluded artificial nutrition and hydration. Following the *Cruzan* decision, artificial nutrition and hydration has been included in most, perhaps all, state statutes as a form of life-sustaining treatment that can be withheld or withdrawn, though sometimes additional requirements are imposed before removing nutrition and hydration [39].

Importantly, the statutes usually do not state that life-sustaining treatment *cannot* be withheld or withdrawn in other patient conditions (if, for example, the patient is in a minimally conscious state, or the life-sustaining treatment in question is not included in the list (e.g., turning off a pacemaker). In fact, most states include a provision that specifies that the constitutional and common law rights of patients to refuse life-sustaining treatment may be broader than those recognized in the statute and are not intended to be limited by the statute [40].

Nevertheless, statutes drafted as safe harbors can have the same effect as a prohibition. They "can be so powerful as to set the standard of practice in ways virtually indistinguishable from a legislative mandate" [36]. In other words, even though most statutes *explicitly allow* withdrawal of life-sustaining treatment for patients in a permanent vegetative state, and they do not *explicitly prohibit* withdrawal of life-sustaining treatment for patients in a minimally conscious state, in practice this language may limit withdrawal of life-sustaining treatment in a minimally conscious state, because health care teams, agents, or a hospital's administrators, risk managers or attorneys erroneously interpret the safe harbor as *only* allowing withdrawal in a permanent vegetative state.

The Need for Reform to Protect the Rights of Patients with Severe Disorders of Consciousness

The triggering medical conditions found in state statutes have an understandable origin. When many of these laws were first passed, hospitals and physicians were hesitant to withdraw life-sustaining treatment in the absence of a court order. A number of high-profile and precedent-setting court decisions determined that life-sustaining treatment could be withheld or withdrawn in accordance with a patient's common law and constitutional rights for patients who had permanently lost decision-making capacity as long as these decisions were made in accordance with the probable wishes of the patient or their best interests [2, 3]. These cases involved patients who were terminally ill or who were in a permanent vegetative state. The statutes codified these precedents, allowing agents and providers to avoid intrusive, stressful, expensive, and time-consuming court review of decisions to withdraw life-sustaining treatment in situations like those in which courts had previously determined that patients had a right to treatment refusal.

The two usual triggering conditions—terminal illness and permanent vegetative state —are situations in which withdrawal of life-sustaining treatment appears reasonable to many people; we would not be surprised if someone who was terminally ill or permanently unconsciousness had expressed a desire to have life-sustaining treatment withdrawn in those situations or that withdrawal of life-sustaining treatment was consistent with their wishes, values, and beliefs. Likewise, in the absence of evidence of a patient's preferences, it does not seem unreasonable for a health care agent to determine that withdrawing life-sustaining treatment that merely prolongs dying from someone suffering at the end of a terminal illness is in the patient's best interests. These are situations in which the likelihood that health care agents are making decisions contrary to patient's preferences and interests appears to be low.

Additionally, these two conditions are ones in which it is less likely that a patient's prior wishes or values conflict with the patient's present best interests. Rebecca Dresser and others have argued that there may be situations in which it is more appropriate to pursue patients' present best interests than honor past preferences that they can no longer appreciate [41]. Respect for patient autonomy is not the only value of importance. Dresser writes that "responsibilities to protect an incompetent patient ought not be suspended because that person once requested an intervention that would now be inhumane or refused an intervention that now offers clear benefit" [41; p.1840]. There are also concerns, as Mary Crossley has explained, that "medical choices for people with disabilities often reflect implicit biases against disabled life and covert rationing" [42].

There remain important and unsettled questions on how to navigate potential conflicts between past preferences and current interests when they arise. For example, how should health care agents, health care providers, and courts respond when a person's advance directive indicates that they do not even want a simple intervention—any antibiotics, for example, to treat a minor and potentially short-term health problem, if they ever have dementia. What if the person with dementia is otherwise physically healthy and appears to be enjoying life? We know from studies that people often change their minds about the acceptability of living life with a form of disability that they formerly believed would be intolerable for them [42].

We are not advocating for any particular solution about how to resolve conflicts between a person's pre-incapacity preferences and post-incapacity interests —only insisting that in all cases decisions to withdraw life-sustaining treatment should be based on what is relevant to the decision for a *particular* patient, not an *abstract* patient or *category* of patient. This, indeed, is the essential problem with triggering medical conditions—while they might serve a function in protecting vulnerable patients from improper decisions, they are too blunt an instrument for universal application [35]. There are other ways that the law and ethical norms can and do protect patients who have become vulnerable because of a loss of capacity—for example, a legal requirement that the patient have permanently lost capacity, so that their opportunity for making these important decisions for themselves may be preserved, or an ethical (and sometimes legal) expectation that their assent for treatment is sought and their protest against treatment respected. Most important is that health care agents and others involved in decision-making—which is sometimes the courts—undertake an individualized assessment of a particular patient's past expressions, wishes, and values, and current interests.

In the *Capes* case, the court did not make its decision based upon a careful scrutiny of Hannah Capes' advance directive or statements to her husband or others, or upon an assessment of the ways in which any minimal consciousness she might have had (of which, again, the judge did not believe she had any) was experienced as beneficial or burdensome to her. Yet "there is no 'typical' MCS patient, but rather a variety of individuals with varying degrees of self-awareness and phenomenal awareness" [43]. In order to respect constitutional rights to self-determination and bodily integrity, an individualized assessment is required for determining both the patient's quality of life and how living in that condition comports with their prior preferences and values. According to Syd Johnson "[M]any persons prospectively considering the possibility of living in a MCS—of being permanently and profoundly disabled, unable to interact meaningfully, but consciously aware—might view it as a fate worse than the vegetative state, and indeed, a fate worse than death" [43]. But for others and their families, withdrawing life-sustaining treatment when there is evidence of some, albeit small, consciousness and/or a possibility for improvement, would not be what they would choose [8]. While withdrawal of life-sustaining treatment may be appropriate for some patients with minimal consciousness, it may not be for others.

Erosion of Clearly-established Rights for Patients in VS/UWS

Neuroscientific advances have allowed us to better understand disorders of consciousness—both to better assess patient awareness and to make more accurate predictions about whether some measurable recovery is possible. Studies show that rates of misdiagnosis for VS/UWS remain unacceptably high. Perhaps as many as 20% of patients diagnosed as permanently vegetative in the past have had the potential for a later diagnosis of a minimally conscious state. Joseph Fins and James Bernat argue that these patients fall into at least four groups: 1) those misdiagnosed as chronic VS who actually are in a MCS; 2) those who with pharmaceutical therapy or neuromodulation may demonstrate characteristics more consistent with MCS; 3) those with "cognitive-motor dissociation (CMD) in whom the behavioral examination was dissociated from detected volitional responsiveness" (Fins later further explains in plainer language: "These patients will show a volitional response on functional neuroimaging, but do not manifest behavioral responses at the bedside."); and lastly 4) those whose internal neurocircuitry changes over time to move them into MCS [12, 44]. Challenges to diagnosis and prognosis are amplified when patients with severe disorders of consciousness do not have access to specialists qualified to perform diagnostic examinations and testing. The harms of misdiagnosis are real and lasting for patients wrongly diagnosed as having VS/UWS when they have some degree of consciousness. Patients may not receive early and consistent rehabilitation efforts that could improve their prospects for recovery, and their present sensory needs—for example, relief of pain or suffering—may go unmet [45]. For these patients and their surrogate decision makers, advances in diagnostic and prognostic tools can offer aid in making critical treatment decisions.

What is less well appreciated, however, is what these neuroscientific advances—although investigational, and the technologies associated with them not generally available—might mean as a practical matter for the ability of health care agents, physicians, and ultimately courts to honor the long-recognized rights of those with chronic VS/UWS to have life-sustaining treatment withdrawn when consistent with their prior wishes or values. As seen in the *Capes* case, in today's era of advanced diagnostics, physicians may be increasingly unwilling to diagnose VS/UWS on the basis of clinical neurological exams alone, despite the guidelines' continued endorsement of serial standardized neurobehavioral assessments. Yet functional neuroimaging and other testing, such as electrophysiological studies, are expensive, there are a limited number of experts capable of performing them, the patient's physical condition may mean the testing carries risks of harm, and the results may ultimately be inconclusive. Currently even the leading scientists in the field have determined there is insufficient evidence to support routine use of functional neuroimaging or other advanced testing [14]. If a diagnosis of permanent VS/UWS is legally necessary— especially if that diagnosis must meet the standard of clear and convincing evidence, then those with VS/UWS are increasingly at risk of having their preferences and values ignored, even when they have been articulated in an advance directive.

Such was the case with Hannah Capes. Her neurooncologist and internist both made statements about her diagnosis that conflicted with their earlier statements. Even an expert in disorders of consciousness was unable, or unwilling, to say whether she was in a chronic vegetative state or a minimally conscious state to a "reasonable degree of medical certainty" without additional neuroimaging, which did not occur in her case.

This hesitation on the part of physicians to diagnose a permanent loss of all consciousness may well be justified and not only for Ms. Capes. The difficulty in determining with certainty how much, if any, consciousness Ms. Capes retained exists for virtually all patients believed to be VS/UWS. While it is always arduous to prove a negative, it is especially so here, when, as Stender et al., write, "no gold standard exists for absence of consciousness" [20]. But the problem is not with the science or the expert physicians. It is with the law or its application.

In Ms. Capes' case, insistence on clear and convincing proof of her condition meant that even if she had permanently lost all capacity for consciousness (and the judge said he believed it was *more likely than not that she had*), her right to withdrawal of life-sustaining treatment could not be honored. Similar results may be expected in the future in other contested cases if the law—whether applied in courtrooms or interpreted by risk managers—is understood as requiring exacting proof of permanent loss of consciousness.

The Need to Review Standard Advance Directives

Would a more carefully drafted advance directive have led to a more appropriate outcome in the *Capes* case? On her advance directive, which was based on a Jehovah's Witness form, Hannah Capes had checked the box indicating that she did not want to prolong her life if her situation was "hopeless." The trial judge did not appear interested in exploring what that term might have meant to her because he was under the impression he could not permit withdrawal of life-sustaining treatment regardless of the advance directive's contents. However, the advance directive would have been probative and the term "hopeless" would have merited exploration for what it meant for Hannah Capes in terms of her probable desires regarding continued life-sustaining treatment. Her husband and faith leader supplied evidence of statements that Hannah Capes had made to them to further the court's understanding of her wishes. Absent additional evidence of this kind, one could well argue that the language in this and many other advance directives is so vague that it allows for too much subjective interpretation to be of much use.

On the other hand, many advance directive forms provide more certain language that contributes to a different problem [46]. Some include boxes to be checked for certain medical conditions in which life-sustaining treatment should be withheld or withdrawn, often for "permanent vegetative state" or "terminal illness." Such forms may limit the situations in which health care agents can direct withdrawal of life-sustaining treatment to the medical conditions specifically identified. These forms operate in a way similar to the legal "safe harbors" in the law—the "triggering conditions" are simply supplied by the signed form rather than the law. (Sometimes the forms are written this way because the state law only expressly recognizes advance directives for these two conditions, although, as explained above, most states also explicitly preserve the common law rights of patients, which would include leaving other forms of expression.)

If Hannah Capes had signed a form expressing a desire for withdrawal of life-sustaining treatment in a "permanent vegetative state" instead of in a condition that was "hopeless," she may have been less, rather than more, likely to have her wishes honored because the physicians who examined her were unable to determine with the requisite certainty that she was not, instead, in a minimally conscious state. The judge may have relied on the advance directive, rather than a categorical bar, to deny withdrawal of life-sustaining treatment, believing that Hannah Capes would *only* refuse life-sustaining treatment in a PVS and would therefore want life-sustaining treatment in a MCS.

Advance directives have been sharply criticized by some commentators as a failed public policy initiative. They have limited uptake by the public (only 3 in 10 Americans have them), are often vague and offer little guidance regarding the medical question at issue, and people may have good reasons to avoid them—they cannot anticipate the medical condition they will later have or they may not have settled ideas about what they would want done in that situation; they may prefer to trust family members to make the decision when the time arrives [34].

We appreciate these critiques. However, given that advance directives are currently relied on by many to help ensure that their wishes are honored, there is a current need to re-assess their content, especially those that have not been updated in recent years. A tool designed to give patients more voice in their future treatment decisions should not culminate in restricting life-sustaining treatment choices in ways that they had neither anticipated nor desired.

Conclusion

Although neuroscientific advances may allow us to see evidence of brain activity that was formerly hidden, they cannot tell us what matters to patients. They cannot tell us whether some small measure of consciousness should matter in terms of preserving life and even what the boundaries of consciousness are. Is it enough to slightly lift your arm as you are dressed? Or for a behaviorally unconscious patient to show brain activity on neuroimaging when a familiar person speaks their name? [47]. Such a response is qualitatively different from purposefully following instructions to imagine playing tennis. Is it consciousness? The new guidelines suggest that it is not; instead, test results of this kind would "suggest []…an increased chance of recovering consciousness within 12 months" [14; p.455]. Some researchers posit that patients who are unresponsive but show "brain activity compatible with (minimal) consciousness represent a border zone between minimally conscious states and unresponsive wakefulness syndrome," and recommend that they be characterized as being in a "non-behavioural minimally conscious state" [20]. This may be helpful for researchers and clinicians studying and treating patients with disorders of consciousness. It may even be helpful in determining how to understand a patient's diagnosis and prognosis and parse the meaning of that response for individualized treatment decisions. But adding further ethical or legal categories—to either allow or limit withdrawal of life-sustaining treatment —in this or that particular condition will not be helpful and is most likely harmful. Instead, we need to jettison the categories that we have. The essential question is what matters to individual patients.

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