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RESEARCH ARTICLE

Best Interests and Decisions to Withdraw Life-Sustaining Treatment from a Conscious, Incapacitated Patient

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Abstract
Conscious but incapacitated patients need protection from both undertreatment and overtreatment, for they are exceptionally vulnerable, and dependent on others to act in their interests. In the United States, the law prioritizes autonomy over best interests in decision making. Yet U.S. courts, using both substituted judgment and best interests decision making standards, frequently prohibit the withdrawal of life-sustaining treatment from conscious but incapacitated patients, such as those in the minimally conscious state, even when ostensibly seeking to determine what patients would have wanted. In the United Kingdom, under the Mental Capacity Act of 2005, courts decide on the best interests of incapacitated patients by, in part, taking into account the past wishes and values of the patient. This paper examines and compares those ethicolegal approaches to decision making on behalf of conscious but incapacitated patients. We argue for a limited interpretation of best interests such that the standard is properly used only when the preferences of a conscious, but incapacitated patient are unknown and unknowable. When patient preferences and values are known or can be reasonably inferred, using a holistic, all-things-considered substituted judgment standard respects patient autonomy.

Keywords: best interests; incapacitated; unrepresented; withdrawal of life-sustaining treatment

Introduction

In the United States and elsewhere, there have been for decades legal precedents for withdrawing life-sustaining treatment (LST), including artificial nutrition and hydration (ANH), from patients in the vegetative state/unresponsive wakefulness syndrome (VS/UWS).[1] Subsequently, there has emerged a widely endorsed view in law and medicine that life may have no value for a chronically unconscious individual. The matter is ethically contested, however, and religious/spiritual doctrines vary regarding the withdrawal of LST, and in particular, the withdrawal of ANH, as well. U.S. state laws frequently carve out permanent unconsciousness (or more often the outdated term "persistent vegetative state" [PVS]) as a triggering condition for permissible surrogate decisions to withdraw LST, alongside terminal conditions and circumstances in which continued treatment would be exceptionally burdensome for the patient.

Although the minimally conscious state (MCS) was named and described two decades ago,[2] to date, no states in the United States specifically address the MCS in their statutes on surrogate decision making.[3] Case law concerning patients in the MCS is scant, but courts in the United States have generally ruled against surrogates seeking to withdraw ANH from MCS patients, in contrast to cases involving patients in the VS/UWS[4]. Some states prohibit surrogates from consenting to withdrawal of ANH from *conscious*

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and incapacitated patients, unless those patients themselves indicated that it was their preference, or unless the patient is terminally ill or treatment is considered futile or especially burdensome and likely to cause suffering.

The MCS is a condition in which there is minimal and inconsistent evidence of responsiveness indicating awareness.[5] It can result from brain injuries or from end-stage neurodegenerative conditions like Alzheimer's dementia. It is sometimes a temporary condition and sometimes chronic and stable. Research on MCS patients indicates that they are capable of experiencing pain and can have varying and fluctuating levels of awareness and functioning.[6] MCS patients can sometimes minimally communicate through gestures and words. In cases in which the patients themselves did not explicitly document their wishes in advance of losing capacity, U.S. courts have frequently refused to grant surrogates the right to withdraw ANH on the grounds that MCS patients may have an unexpressed interest in continuing to live.[7] The courts have considered less compelling the alternative possibility that MCS patients, because they may experience pain and distress, may have an unexpressed desire to die.[8] MCS patients are unable to direct their own care and treatment in accordance with their preferences and thus may see their legal and moral right to self-determination eroded by paternalistic concerns.

This problem is not unique to MCS patients. Other patients who are conscious but lack decisionmaking capacity are in a similar predicament. This can include persons with dementia, and some individuals with severe cognitive or developmental disabilities. Their surrogates may be legally blocked from deciding to withdraw LST even if the patient is suffering or had informally expressed preferences for withdrawal of treatment. Patients who never expressed preferences, or never could express them, and unrepresented patients who lack effective advocates and surrogates, are in the most precarious and vulnerable position, caught between under- and overprotection of their rights as patients and as persons, and correspondingly, facing the possibility of under- or overtreatment.[9]

In the United Kingdom, by contrast, the Court of Protection has sometimes permitted the withdrawal of ANH from conscious but incapacitated patients. Under the Mental Capacity Act of 2005 (MCA), the court must determine whether an act or decision is in the best interests of the patient by incorporating evidence of the patient's past or current preferences and values alongside other evidence. Advance decisions by patients to refuse treatment are to be followed, but if they concern the withdrawal of LST, they must be specific, in writing, signed, and witnessed. Advance decisions regarding treatment, or treatment refusal, are not applicable if either the treatment or the circumstances of the patient were not specified or the circumstances of the patient were not anticipated at the time of the decision.[10]

In both the United States and the United Kingdom, cases involving patients in the MCS have posed extraordinary challenges with regard to the relevant decisionmaking standard and application of that standard.

Decision making for patients who lack capacity

Patients with disorders of consciousness, including those in the VS/UWS and the MCS, are disabled, dependent, and incapacitated. Decisionmaking on behalf of these patients can be exceedingly difficult, complicated by uncertainty about their sentient capacities and their diagnosis and prognosis.[11] Patients with developmental disabilities who have never had decisional capacity and never could express their preferences are similarly situated with respect to the difficulty of making decisions on their behalf. Some of these patients have family members or surrogates to advocate for their care and protect their interests. However, patients who are disabled, dependent, institutionalized, and incapacitated, and who are unrepresented or have legal guardians whom they do not know and have not chosen themselves, are uniquely and exceptionally vulnerable. They can neither express their own preferences nor protect and advance their own interests. They are dependent on others to be vigilant in protecting their rights and interests. When these patients have lengthy histories of chronic and untreated medical ailments, mental illness, and housing or social instability, they can be additionally vulnerable to serious and incapacitating medical crises and poor health. Moreover, their unstable social circumstances may work against the possibility of having accessible medical records, advance directives, or relationships with persons who could act as informed decisional surrogates.

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These patients can be caught in two quite different situations, depending on the laws in their jurisdiction. Some U.S. statutes are designed to protect these vulnerable patients from undertreatment, from being regarded as "disposable," and thus mandate treatment irrespective of their condition.[12] Some U.S. jurisdictions permit withdrawal of LST when patients have a terminal condition or are diagnosed as "persistently" unconscious or in an end-stage condition. In both types of jurisdictions, patients' preferences, their right to treatment, and their right to participate in treatment decisions may be neglected. The U.K.'s MCA uses a hybrid best interests/precedent autonomy standard intended to protect patients by ensuring that decisions made on their behalf are in their best interests, while in some circumstances explicitly requiring consideration of the patient's own preferences.

Decision making standards

In contrast to the MCA's global application of the hybrid best interests standard, U.S. courts typically follow a traditional legal/ethical hierarchy of decisionmaking for a patient lacking decisional capacity.[13] The requirement to respect and honor the self-determination and preferences of autonomous patients who have decisional capacity is well-established in American law as well as in medical ethics.[14] *Precedent autonomy* prevails when individuals have lost their capacity for autonomous decisionmaking, either temporarily or chronically. It gives legal and ethical force to their prior decisions and choices concerning medical treatment, including refusals of treatment that could result in death.

When the patient's own wishes have not been communicated or are not known, a surrogate or court can attempt to decide on the basis of *substituted judgment*, involving a determination of what the patient would have decided for themselves, had they been capable. The substituted judgment standard, like the precedent autonomy standard, prioritizes patient autonomy, still requiring some knowledge of the patient's preferences, values, or beliefs, and requiring that the surrogate decide "by engaging in some speculation and 'inferring' the patient's wishes from her prior statements and conduct."[15]

In practice, evidence can sometimes be relevant to more than one decisionmaking standard. A patient's statements that they "don't want to be hooked up to machines," for example, may not be precise enough to conclude that the patient had previously expressed a desire to refuse current treatments but may still offer insight into the patient's values, preferences, and beliefs. The difference between precedent autonomy and substituted judgment is a matter of degree.

In the absence of known patient preferences, surrogates, guardians, and courts are left to decide on the basis of the *best interests* of the patient, involving an evaluation of and judgment concerning their current welfare and what would best promote their well-being.[16] Such a judgment requires conjecture when a patient is unable to communicate regarding their *current* subjective state, and when the interests under consideration do not include the patient's own preferences, or even knowledge of their values. Precedent autonomy and substituted judgment ground decision making in the patient's own subjective preferences, values, and beliefs. The best interests standard, grounded legally in the state's *parens patriae* power rather than protection of the patient's right to autonomy, is necessarily less subjective than either of them because information about the patient's preferences and values are lacking. For that reason, in the United States, the traditional best interests standard, which balances the burdens and benefits of treatment for the patient, is typically a last resort when the patient's wishes, values, and beliefs are unknown (see Table 1).

Application of the best interests standard is thought to be more objective, but it often involves a judgment about the patient's current and future welfare as an oblique indicator of their interests. Someone other than the patient must judge, however, because a decisionmaker has concluded that there is insufficient evidence of the patient's own past preferences and values to undergird a decision. For example, most individuals find pain to be subjectively bad and undesirable, with the severity of pain crudely tracking its disvalue and negative impact on overall well-being. Courts have frequently considered the balance of pains and pleasures in evaluating a patient's best interests. Yet, many people live with chronic pain and find value in their lives, all things considered. Some would continue medical treatment, including treatment that prolongs or sustains life, thus prolonging a life lived in pain. Others would not. Without the patient's own preferences and values to consider, evaluating their best interests requires

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Table 1. Surrogate Decision Making Standards

Decision making standard			Recommendation
Precedent autonomy	Respect patient autonomy and preferences. Utilize advance directives, past statements concerning relevantly similar circumstances		Preferential standard for decision making whenever possible
Substituted judgment	Surrogate makes decisions consistent with what the patient would choose for themselves, if they could. Requires knowledge and familiarity with patient to inform inferences from values, beliefs and known preferences of the patient to their present circumstances.		*Holistic substituted judgment* should be more widely used in cases where the patient has not specifically anticipated or addressed their present circumstances, but relevant and appropriate inferences from other statements, preferences, and values are possible by individuals familiar with and knowledgeable about the patient and their present circumstances
Best interests	*Traditional view* (as interpreted by U.S. courts) Considers medical diagnosis, prognosis, and quality of life for patient, including pain, suffering, potential for inhumane treatment. Shortcomings: Abstract. Difficult to avoid imposing social, personal, cultural values on patients.	*Hybrid view* (MCA; United Kingdom) Considers medical diagnosis, prognosis, and quality of life, including calculated balancing of pains/pleasures, value of current/future existence. Considers past statements, preferences, values, beliefs of patient when specific and relevant to present circumstances. Shortcoming: Can paternalistically overrule patient's preferences.	*Limited view* Bests interests standard should only be used to make decisions on behalf of patients when their own views are entirely unknown and unknowable. Use of the standard should be well-justified, and aim for neutrality/agnosticism concerning values (e.g., "sanctity of life")

making an abstract, ostensibly objective judgment about that which is intrinsically subjective. Treatment and nontreatment decisions purporting to be made solely on the basis of a patient's best interests (without consideration of preferences or values) are thus among the most abstract and difficult of all medical decisions.

As Thaddeus Pope points out, while the best interests standard is "seemingly objective," applying it is "necessarily somewhat mediated by the surrogate's own values and attitudes."[17] A best interests standard involves consideration of objective facts through the lens of either the *decisionmaker's* personal values or *socially shared* criteria and values. In both cases, there is the possibility that the patient's own values will not be represented. This is illustrated by cases involving MCS patients in which court decisions frequently leaned heavily on the intrinsic value of preserving life, a value that is not given equal weight by all persons. Perhaps for this reason, some courts in the United States explicitly have recognized the propriety of including evidence about the patient's subjective wishes—similar to the way they inform decisions under the MCA—when balancing factors to determine a patient's best interests.[18]

The MCA requires that best interests assessments include the known preferences of the patient. This, in effect, blurs the lines between the precedent autonomy, substituted judgment, and best interests

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standards as they are traditionally understood. The MCA requires that the patient be permitted to participate in decisions to the extent possible, and that the best interests assessment consider:

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
(b) the beliefs and values that would be likely to influence his decision if he had capacity, and
(c) the other factors that he would be likely to consider if he were able to do so.[19]

John Coggon argues that the conceptual distinction between substituted judgment and best interests thus is blurred in the MCA such that "Depending on how it is cashed out, the patient-centred decision-making standard … for patients who lack but once had relevant capacity could as comfortably be labelled best interests as substituted judgment."[20]

Substituted judgment in cases involving MCS patients: Precedent autonomy in disguise

U.S. courts reviewing surrogate substituted judgment decisions have been loath to grant permission to withdraw LST from MCS patients and other incapacitated but conscious patients, even when credible witnesses attested to the prior, informally expressed wishes and preferences of the patients. They generally have required evidence that the patients, when competent, had expressed their wishes about treatment with a specificity that is practically impossible to satisfy. That is, they treat substituted judgment decisions like precedent autonomy decisions, which effectively rules out the possibility of substituted judgments. Eliminating in practice the possibility of substituted judgments leads to application of the best interests standard, placing a substantial barrier in the way of surrogates trying to act on a patient's own preferences.

In *In re Martin*, a Michigan court refused to permit withdrawal of a feeding tube although the patient, Michael Martin, had, while competent, stated to multiple witnesses that he would not want to be dependent on others or machines, or to exist in a VS.[21] According to his wife, Martin had been "adamant and made it very clear that he did not want to be kept alive" in a coma or a VS, on numerous occasions, in different settings, and "under a variety of circumstances." To uphold refusal of treatment using the substituted judgment standard, the Michigan Supreme Court required that it be "clear that the particular patient would have refused the treatment under the circumstances involved."[22] It ruled that Martin's wife had not presented clear and convincing evidence of his pre-injury statement of a desire to refuse LST under the specific circumstances (i.e., being in an MCS). This was despite testimony from his wife that Martin had said "[p]lease don't ever let me exist that way because those people don't even have their dignity" after watching movies about people "who no longer were mentally competent either due to illness, accident, or old age" and "people who could no longer do anything for themselves, such as persons who lived in a nursing home and could no longer feed or dress themselves and needed to wear diapers or have other measures taken to continue existing."[23]

In *Conservatorship of Wendland*, a California court required that a feeding tube remain in place although the patient, Robert Wendland, had repeatedly pulled it out. Days before the accident that left him in a chronic MCS, Wendland discussed the protracted death of his father-in-law and told his wife "Don't let that happen to me. Just let me go."[24] A judge in Wendland's case ruled that although he had a "strong suspicion" that Wendland would have wanted to die under the circumstances, the evidence of his wishes was not explicit enough to support termination of ANH using a substituted judgment standard.[25] The court sought "more explicit direction," despite testimony from Wendland's daughter that he "would not want to live" if "he could not do all the things that he enjoyed doing, just enjoying the outdoors … feeding himself, talking, communicating."[26] The court required an exact "on-all-fours description" of his current condition to support withdrawal, thus requiring evidence sufficient to support precedent autonomy decisionmaking.

These U.S. court rulings closely resemble a ruling in the United Kingdom that has been widely criticized as incorrectly decided, *W v M*. There, the Court of Protection refused to authorize the withdrawal of ANH from a woman known as "M" whose family had testified that she "many times"

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had stated "that she would not have wanted to remain alive in a completely dependent condition" and in a care home.[27] M experienced pain and discomfort every day, perhaps 25–30% of the time according to her caregivers. The court, as required by the MCA, applied the best interests standard explicitly requiring consideration of evidence more commonly part of a precedent autonomy determination. Thus, similar to *Wendland*, the court applied the following standard:

> that an advance decision must address specifically the circumstances in which it will be binding and is made in the knowledge that it will be decisive if those circumstances arise … [Here,] there is no evidence that M ever specifically considered the question of withdrawal of ANH, or ever considered the question whether she would wish such treatment to be withdrawn if in a minimally conscious state.[28]

The court conjectured that M might value her current life, notwithstanding the numerous prior statements to the contrary reported by her family. Her family members, who undoubtedly knew her better than the court did, conversely had no doubt about those statements' meaning, or how to interpret them in M's circumstances. Even with evidence of the patient's wishes concerning similar (but not identical) circumstances, the court in M's case was reluctant to authorize withdrawal of ANH from an MCS patient absent an exact "on all fours" statement of preferences. This is consistent with the MCA's incorporation of subjective elements within the best interests standard:

An advance decision is not applicable to the treatment in question if:

(a) that treatment is not the treatment specified in the advance decision,
(b) any circumstances specified in the advance decision are absent, or
(c) there are reasonable grounds for believing that circumstances exist which [the patient] did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.[29]

In *Martin*, *Wendland*, and *W v M*, there was sufficient evidence of the patient's preferences, based on their previous, witnessed statements, to support substituted judgment decisions about treatment withdrawal. If, however, substituted judgment is interpreted so that it requires a statement of preferences that specifies the exact circumstances of the patient—which would, in practice, require the patient to have anticipated very many possible circumstances—then the substituted judgment standard is, in effect, a precedent autonomy standard for decisionmaking. That, in fact, is how those courts interpreted it.

A less rigid understanding of the substituted judgment standard is possible. John Phillips and David Wendler argue for an alternative interpretation—the endorsed life approach—that would accommodate and give force to the kinds of inexact statements typically made by patients. In saying "a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms," the MCA appears to endorse such an interpretation.[30] Phillips and Wendler state that "Even patients who never indicated how they wanted to be treated in the event of incapacity likely offered indications of the sort of life they valued for themselves, or the kind of treatment that they regarded as good or bad for them." The "endorsed life" approach "involves basing treatment decisions on the type of life that the patient, in fact, endorsed for themselves. This approach respects patient autonomy by allowing the course of life that the patient endorsed while competent, their values and dreams, to continue to determine the course of their lives, even after they are no longer competent."[31] Indeed, a reasonable interpretation of substituted judgment should permit decisionmaking based on inexact statements that nonetheless express the values and preferences of the patient.[32] Coggon argues that the MCA permits inferences about the patient's preferences and that the court thus erred in *W v M*:

> The law's paradigmatic position asks that we attempt to apply the patient's reflectively endorsed values, whether these are inferred directly by asking for consent (in the case of a patient with capacity) or drawn through inferences given facts that can be determined about a patient's values by other means (in the case of a patient who lacks, but once had, relevant capacity). In either case, of themselves, the patient's values should not themselves be displaced at law.[33]

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By requiring undue and unrealistic precision in patients' prior statements, courts displace patients' values and disempower both patients and surrogates by effectively making substituted judgments impossible.

Substituted judgment requires making inferences from available evidence of patient preferences. Adequate procedures for assessing evidence of preferences must be capable of accurately identifying those preferences but flexible enough to consider various types of evidence and expressions. Allen Buchanan and Dan Brock, for example, recommend assessing the "strength of evidence" in substituted judgment cases such that preferences that are more determinate and repetitive should be given more weight, and the strength of the evidence should be evaluated by considering the number of sources of evidence (e.g., the number of witnesses) and the reliability of the sources. This kind of weighting still risks limiting the possibility of making substituted judgment decisions in many cases, if it hews too closely to the "exact on all fours" standard that demands evidence akin to an exceptionally specific and prescient advance directive.[34]

Where a patient did express preferences, evidence of a conscious, incapacitated patient's previously expressed wishes with respect to *relevant and analogous* (if not identical) factual situations should suffice for application of *substituted judgment* to withhold or withdraw LST. Prior directives "on all fours" with the patient's current condition are both unnecessary and unrealistic, and fail to respect patient preferences and rights.[35] Requiring an exact on all fours directive effectively imposes a precedent autonomy standard, implying that substituted judgment simply cannot be used in MCS cases or in others involving conscious but incapacitated patients. Such a requirement renders almost meaningless the right of self-determination for these patients. In short, as illustrated by *W v M* in the United Kingdom and *Martin* and *Wendland* in the United States, courts have frequently required unduly precise evidence when determining whether LST should be withdrawn from patients in the MCS. It is unrealistic to expect patients in the MCS to have specifically anticipated their future diagnosis and treatments when expressing their wishes. Yet that is what the courts have often required in order to affirm surrogate decisionmakers' decisions about what MCS patients would have wanted. That is not consistent with respecting patient autonomy.

Best interests and patients in the MCS: Consideration of a patient's own preferences and values

As the best interests standard is traditionally understood and employed in the United States in medical and legal contexts, a surrogate decisionmaker is to apply the best interests standard if they lack evidence of a patient's specific wishes or their relevant values, preferences, and beliefs. The focus then shifts from attempting to honor the patient's wishes to attempting to determine what will promote their well-being and their best interests under the circumstances. Yet some U.S. states continue to seek precise statements of patient wishes within best interests analyses.

In *In re Edna MF*, in Wisconsin, the sister of a 71-year-old woman with Alzheimer's dementia, acting as her guardian, sought to withdraw ANH. The only evidence of Edna's prior wishes was a statement from 30 years before, when she said, "I would rather die of cancer than lose my mind."[36] Reviewing the withdrawal decision through a best interests lens, the court turned to a Wisconsin statute that defined "best interests" as requiring patients in the MCS to have been more specific in previously expressing their wishes than patients in the PVS with the same or similar prognoses. The court deemed the evidence insufficient to demonstrate "a clear statement of desire" for withdrawal on the part of the patient.

Complicating factors in Edna MF's case were that the statement she made was fairly specific, referring to a preference for dying of cancer over losing her mind, and that the conversation with her sister occurred three decades earlier. People change over time and so too can their values, beliefs, and preferences. We might wonder, then, how much weight to give to the musings of a 40-year-old woman when she is 71 and incapacitated by dementia. One could reasonably infer that a preference for a potentially painful and prolonged death over "losing one's mind" is a relevant and informative statement of values and close enough to guide decisionmaking in the absence of more explicit statements. Yet the controlling statute required a "clear statement" of her "desires in these circumstances" instead.

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That statute defined "best interests" as requiring patients in the MCS to have been more specific in previously expressing their wishes than PVS patients with the same or similar prognoses. The statute provided it could only be in the best interests of a patient to withdraw ANH if that patient was in a "persistent vegetative state" or "if her guardian can demonstrate by a preponderance of the evidence a clear statement of [her] desires in these circumstances."[37]

In other words, the governing statute effectively declares that it *can* be in the best interests of someone in a "persistent vegetative state" to have LST withdrawn, but it is *not* in the best interests of a patient to withdraw LST if they are conscious, unless they have "clearly" indicated that they desire withdrawal of LST. This interpretation of best interests implies that nothing can be in a conscious patient's best interests unless it honors wishes that are known (where being known requires that they were expressed in the right way).

In *Wendland*, the court proceeded to consider whether withdrawal of ANH was in the best interests of Robert Wendland once it had ruled that the conservator seeking withdrawal had not proven that he had expressed his desire to refuse that treatment explicitly enough. There, the applicable statute required that the conservator consider "the conservatee's personal values to the extent known to the conservator" as part of a best interests determination. The court ruled that the conservator had produced "legally insufficient evidence to the effect that [Robert Wendland] had wished to die."[38] The result, again, conflates best interests and precedent autonomy as decision making standards, effectively making it impossible to use the best interests standard for deciding on behalf of many conscious patients who previously had decisional capacity.

In the United Kingdom, a few years after *W v M*, in the case *M v N*, also involving a patient in the MCS, the Court of Protection ruled in favor of withdrawing tube feeding, noting that doing so was in the patient's best interests.[39] N had multiple sclerosis, and her condition had resulted in a steady decline of her physical and cognitive capacities over several decades. When her family petitioned the court to allow withdrawal of tube feeding, she lacked capacity and was thought to be in the MCS. She had in the past indicated to her family that she would not want to live if severely disabled. After visiting her parents, who lived in a care home and had dementia, she told her daughter "if I ever get like that shoot me!"[40] Following her MS diagnosis, she told her son she wanted to die. Her family maintained that these and other comments clearly reflected what she would want. Incorporating evidence relevant to both substituted judgment and best interests determinations, the Court was satisfied that N's views were accurately conveyed by her family that "respect for Mrs. N's dignity and human freedom overwhelms further prolongation of life"[41] and that it was in N's best interests to be transferred to hospice and for ANH to be withdrawn.

The courts in both *M v N* and *W v M* used the "balance sheet" method, described in the MCA Code of Practice,[42] to calculate the patient's best interests, but with very different results, perhaps because the court in *M v N* gave more weight to the family's testimony about N's personality, preferences, and values concerning her illness and did not require an exact statement of her preferences concerning ANH. The decision in *M v N* was thus less a best interests decision than a substituted judgment decision.

The U.K. Supreme Court has noted that the "best interests test should also contain a strong element of substituted judgment" because "the preferences of the person concerned are an important component in deciding where his best interests lie." In *Aintree v James*, the patient, David James, was in a MCS after a difficult hospital course that included a stroke and lengthy cardiac arrest that resulted in severe neurological injury. As the court noted, "Daily care tasks could cause discomfort, pain and suffering. Overall, his prospects of leaving the critical care unit, let alone the hospital, were extremely low."[43] Mr. James, aged 68, was a former professional musician with a large extended family who visited him regularly in the hospital. The hospital sought permission from the Court of Protection to withhold certain intravenous medications, hemodialysis, and cardiopulmonary resuscitation, arguing that it would not be in the patient's best interests to "face a prolonged, excruciating and undignified death."[44] His family disagreed and stated that he greatly enjoyed seeing his family and friends and that he would want to continue life-prolonging treatment. James died of cardiac arrest during the appeal of his case, but the Supreme Court rendered judgment anyway. Regarding how a best interests determination is to be made, the court describes it in expansive terms:

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> [I]n considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.[45]

The court also discusses the best interests test and how it is meant to incorporate the patient's own values:

> The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless." But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.[46]

The Supreme Court in *Aintree* ultimately upheld a Court of Appeal decision that it was in James' best interests to withhold invasive treatments and resuscitation, despite his family's protests, because his condition had by then significantly deteriorated. Interestingly, the Supreme Court decided that the Court of Appeal had "reached the right result but for the wrong reasons," by not basing their decision on the clinical evidence of James' poor prognosis and quality of life.[47]

It is consistent with respecting autonomy and avoiding paternalism to act on a patient's autonomous wishes and preferences because autonomous individuals care that their values, beliefs, and preferences guide their medical treatment. But the courts, as in *Wendland*, *Edna MF*, and *W v M*, run aground when they limit what can possibly be in a conscious patient's best interests to only that which they have themselves unequivocally stated. Doing so implies that nothing can be in the best interests of a patient who never did or never could express their preferences about medical treatment. It defies common sense to say that someone's best interests are contingent on the specific form and content of their prior expressions. The relevant considerations are whether those prior wishes are known, can be known, or can be interpreted or inferred by those who understood the patient. If we grant that it *can* be in an individual's best interests to withdraw LST, resulting in their death, then that possibility exists even if the patient never did or could communicate their preferences concerning LST. Otherwise, we would have no path to making decisions for those who were never autonomous and decisionally capable or who were never known to express their preferences to anyone who could report on them.

In cases involving MCS patients, we frequently see both the best interests standard and the substituted judgment standard conflated with precedent autonomy, leaving most patients, who do not make exact "on all fours" statements regarding their preferences, with a diminished or silenced voice in decisions concerning their treatment. Giving a patient's past statements no weight, and treating them as a blank slate upon which someone else's (or some society's or some court's) values and preferences can be written, is objectionably paternalistic, and an outcome to be avoided. Acknowledging the importance of and respecting an adult patient's right of self-determination necessitates taking more seriously a patient's expressions of their values and preferences, however inexactly they were expressed. To require exact expression of their values or interests to apply the best interests standard effectively eliminates the possibility of withdrawal of LST, depriving those patients of an option other patients have.

The hybrid best interests standard as described in the MCA and some U.S. courts (at least in cases involving conscious patients) is more accurately a proscribed precedent autonomy standard in that it is meant to take into account the patient's expressed preferences and values in arriving at a determination

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of what is in the patient's best interests. However, to decide on behalf of a patient that what is in their best interests may diverge from their preferences and values (as in *Aintree*) is paternalistic.[48] We argue that the best interests standard avoids objectionable paternalism and is only appropriate when patients have not previously expressed their values or preferences, or when there is no evidence of such expression.

Applying a best interests standard in adult MCS cases

What is in someone's best interests is profoundly subjective and individual, and stubbornly resistant to objective, third-party assessment, no matter how well-meaning and careful. That is a significant reason why in the United States the best interests standard is considered the last resort for legal and ethical decision making for incapacitated patients. Coggon maintains that per the MCA, "the objectivity that the courts should be aiming at obtains in making a finding of fact about what the patient's relevant, endorsed, subjective values are."[49] In other words, any objectivity to be achieved by the hybrid best interests standard described by the MCA is limited to an objective finding about the patient's subjective preferences. In the specific context of adult MCS patients who previously had decisional capacity, we argue, *contra* the MCA, that the best interests standard should be employed only in the limited category of cases in which the patient's prior values and preferences are both *entirely unknown and unknowable* and cannot reasonably be inferred or interpreted from relevant and "close enough" expressions of preferences and values made when the patient had capacity. The need to use the best interests standard rather than precedent autonomy or substituted judgment standards should be well-justified by the absence of evidence of the patient's preferences.[50]

It would be true of relatively few adult patients, however, that their values and preferences are entirely unknown and unknowable. The values and preferences of adults who did not make explicit, detailed declarations can usually be reasonably inferred by individuals who knew them (including friends and family members) from *relevant* statements. Both Michael Martin and Robert Wendland made such statements, as did M and N, even if none of them explicitly discussed the MCS. The substituted judgment standard could and should have been used to allow their surrogates to request withdrawal of treatment; in *Aintree*, the family's testimony about Mr James' values did not support the decision of the courts to allow unilateral withholding of treatment.

Only once it is evident that a patient's preferences and values about treatment are unknown and unknowable, so that a best interests determination is justified and appropriate, can the question of identifying a patient's best interests become relevant. Below we discuss *In re Young*, a U.S. case decided in Florida, as an example of an appropriate and justified use of the best interests standard by a court.

In re Young

In May 2020, a public guardian petitioned a circuit court in Florida to approve the withdrawal of ANH from Lizbeth Young, a 70-year-old woman with a lengthy history of mental illness who was hospitalized with an infection.[51] The court decision contains descriptions of Young making guttural sounds and staring fixedly ahead during the judge's visit. She was observed by the court to be unresponsive to sound and touch. She opened her eyes and made sounds "not driven by cognition."[52] Young's doctors testified that she had "almost no functional cognition" but might be able to feel pain and discomfort, a description consistent with the diagnosis of MCS. Her doctors had also testified that she satisfied one of Florida's other statutory triggering conditions by existing in a terminal condition, specifically advanced dementia.[53] Florida law, like laws in many other states in the United States, permits a healthcare surrogate to consent to withdrawal of LST from an incompetent patient when it can be determined by the patient's primary physician and a consulting physician that

> (a) The patient does not have a reasonable medical probability of recovering capacity so that the right could be exercised by the patient … [and] (b) The patient has an end-stage condition, the patient is in a persistent vegetative state, or the patient's physical condition is terminal.[54]

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Testimony from Young's doctors confirmed that both requirements were met. Her advanced dementia constituted a terminal condition that resulted in irreversible incapacity, and the possibility of her recovery was judged to be "slim to none."[55]

Lizbeth Young had a complicated and difficult life. She sustained a brain injury in childhood and had a history of mental illness beginning in early adulthood. She was estranged from her family, including a sister who had last seen her 4 years prior to the legal case, and adult children who had not spoken to her in decades. She spent several years in shelters for unhoused persons. A public guardian was appointed for Young at her sister's request in January 2015, at which time Young was delusional and found to be decisionally incapacitated. She was hospitalized with an infection and hypotension in April 2020. During her lengthy hospital stay, she required a nasogastric (NG) feeding tube due to aspiration pneumonia.

Young's guardian petitioned to have ANH withdrawn and for Young to be transferred to hospice for end-of-life care. Young was suffering from several severe, harmful effects of NG tube feeding and prolonged immobilization, including infections, malnutrition, deep tissue injuries, fluid accumulation that seeped through her pores, skin ulcers covering much of her body, swelling of her extremities, and gastrointestinal bleeding. Judge David Frank described her appearance as "gruesome."[56] Her primary physician described continuation of treatment as "almost cruel." Young's fragile health made her a poor candidate for surgical placement of a percutaneous endoscopic gastrostomy tube, a permanent alternative to the temporary NG tube.

Young had no known preferences concerning end-of-life care, and no one could be identified who knew or understood her well enough to be able to judge what she might have wanted. Lizbeth Young's lengthy cognitive decline and history of stroke; mental illness beginning in early adulthood; delusions; dementia; estrangement from her family; and the appointment of a public guardian for her after she had already lost decisional capacity, all made it "realistically impossible to determine the incompetent patient's wishes," so neither precedent autonomy nor substituted judgment were available as decision-making standards.[57]

The *Young* case represents one clear example in which withdrawal of LST was in a patient's best interests. Withdrawal of LST can be in a patient's best interests when there is evidence of iatrogenic suffering that cannot be relieved without further diminishing the patient's capacities (e.g., in Young's case, by sedating her into unconsciousness to ensure she experienced no pain or distress).[58]

Some have argued that life should never be cut short even if harm might result from treatment. Disabled activists, for example, have sometimes endorsed a "sanctity of life" viewpoint out of well-founded concerns that biased and ableist consideration of the quality of a disabled patient's life will inevitably lead to devaluation of their lives.[59] Evidence from centuries of discrimination against disabled persons supports the need for caution in any circumstance in which a person's life might be undervalued or devalued because of disability, resulting in undertreatment or unwanted and avoidable death or harm. But it does not support the imposition of unrealistic and unattainable standards for end-of-life decision making that would also catch, and might harm, persons who identify as disabled. We should not endorse the imposition of values upon *any* individual that they do not themselves endorse. The primacy of patient values, preferences, and self-determination is always paramount.

For a patient like Lizbeth Young, whose preferences are unknown and unknowable, and whose capacities cannot be restored, withdrawal of treatment emphasizes the prevention or amelioration of iatrogenic harm, and specifically suffering that cannot be relieved without further diminishing the patient's capacities. In *Aintree*, the courts might have been moved by similar concerns. As the Supreme Court noted, "the prospect of his regaining even his previous quality of life appeared very slim."[60] But quality of life is subjective, and given that James had caring surrogates who could speak on his behalf, it was inappropriate and paternalistic for the court to rule in favor of withholding potentially effective treatments.

The right decision … but for the right reasons?

The iatrogenic harm and suffering Lizbeth Young experienced as a result of tube feeding, for which there were no medically feasible alternatives, made her situation one in which it was reasonable to conclude

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that it could not be in her best interests to continue LST. The judge found that the evidence clearly and convincingly demonstrated that it was in her best interests for the guardian to consent to removal of the NG tube, arrange for hospice care, and consent to a Do Not Resuscitate order.[61] The likelihood that Young experienced irremediable pain and suffering as a result of continuing treatment is both ethically and legally crucial to the conclusion that her best interests were not served by ANH. *In re Young* illustrates the predicament in which surrogates, medical professionals, and courts can find themselves if they are precluded from determining that a conscious but severely cognitively impaired patient's best interests would be served by foregoing LST. In Young's case, we argue that the conditions were satisfied for applying a best interests standard: the patient's preferences were entirely unknown and unknowable. There was also clear evidence of iatrogenic harm from continued ANH and that harm could not be remedied without further diminishing her capacities. This justified the decision to withdraw ANH.

Viewed alongside other legal decisions involving MCS patients, the *Young* decision was an exception to the general rule. The remaining question is whether the rule is generally right. We have argued that it is not. An excessively strict standard for accepting evidence of treatment preferences for patients who are conscious but incapacitated, one that requires explicit expression of preferences that match the patient's current (and previously unpredictable, perhaps even inconceivable) circumstances, cannot be met in most cases. It is what the MCA demands, in word if not always in practice. It requires an idealized version of decision making for decidedly nonideal circumstances. It flattens both substituted judgment and best interests decision making into precedent autonomy. It renders surrogates functionally impotent to make the kinds of decisions they are meant to consider and make. It can impose unwanted and unvalued harm and suffering on patients and retrospectively violates their autonomy by imposing someone else's values on them. Laws that limit permissible surrogate decisions to withdraw LST when patients are conscious risk burdening patients with unwanted treatment at precisely the moment when they would not want to be so burdened, and when they are powerless to enact their own will. Laws that allow judges to substitute their own judgments about what is in a patient's best interests similarly invite trodding on patient self-determination.

Irresolvable tensions

When a formerly autonomous adult patient lacks decisional capacity and their preferences are unknown and unknowable, the tension between protecting the right to die or refuse treatment and the right to life is irresolvable, because the patient cannot themselves resolve it. The moral and prudential values that could tip the balance may similarly be unknowable. For these reasons, preferred surrogate decisionmakers for those who have not appointed them are usually those most likely to share values and beliefs with the patient, and most likely to be motivated to do what will benefit the patient by satisfying their subjective interests. For unrepresented patients like Young, public guardians and courts become ersatz surrogates but without the benefit of knowing the patient. On what, then, can their judgments about the patient's best interests be based?

There is no objective medical, ethical, or legal standard for what is in an individual's best interests, particularly when the question is momentous and concerns whether it is better to live or die. In a pluralistic society, there are diverse spiritual, ethical, and deeply personal views on the value of life and death, and on what makes a life good, flourishing, and worth living. There is no consensus view, no common belief to which all persons subscribe, and thus no standard against which a particular life might be judged. Hence, social and legal policies concerning permissible withdrawals of LST from incapacitated patients based on the best interests standard are frequently restricted to those patients who are terminally ill (i.e., those for whom there is no viable alternative to death), and those who are chronically unconscious, for whom, it is commonly thought, continued existence can have no subjective value. This notably excludes patients who are incapacitated but conscious and not terminally ill, such as those in liminal states like the MCS, some of whom may suffer considerable and unwanted burdens from continued treatment.[62] Equally problematic are "objective" best interests judgments that override patient preferences for continued treatment.

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One factor that weighs against treatment is that the patient did not choose it. Treating without consent risks violating patient autonomy and is justified in limited (and time-limited) circumstances, including when medical treatment is urgently needed to save the patient's life or prevent grave, permanent harm, and when there is the potential to restore the patient's autonomy and decisional capacity, enabling them to later choose for themselves. For some MCS patients, and other patients with incapacitating illnesses or injuries, LST may support them in the short run with the goal of restoring their autonomy and decisional capacity. Those are circumstances in which it is reasonable to conclude that the possible harms of short-term treatment (including iatrogenic harms, and the moral harm of violating autonomy) are outweighed by the potential benefits. That is, when the patient's preferences are unknown and unknowable, it is reasonable to treat them so that they can later make their preferences known and can direct their own treatment.

A reasonable question is whether simply prolonging life is an important benefit of treatment, and how much weight it should have in the balancing of harms and benefits. People disagree about the benefit of extending their own lives and much depends on the subjective preferences and values of the patient. Foregrounding patient values and preferences is of the utmost importance, but where U.S. courts have previously ruled against withdrawing LST from MCS patients, they have implicitly upheld an *intrinsic value of life* position by demanding excessively specific expressions of preferences, rather than expressions like "I don't want to live like that" or "let me die" that match the way people speak about their values and preferences in the real world. The court in *W v M* similarly erred. At the other extreme is having excessively lax standards, such as the presumption that life never has value for disabled patients or those in a VS/UWS. To say that patient values and preferences are *unknown and unknowable* is to say that they cannot be reasonably interpreted or inferred from the patient's past expressions or behaviors. In many cases they can be, and to ignore the patient's voice is a kind of retrospective violation of autonomy.

Regarding cases of adult patients who have lost their decisional capacity, and whose subjective preferences and values are unknown and truly unknowable, we have no more reason to think they would value continuing life and treatment than to think they would not—and no presumptions can be made that don't risk harming them by violating their preferences. But for those situations, the balance can be rightly tipped by other considerations, such as the presence of irremediable iatrogenic harms and suffering. In Young's case, the evidence of such harm was written on her deteriorating body and was rightly considered in a best interests judgment. But the question in Young's case was not whether *life* should be prolonged, for that is unknowable absent understanding of the patient's preferences and values. The right question to ask in such cases is whether *specific* treatments should be continued, and whether they do more harm than good. For some patients, it will be less obvious that continued treatment is harmful, but it remains necessary to consider whether treatment is in the patient's best interests, whether it will restore lost capacities, and whether it on balance benefits the patient, without imposing someone else's values on the patient. The best interests standard is appropriately used to answer the question *Should this/these medical treatment(s) be continued?* when the patient cannot provide an answer.[63] The black box of the patient's preferences and values should not be filled by others.[64]

Conclusion

We have argued for a limited best interests standard, as a legal and ethical standard for decision making on behalf of adult MCS patients and other conscious, incapacitated patients who previously had decisional capacity. It is appropriately used only in the limited circumstances in which the patient's preferences regarding treatment are unknown and unknowable. Whenever possible, it is appropriate to consider the patient's own values and preferences in decision making, thus balancing protection of patient autonomy with exercise of the state's *parens patriae* power (see Table 1). The MCA, in blending best interests and precedent autonomy, permits decisions in which the patient's preferences and values can be overridden by "best interests" considerations that can impose someone else's values on the patient in ways that are objectionably paternalistic.

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One circumstance in which withdrawing LST would be in the best interests of a patient is when treatment causes iatrogenic harm and suffering that cannot be relieved without further diminishing the patient's capacities. We think the best interests standard was appropriately applied in *In re Young* because it met the criteria we have laid out: The patient's preferences were unknown and unknowable. The standard was appropriately applied to the specific treatment decision as well, for LST in Young's case caused iatrogenic suffering that could not be relieved without further diminishing her capacities. For other adult patients, like those in the MCS who previously had decisional capacity, but whose stated preferences did not involve an exact "on all fours" description of their current condition, the law should respect precedent autonomy exercised through surrogates by applying realistic and practical evidentiary standards for holistic, all things considered substituted judgment decisions to honor the values and preferences of the patient.

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Competing interest. The authors declare no potential conflicts of interest.

Notes

1. In re Quinlan. A 2d: NJ: Supreme Court, 1976:647; Nancy Beth Cruzan, by her Parents and Co-Guardians, Lester L. Cruzan, et ux., *Petitioners v. Director*, Missouri Department of Health, et al. 497, 1990.
2. Giacino JT, Ashwal S, Childs N, et al. The minimally conscious state: Definition and diagnostic criteria. *Neurology* 2002;58(3):349–53. doi: 10.1212/wnl.58.3.349; Bruno MA, Vanhaudenhuyse A, Thibaut A, Moonen G, Laureys S. From unresponsive wakefulness to minimally conscious PLUS and functional locked-in syndromes: Recent advances in our understanding of disorders of consciousness. *Journal of Neurology* 2011; **258**:1373–84.
3. Johnson LSM, Cerminara KL. All things considered: Surrogate decision-making on behalf of patients in the minimally conscious state. *Clinical Ethics* 2020;**15**(3); Meisel A, Cerminara KL, Pope TM. The right to die: The law of end-of-life decisionmaking: Aspen Publishers Online 2004; Cerminara KL. Cruzan's legacy in autonomy. *SMU Law Review* 2020;**73**(1):27–46. A few states include "end-stage condition" as a possible triggering condition for withdrawal of LST. Florida, for example, has done so and has defined the term as "an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective" (Fla. Stat. § 765.101(4) (2022)). It is possible, that a patient in an end-stage condition would be minimally conscious, just as it is possible that a patient in a terminal condition would be minimally conscious.
4. Although VS/UWS patients are frequently considered to be unconscious, consciousness in the clinical sense is divided into two components: wakefulness/arousal, and awareness. By definition VS/UWS patients have states of sleep/arousal without awareness of self or the external world. MCS patients demonstrate inconsistent but reproducible evidence of awareness, often fluctuating.
5. See note 2, Giacino et al. 2002.
6. Boly M, Faymonville M-E, Schnakers C, et al. Perception of pain in the minimally conscious state with PET activation: An observational study. *The Lancet Neurology* 2008;**7**(11):1013–20; See note 2, Bruno et al. 2011.
7. Conservatorship of Wendland. P 3d: Cal: Supreme Court, 02001:151; In re Clark: N.J. Super., 1986.
8. Johnson LSM. The right to die in the minimally conscious state. *Journal of Medical Ethics* 2011;**37**(3):175–78; In re Christopher. 675 NYS2d 807: Sup. Ct., 1998.
9. See note 8, Johnson 2011.
10. Mental Capacity Act 2005 (c. 9), https://www.legislation.gov.uk/ukpga/2005/9 (accessed 17 December 2024), Section 25.

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11. Buchanan AE and Brock DW. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge University Press; 1990.
12. Sequeira ALS, Lewis A. Ethical and legal considerations in the management of an unbefriended patient in a vegetative state. *Neurocritical Care* 2017;**27**(2):173–79. doi: 10.1007/s12028-017-0405-8.
13. Pope TM. Legal fundamentals of surrogate decision making. *Chest* 2012;**141**(4):1074–81.
14. *Schloendorff v. New York Hospital* – Basic right to consent to medical care: Court of Appeals of New York, 1914.
15. See note 13, Pope 2012, at 1077.
16. See note 13, Pope 2012. Florida's law states: "if there is no indication of what the patient would have chosen the proxy may consider the patient's best interests in deciding that proposed treatments are to be withheld or that treatments currently in effect are to be withdrawn" (Fla. Stat. Ann. § 765.401(2)).
17. See note 13, Pope 2012, at 1078.
18. For example, In re Conroy (NJ S. Ct.) recognized the existence of what it called a "pure-objective" test and a "limited-objective" test incorporating both evidence of patient wishes (but not enough to support substituted judgment) and objective considerations like likelihood of survival.
19. See note 10, Mental Capacity Act 2005, at Section 4.
20. Coggon J. Mental capacity law, autonomy, and best interests: an argument for conceptual and practical clarity in the Court of Protection. *Medical Law Review* 2016; **24**(3): 396–414, 411–2.
21. In re Martin. Mich: Mich: Supreme Court, 1995:204.
22. See note 21, In re Martin 1995.
23. See note 21, In re Martin 1995.
24. See note 7, Wendland 2001.
25. Eisenberg JB, Kelso JC. The Robert Wendland case. *Western Journal of Medicine* 2002;**176**(2):124–24.
26. See note 7, Wendland 2001.
27. Baker J. *W v M* & *Ors*: Royal Courts of Justice, 2011.
28. See note 28, *W v M* 2011. *W v M* is an anomaly in the United Kingdom. Subsequently, the U.K. courts, unlike U.S. courts, have generally approved requests to withdraw treatment from both VS/UWS and MCS patients using the best interests standard outlined in the Mental Capacity Act of 2005.
29. See note 10, Mental Capacity Act 2005, at Section 25.
30. See note 10, Mental Capacity Act 2005, at Section 24.
31. Phillips J, Wendler D. Clarifying substituted judgement: the endorsed life approach. *Journal of Medical Ethics* 2015;**41**(9):723–30, 725.
32. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine* 2006;**166**(5):493–97; Kelly B, Rid A, Wendler D. Systematic review: Individuals' goals for surrogate decision-making. *Journal of the American Geriatrics Society* 2012;**60**(5):884–95. While surrogates do not always accurately predict a patient's treatment preferences, surrogates who know the patient well are better suited than courts to understand and interpret the patient's values. Moreover, patients prefer that their families make decisions on their behalf.
33. See note 20, Coggon, at 404.
34. See note 11, Buchanan and Brock 1990, at 120–121.
35. See note 3, Johnson and Cerminara 2020.
36. In re Edna MF. NW 2d, 1997:485.
37. See note 36, In re Edna MF.
38. The court also rejected the conservator's argument to the effect that her judgment of the patient's quality of life should suffice, without further proof, to support a decision to withdraw LST.
39. M v N [2015] EWCOP 76 (Fam).
40. See note 39, MvN, at 55.
41. See note 39, MvN, at 79.

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42. Mental Capacity Act 2005 Code of Practice 2007 https://assets.publishing.service.gov.uk/media/5f6cc6138fa8f541f6763295/Mental-capacity-act-code-of-practice.pdf (accessed 17 December 2024).
43. *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, p3
44. See note 43, Aintree 2013, at 6.
45. See note 43, Aintree 2013, at 16.
46. See note 43, Aintree 2013, at 18.
47. See note 43, Aintree 2013, at 19.
48. There are, of course, exceptions. Patients cannot demand ineffective or unproven treatments the use of which diverges from established medical practice. Patients or their surrogates cannot, similarly, demand that CPR continue for hours, or that physiologically futile treatments be administered. It might nonetheless be in a patient's interests, all things considered, to attempt CPR, or antibiotics, or other treatments because "doing everything possible" is consistent with the patient's wishes or values, or might buy them some amount of extra time. What is in a patient's best interests extends in scope beyond their medical interests.
49. See note 20, Coggon, at 414.
50. As noted, the understanding of "best interests" in the MCA incorporates both precedent autonomy and substituted judgment. While a person's best interests surely include their own preferences and values, we maintain that third-party determinations about someone's best interests should not override that person's own preferences and values.
51. In re Young: Fla. Cir. Ct. Liberty County, 2020. Lizbeth Young died on July 9, 2020. All information herein about her and the legal case is in the public record and is particularly taken from the court decision and her published obituary.
52. See note 51, In re Young 2020.
53. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *New England Journal of Medicine* 2009;**361**(16):1529–38; 85 Opinions of the Attorney General, 2000. There are several complications common among dementia patients near the end of life, including recurring pneumonia and infections, and eating/swallowing dysfunction (including aspiration pneumonia). Survival is poor after the onset of these complications, and approximately half of dementia patients with these complications die within 6 months. As noted previously, Young's dementia could possibly have been considered an end-stage condition, although neither the parties nor the court seem to have raised that possibility.
54. FLA. STAT. § 765.305(2)(a), 2022.
55. See notes 3, Meisel et al. 2004 and 53 In re Young.
56. See note 51, In re Young.
57. See note 51 In re Young
58. A New York trial court permitted refusal of a PEG tube and transfer to hospice for A.M., a 92-year-old nursing home resident with dementia and terminal cancer. A.M.'s dementia resulted in "impaired judgment and other cognitive dysfunction." Like Young, A.M. was conscious, and his preferences and values were unknown and unknowable. Withdrawal of tube feeding was permitted under the NY Family Health Care Decisions Act, which permits withdrawal or withholding of treatments that involve "such pain, suffering, or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition" (*In re Northern Nursing Home* 2011).
59. ADA Watch, ADAPT, AIMM, et al. Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues, Say National Disability Organizations. *Ragged Edge Magazine*, 2003; Rahdert GK, Lapertosa M, Walden KM, Kaliski A. Brief of Amici Curiae not Dead Yet et al., Jeb Bush V. Michael Schiavo. *Issues in law & medicine* 2004;**20**(2):171; Johnson LSM. *The Ethics of Uncertainty: Entangled Ethical and Epistemic Risks in Disorders of Consciousness*. Oxford: Oxford University Press 2022, 107–10, 234–46; Reynolds JM, Peña-Guzmán D. The harm of ableism: Medical error and epistemic injustice. In *Ethics and Error in Medicine*. New York: Routledge 2019, at 167–99; Janz HL. Ableism: the undiagnosed malady afflicting medicine. CMAJ. 2019; **191**(17):E478–9.

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60. See note 43, *Aintree* 2013, at 18

61. See note 3, Meisel et al. 2004. Legally speaking, clear and convincing evidence is evidence that "produces in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established." Adopted only in cases involving particularly important personal interests, the clear and convincing evidentiary standard precludes a decision to withdraw LST if the evidence is equivocal. Doubts can exist, as the existence of contradictory evidence does not preclude a conclusion that withdrawal of LST is appropriate. That conclusion, however, must be capable of being reached with confidence rather than hesitantly.

62. See note 7, Wendland 2001.

63. That is precisely the question the *Aintree* court attempted to answer. Where that court erred was in discounting the patient's preferences in deciding that continued treatment was not in his best interests.

64. It is worth noting that sometimes, a harmful treatment might be replaced by one that is less harmful or burdensome for the patient. In Young's case, that was not possible. One of the benefits of decision making that focuses on treatments rather than philosophical and value-laden questions about the value of life is that they are less prone to involve imposing unshared values on the patient.

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