

A Legal and Ethical Analysis of the Effects of Triggering Conditions on Surrogate Decision-Making in End-of-Life Care in the US

J. Clint Parker¹ · Daniel S. Goldberg¹

Published online: 18 June 2015
© Springer Science+Business Media Dordrecht 2015

Abstract The central claim of this paper is that American states' use of so-called "triggering conditions" to regulate surrogate decision-making authority in end-of-life care leaves unresolved a number of important ethical and legal considerations regarding the scope of that authority. The paper frames the issue with a case set in a jurisdiction in which surrogate authority to withdraw life-sustaining treatment is triggered by two specific clinical conditions. The case presents a quandary insofar as the clinical facts do not satisfy the triggering conditions, and yet both the appropriate surrogates and the care team agree that withdrawal of life-sustaining treatment is in the best interest of the patient. The paper surveys applicable law across the 50 states and weighs the arguments for and against the inclusion of such triggering conditions in relevant legal regimes. The paper concludes by assessing the various legal and policy options states have for regulating surrogate decision-making authority in light of the moral considerations (including epistemic difficulties), and notes the possibility for conflict within ethics teams arising from the potential tension between prudence, risk-aversion, and moral obligation.

Keywords Triggering conditions · End-of-life care · Surrogate decision-making · Obligation · Safe harbors

✉ Daniel S. Goldberg
goldbergd@ecu.edu
J. Clint Parker
parkerjo@ecu.edu

¹ The Brody School of Medicine, East Carolina University, 600 Moye Blvd, MS 641, Greenville, NC 27834, USA

1 Introduction

With the advent of modern medical technology, it has become possible for us to sustain biological existence even in the context of severe neurological disability. Such capabilities raise profound philosophical questions about the nature of death, the meaning of life, and the proper scope of human freedom to make decisions to discontinue medical treatments that sustain biological existence but do not restore the capabilities that many believe make life meaningful.

In response to the profoundly difficult questions raised by modern life-sustaining treatments (LST), state and federal governments have attempted to balance two important goals: protecting the lives of innocent citizens from premature and unwanted death and respecting the rights of citizens to determine what happens to their own bodies. Courts have given guidance in a number of paradigm cases that have attempted to strike a reasonable balance between these competing concerns (Meisel et al. 2013; Winslade and Goldberg 2007). Legislatures have in turn passed laws that describe legally sanctioned procedures for patients, surrogates, and health care providers to withdraw LST.

Generally, legislatures have given competent patients broad discretion to refuse any type of medical treatment, whether life-sustaining or not. However, with respect to surrogates making decisions for others, many legislatures require “triggers” or necessary conditions that must be met prior to withdrawal of LST.¹ In contrast, the ethical paradigms promoted by medical and bioethics communities have focused on identifying the appropriate surrogate decision-maker and the appropriate decision making-paradigm—the who and how of surrogate decision-making (Buchanan and Brock 1989).

Sometimes, however, an appropriate surrogate using an appropriate decision-making paradigm in conjunction with a medical team who is in agreement may decide that withdrawal of LST is morally appropriate even if a state-imposed triggering condition is not met. Such situations raise the following dilemma: Should physicians and health care institutions respect the decisions of appropriate surrogates to withdraw LST from their loved ones when the surrogate has used ethically appropriate decision-making procedures even if legal triggering conditions have not been met? Or, should physicians and institutions refuse to honor such requests in deference to the legislatures’ specifications regarding the precedent conditions that must be satisfied before surrogates are authorized to withdraw LST?

In this paper, we will first present a case that presents a conflict between surrogate decision-makers’ decision to withdraw LST from their neurologically-devastated child and legislatively imposed triggering conditions for withdrawal of LST. This case occurs in North Carolina where the two pertinent triggering conditions for withdrawal of LST in this case include (1) that the patient “has an incurable or irreversible condition that will result in the person’s death within a

¹ One might ask, “Necessary for what?” One view is that these conditions help demarcate a legal safe-harbor that immunizes providers from criminal or civil prosecution. Another view, however, is that these conditions demarcate a line between legal and illegal activities. We will discuss this question in a later section.

relatively short period of time” or (2) that the patient “is unconscious and, to a high degree of medical certainty, will never regain consciousness” (North Carolina. Gen. Stat. § 90–322 2012). In Sect. 2, we will discuss how other states use triggering conditions similar to those in North Carolina. We will discuss in Sect. 3 whether these triggering conditions simply create a “legal safe harbor” for removal of LST or whether they demarcate a clear line between legal and illegal removal of LST. In Sect. 4, we will discuss arguments that support the use of legal triggering conditions for the withdrawal of LST. We will then weigh arguments in Sect. 5 for eliminating triggering conditions from statutory language. We will also discuss conflicts that can arise between a risk management perspective and a bioethics perspective when approaching this issue. Finally, in Sect. 6, we return to North Carolina and conclude with two points. First, we note that triggering conditions are one option among several public policy alternatives available to states for the regulation of withdrawal of LST. Second, we argue that the current state of affairs in which some states have adopted triggering conditions and some states have not, both reflects, in a general sense, the underlying values of the state and represents an opportunity for states to learn by examining the success or failures of other public policy models.

1.1 Case Presentation

What follows is a case set in North Carolina:

Mary is bright and playful 5-year-old girl who has just started kindergarten at a local public school. She loves math and playing with her Barbie dolls. Her parents are currently divorced. Her mother is disabled due to chronic back pain, lives on a fixed income and has two other small children at home. Her father is currently unemployed and has a history of addiction problems. On a Saturday night after going out to eat for cheeseburgers (Mary’s favorite) with her mother, Mary’s mother runs a red light and is hit by an oncoming car. Mary’s mother is unharmed, but Mary suffers a severe high spinal cord (C1–C2) injury. When EMS arrived 10 min after the accident, Mary was unresponsive, not breathing and in cardiac arrest. She was aggressively resuscitated, intubated and ultimately placed on a ventilator in a local pediatric intensive care unit. Over the next few weeks, neurologists evaluate Mary and determine that she has suffered extensive anoxic brain injury and due to her spinal cord injury will never be able to move her arms or legs, will require permanent ventilator support, and will ultimately require a percutaneous endogastric (PEG) tube for nutritional support. She is minimally conscious and responds to painful stimuli. Due to the extent of Mary’s injuries and due to their own financial situation, Mary’s parents cannot keep her at home. Mary will need to be transferred to a long-term ventilator facility located approximately 8 h away. Because of the long distance, neither Mary’s mother nor father will be able to visit often. Medical experts determine that Mary could survive in

this state for several years and is not unconscious. Neurologists, indicate however, that her conscious moments seem to be mostly filled with discomfort, confusion and pain. When confronted with this scenario both Mary's father and mother agree that it would be best to withdraw life support and let Mary die peacefully. The medical team is also in agreement with the parents' decision, as the team believes that the benefits of continued life in this condition are outweighed by the extensive burdens. Risk management personnel at the hospital point out, however, that under North Carolina law a legal safe harbor for the withdrawal of LST only exists if the patient (1) "has an incurable or irreversible condition that will result in the person's death within a relatively short period of time" or (2) "is unconscious and, to a high degree of medical certainty, will never regain consciousness". They also point out that, according to the medical experts in this case, Mary could live for years on a ventilator with a feeding tube in a minimally conscious state, albeit one filled mostly with confusion and pain. One of the risk managers argues that since Mary's condition does not fall into the legal safe harbor laid out by the North Carolina Right to a Natural Death Act, removing her from the ventilator would be a "kind of willful, deliberate and premeditated killing" and as such would fall under the homicide statutes of North Carolina (N.C. Gen. Stat. § 14–17 2012). Another risk manager argues that she did not think the homicide statutes would be invoked but that withdrawal of care could potentially create a risk of civil liability if a third party such as a grandparent objected after the fact.

2 Broader Discussion of the Law

Before delving into some of the broader US law that bears on Mary's case and others like it, it is important to note that we are not offering a sociological explanation of why legislators and policymakers enact any given legal regime intended to regulate end-of-life and surrogate decision-making. This latter question is of course an empirical one, and there are studies that examine social, legal, political, economic and religious factors that motivate any relevant legal scheme (Emanuel and Emanuel 1992; Bachman et al. 1996). We are here interested in the possible rationalizations for different public policies regarding end-of-life and surrogate decision-making. Such rationalizations do not depend on the specific motivations of policymakers in enacting the particular legal regime used to balance the various interests involved in end-of-life decision-making.

Examination of each state's legal and regulatory approach to end-of-life decision-making in cases like Mary's shows both uniformity on the legal regime's boundaries and considerable variety within those bounds. Indeed, given the influence of the Model Natural Death Act in shaping state legal landscapes in this context, it would be surprising if the general schemes were not similar at least in their broad outlines. The vast majority of jurisdictions to have addressed the issue

Table 1 Fifty-state survey of triggering-conditions language

Jurisdiction	Relevant laws	Specific triggering conditions explicitly listed	Language constraining withdrawal of LST during pregnancy	Language constraining withdrawal of ANH
Alabama	Code_of_Ala._§_22-8A-3, 8A-4, 8A-11	N	Y	N
Alaska	Alaska_Stat._§_13.52.010, § 13.52.390	N	N	N
Arizona	Arizona R.S._§_36-3231	N	N	N
Arkansas	Arkansas C.A._§_20-17-201-203	Y	Y	Y
California	Cal_Health_&_Saf_Code_§_7185.5; Cal_Prob_Code_§_4683	N	N	N
Colorado	C.R.S. 15-14-505, 506; C.R.S. 15-18-103, 104, 107	N	Y	N
Connecticut	Conn._Gen._Stat._§_19a-570, 571, 574	Y	Y	N
Delaware	16_Del._C._§_2501, 2507	Y	Y	N
District of Columbia	D.C._Code_§_21-2206	N	N	N
Florida	Fla._Stat._§_765.101, 105; 205; 301–309	Y	Y	N
Georgia	O.C.G.A._§_31-32-2, 7–9	Y	Y	Y
Hawaii	HRS_§_327E–2, 3, 5	N	N	Y
Idaho	Idaho_Code_§_39-4514_	N	Y	Y
Illinois	755_ILCS_40/20	Y	Y	N
Indiana	Burns_Ind._Code_Ann._§_16-36-4-1, 4-5; 16-36-1-14	N	Y	N
Iowa	Iowa_Code_§_144A.2, 144B	N	Y	N
Kansas	K.S.A._§_58-629; K.S.A._§_65-28,102; 65-28,105	N	Y	N
Kentucky	KRS_§_311.621, 629	N	Y	Y
Louisiana	La._R.S._401299.58.2, 58.5	N	Y	N
Maine	18-A_M.R.S._§_5-801, 5-805	Y	N	N
Maryland	Md._HEALTH-GENERAL_Code_Ann._§_5-601–5-606; 5-611; 5-613	Y	N	N
Massachusetts	ALM GL ch. 201D, § 1–17	N	N	N
Michigan	MCLS_§_333.5653, 5655	N	Y	N
Minnesota	Minn._Stat._§_145B.02, 145B.12–13	Y	Y	N
Mississippi	Miss._Code_Ann._§_41-41-203, 209	N	N	N
Missouri	§_404.820_R.S.Mo., 404.828; 404.830; 459.010	N	N	Y
Montana	Mont. Code Anno. § 50-9-105, 106, 202	Y	Y	N
Nebraska	R.R.S. Neb. § 20-408; 30-3417; 30-3418	Y	Y	Y

Table 1 continued

Jurisdiction	Relevant laws	Specific triggering conditions explicitly listed	Language constraining withdrawal of LST during pregnancy	Language constraining withdrawal of ANH
Nevada	Nev. Rev. Stat. Ann. § 449.624; 449.626	Y	Y	N
New Hampshire	N.H. R.S.A. 137-J:10	Y	Y	N
New Jersey	N.J. Stat. § 26:2H-67	Y	N	N
New Mexico	NM. Stat. Ann. § 24-7A-5	N	N	N
New York	NY CLS Pub Health § 2961; 2965; 2994-d; 2994-g	Y	N	N
North Carolina	N.C. G.S. § 32A-19; § 90–321	Y	N	N
North Dakota	N.D. Cent. Code § 23-06.5-03	N	Y	Y
Ohio	ORC Ann. 1337.13, .15; § 2133.08	Y	Y	Y
Oklahoma	63 Okl. St. § 3080.3; § 3101.4	Y	Y	Y
Oregon	ORS § 127.531; 127.540; 127.580; 127.635; 127.640	Y	N	Y
Pennsylvania	20 Pa.C.S. § 5429, 5454, 5456, 5462	Y	Y	Y
Rhode Island	R.I. Gen. Laws § 23-4.10-2, .10-5	N	Y	N
South Carolina	S.C. Code Ann. § 62-5-504	Y	Y	Y
South Dakota	S.D. Codified Laws § 34-12D-3; 34-12D-5; 34-12D-10	Y	Y	Y
Tennessee	Tenn. Code Ann. § 32-11-103; Tenn. Comp. R. & Regs. R. 1200-08-36-.16	N	N	Y
Texas	Tex. Health & Safety Code § 166.031; § 166.049	N	Y	N
Utah	Utah Code Ann. § 75-2a-103; 115; 117	N	N	N
Vermont	18 V.S.A. § 9702	N	N	N
Virginia	Va. Code Ann. § 54.1-2986; 2990	N	N	N
Washington	Rev. Code Wash. § 122.030	N	N	N
West Virginia	W. Va. Code § 16-30-15, 16-30-19	N	N	N
Wisconsin	Wis. Stat. § 154.02, .03; § 155.70	N	N	N
Wyoming	Wyo. Stat. § 35-22-403	N	N	N

include statutory language that frame end-of-life decision-making in terms of (1) irreversibility; (2) the existence of a terminal illness or condition; and/or (3) permanent loss of consciousness.

However, many states do not explicitly set out triggering conditions which, when met, authorize a surrogate decision-maker to make end-of-life decisions for an

incapacitated patient (Table 1).² Among these states, end-of-life decision-making is envisioned simply as being within the general purview of medical decision-making for which duly authorized surrogates are charged. So, while Florida, for example, includes definitions for “end-stage condition” and “persistent vegetative condition” that use the language “irreversible” and “permanent... condition of unconsciousness”, other than the generic fact of the patient’s incompetence, Florida also does not expressly set forth triggering conditions under which a surrogate’s decision-making power arises in end-of-life contexts (Table 1).

In contrast, other jurisdictions have carefully regulated end-of-life decision-making in the context of surrogacy and/or triggering conditions. Maryland, for example, specifically provides that a physician “may not withhold or withdraw life-sustaining procedures... on the basis of the authorization of a surrogate” unless either of two conditions are met (Table 1). First, the patient’s attending physician and an additional physician must certify that the patient is either in a terminal or an end-stage condition. Second, two physicians, one of whom must be a neurologist, a neurosurgeon or a practitioner with specific expertise on “the evaluation of cognitive functioning” must certify that the patient is in a persistent vegetative state (Table 1). The applicable Maryland statutes also define highly specific terms such as “end-stage condition”, “terminal condition” and “persistent vegetative state”, therein creating a legal regime that spells out in close detail the standards that must be satisfied and the exact procedures needed before a surrogate is empowered to authorize the withdrawal of LSTs (Table 1). The criteria for triggering conditions are essentially contained in the definitions of the conditions and the procedures through which a surrogate is duly authorized to request the withdrawal of such interventions.

Furthermore, Maryland also specifically provides that a surrogate may not base a decision to withdraw life-sustaining procedures “in whole or in part, on either a patient’s preexisting, long-term mental or physical disability, or a patient’s economic disadvantage” (Table 1). This reinforces the idea that the state deems important the specific standards and procedures through which surrogates engage in end-of-life decision-making, important enough to regulate specifically and issue constraints on the authority with which surrogates are and are not invested.

To take another example, the state of Kentucky also demonstrates an interest in regulating such decision-making, although its approach differs in important ways from that adopted by Maryland. Kentucky does include fairly standard triggering conditions language, defining in the context of end-of-life surrogate decision-making a “terminal condition” as an injury, disease or illness which, to a “reasonable degree of medical probability, as determined solely by the patient’s attending physician and

² Lexis-Nexis maintains a 50-state survey of advance directives that formed the basis for the construction of Table 1. Nevertheless, Table 1 differs from the Lexis-Nexis survey in a variety of ways. First, the Lexis-Nexis survey includes all statutes and regulatory provisions that pertain to advance directives and end-of-life care. In contrast, Table 1 is specifically constructed to illuminate the narrower issue of whether jurisdictions explicitly list triggering conditions necessary for a health care surrogate’s authority. Second, compared to the extensive list of all laws related to advance directives in the Lexis-Nexis survey, Table 1 is the product of a careful curation process. In this process, we iteratively analyzed each potentially relevant state statute and regulation to discern the extent to which it illuminated central issues of surrogate authority to withdraw life-sustaining treatment, including any possible limitations on such authority in cases where the patient is pregnant or where artificial nutrition and hydration is implicated.

one other physician, is incurable and irreversible and will result in death within a relatively short time, and where the application of life-prolonging treatment would serve only to artificially prolong the dying process” (Table 1). However, Kentucky law pays special attention to artificial nutrition and hydration (ANH) which, in Maryland law, is specifically included within the definition of “life-sustaining procedures” writ large. In contrast, Kentucky law provides that ANH may only be withdrawn by a duly-authorized surrogate in several discrete circumstances. First, ANH may be withdrawn where death is imminent, imminence explicitly defined *only* for purposes of the Kentucky Living Will Directive Act as “when death is expected, by reasonable medical judgment, within a few days”. Second, ANH may be withdrawn where the patient has specifically authorized withholding or withdrawing ANH in a relevant advance directive. Third, where artificial nutrition “cannot be physically assimilated” by the patient, withdrawal of ANH is authorized (Table 1).

The Kentucky statute does seem to provide a way out of the strictures imposed on the withholding or withdrawing of ANH, noting that ANH may be withheld or withdrawn “when the burden of the provision of artificial nutrition and hydration itself shall outweigh its benefit”. The four provisions specified in the Kentucky statute are disjunctive, and the appearance of the fairly traditional proportionality test creates something of a confusing state of affairs politically if not legally for a care team, risk manager, bioethicist, family, and/or surrogate decision-maker weighing whether to withhold or withdraw ANH for an incapacitated patient who satisfies the applicable triggering conditions in the statute. While the law seems to sanction a surrogate’s decision to withhold or withdraw ANH where there is agreement that the burdens outweigh the benefits, the state’s specific attention to ANH and the additional restrictions it imposes suggest at least some discomfort with surrogate decisions to withhold or withdraw ANH even where the triggering conditions are satisfied. Further evidence of Kentucky’s reluctance is contained in the very next provision, relatively common among the fifty states (Table 1), which provides that neither ANH nor life-sustaining procedures in general may be withdrawn from an incapacitated pregnant woman unless it can be shown that continuing such treatment “will not maintain the woman in a way to permit the continuing development and live birth of the unborn child, will be physically harmful to the woman or prolong severe pain which cannot be alleviated by medication” (Jerdee 1999; Burch 1995; Benton 1990).

The fact that Kentucky, among over thirty other states (Table 1), distinguishes pregnancy under the applicable law regarding surrogate and end-of-life decision-making is of course important. Pregnant bodies, along with women’s reproductive status and health, have long been sites of enormous contest and moral panic (Wolff 2011; Bell et al. 2009; Heilborn et al. 2007; Armstrong and Abel 2000; Stabile 1992). Given these contests, it is unsurprising that there is some variety even among the states that treat pregnant women differently from other persons who lack capacity for medical decision-making. Some states, such as Texas, simply bar withdrawal of LST from pregnant women: “A person may not withdraw or withhold LST under this subchapter from a pregnant patient” (Table 1). Other jurisdictions, such as Kentucky (noted above) erect considerable barriers to a surrogate’s decision to withdraw LST from a pregnant woman, but such constraints are at least in theory surmountable under the circumstances specified in the statute.

The idea of procedural constraints is in our view extremely important, for it characterizes much of what states do in delineating the legal boundaries of surrogate end-of-life decision-making regardless of how specifically a jurisdiction regulates the process itself. Although constraints typically convey connotations of negative liberty, at least some constraints can actually empower actors, at least in a legal sense. For example, safe harbor provisions almost certainly carry some kind of constraining authority, in the sense that those acts that do not satisfy the relevant criteria fall outside the safe harbor and may subject the actor to civil or criminal liability. Safe harbor provisions therefore provide both inducements to behave in certain ways and constraints on behaving in other ways, at least inasmuch as the specter of liability is a sufficient stimulus to modify the relevant behavior. But such safe harbor provisions are in a sense empowering to the extent that they lay out explicitly what an actor may and may not do if achieving safe harbor protection is a goal of action.

In fact, the incentive to act in certain ways and/or avoid acting in others that flows from a statutory safe harbor provision can be so powerful as to set the standard of practice in ways virtually indistinguishable from a legislative mandate. In a 2012 article, Thaddeus Pope lays out a taxonomy for medical safe harbors intended to provide immunity to physicians for acting in clinically appropriate ways that might, absent the safe harbor, expose the physician to legal risk. Pope delineates four categories of safe harbor provisions:

1. Those that shield low-risk conduct;
2. Those that provide procedures for shielding low-risk conduct that evade easy definition;
3. Those that shield risky conduct; and
4. Those that shield conduct solely for the self-protection of the parties involved.

Pope locates end-of-life decision-making generally within the third category, but also notes that some states, such as Texas, specify procedures that physicians and health care entities must follow to fall within the safe harbors crafted for end-of-life decision-making (Pope 2012).

However, as Pope points out, there is a serious deficiency in the application of safe harbor provisions to medical practice in general. Namely, any safe harbor which is linked to the provision of clinical care is “vague and uncertain” because the “determination of the standard of care is set *ex post*...” (Pope 2012). While states like North Carolina have specified procedures for shielding surrogate end-of-life decision-making, the difficulty of Mary’s case is precisely that said procedures *introduce* additional legal ambiguity. There is of course a measure of clinical uncertainty regarding the phenomenology of Mary’s illness (i.e., what does it feel like? Is Mary capable of feeling or experiencing mental states?), but the fact that the triggering conditions create a legal safe harbor could induce actors to avoid acts that fall outside the specific procedures to which the safe harbor attaches.

There is also the potential for conflict between a bioethics perspective and a risk management perspective here given the fact that steering outside the procedural constraints demarcating the safe harbor might for the former be ethically mandated at the same time that such behavior might create intolerable levels of uncertainty

and risk for the risk manager. We shall say more about the possible tension between bioethicists and risk managers in scenarios like Mary's case below.

For now, it is plain that state regulation of surrogate authority in end-of-life decision-making raises a number of important legal and moral questions that are difficult to answer. In setting constraints on such authority, whether via specification of conditions that trigger surrogate authority, or via other explicit standards and procedures, are states simply engaging the holding in *Cruzan* constitutionally authorizing the requirement that certain standards of proof be met before surrogates can order that LSTs be withdrawn? What are the public policy goals that greater or lesser constraints on surrogate authority in contexts of end-of-life decision-making are meant to serve? And are such goals better served in jurisdictions that simply regard such decision-making as a subset of the generic class of medical decision-making or in those which treat surrogate end-of-life decision-making as a special case meriting explicit statutory attention?

3 A Common Approach to Ethical Decision-Making

It is not uncommon in medicine for clinicians to encounter patients, who like Mary, are unable to make decisions regarding their own healthcare. When such a situation arises, clinicians generally try to answer two fundamental questions: first, who should make decisions for the patient? And second, how should these decisions be made? In bioethics, these questions are generally discussed under the broad heading of surrogate decision-making.

When making decisions for other persons, a surrogate decision-maker should try to promote two important values: the patient's self-determination and well-being (President's Commission 1982). Many individuals value the right to make important decisions regarding the fundamental affairs that intimately affect their lives. They also value the freedom to pursue what they believe to be a good life without intrusive interference from others. In addition, an individual's well-being has subjective components that are known best by the individual himself or those close to him. This fact often makes the individual himself the best judge of what is in his best interest. Finally, exercising the capability to make fundamental decisions about one's life and, in so doing, to deliberately pursue a life plan gives persons a special dignity.

Ideally, a surrogate decision-maker is someone who has a close, longstanding relationship with a patient and can accurately communicate the patient's preferences and values. This knowledge will help guide the surrogate in making decisions that reflect what the patient would have wanted done in a particular clinical circumstance and will help to promote the patient's well-being in so far as this well-being is at least, in part, determined by the patient's subjective conception of the good.³ Oftentimes, the surrogate will be a family member or close friend of the

³ Note this does not mean that the patient's preferences would fully determine what his good is but they do play an important role. Thus, we leave open the possibility that there may be goods other than preference-satisfaction. For discussion on this, see Griffin (1986).

patient because familial relationships and close friendships are often intimate enough to allow the acquisition of the prerequisite knowledge needed to act as a good surrogate. In the case of minors, parents often play the role of surrogate decision-makers because of the special nature of the parent–child relationship and the special obligations parents have toward their children. In our case, Mary is a minor and her parents are acting as her surrogate decision-makers.

Once the surrogate decision-maker is identified one must then decide how decisions should be made. In modern bioethics teaching, three models of decision-making are often discussed and in practice these are often utilized in a hierarchical fashion. These three models are the advance directive model, the substituted judgment model and the best interest model (Buchanan and Brock 1989).

In the advance directive model, we ask ourselves if the patient either formally or informally gave specific guidance regarding what she would want done in the situation. These preferences might be conveyed by either written or verbal means. The key concept that defines this standard is epistemic specificity: the patient has let it be known what they would want in a particular circumstance. For example, a patient may communicate a preference never to undergo a dialysis treatment under any circumstance or a preference never to have a feeding tube placed if they suffer from dementia.

Often there is a lexical priority given to this standard of decision-making. Even in situations in which others may not agree that the decision is actually in the best interest of the patient, we tend to give priority to the liberty interests of individuals to decide for themselves what happens to their body and also to the individual's own conception of well-being.⁴ Usually, when such knowledge is available, the job of the surrogate decision-maker is to simply make the patient's preferences known so that they can be implemented. Generally, this type of commitment is strongest when it involves a preference to avoid an intervention rather than a preference for an intervention. This is so because the latter requires other agents to participate in promoting the patient's preference while the former simply involves non-interference.⁵

⁴ Certainly a surrogate might question this type of priority. A surrogate might argue that he should not consent to anything that he believes would harm the patient even if the patient did not share that belief. Thus, we may have a fundamental disagreement about the role of the surrogate. On one account, the surrogate's role is first and foremost to promote the patient's self-determination and only secondly to advocate for what the surrogate believes promotes the patient's well-being. On another account, the surrogate may see his primary obligation to promote the patient's well-being and to avoid acting in an all-things-considered wrongful way—even if this means acting against what the patient would have actually wanted.

⁵ Thomas Nagel argues that some human interests give rise to impersonal values that generate agent-neutral reasons for others to support our projects; however, other interests do not give rise to such reasons.

Though some human interests (and not only pleasure and pain) give rise to impersonal values, I now want to argue that not all of them do. If I have a bad headache, anyone has a reason to want it to stop. But if I badly want to climb to the top of Mount Kilimanjaro, not everyone has a reason to want me to succeed. I have a reason to try to get to the top, and it may be much stronger than my reason for wanting a headache to go away, but other people have very little reason, if any, to care whether I climb the mountain or not. Or suppose I want to become a pianist. Then I have a reason to practice but other people have little or no reason to care if I practice or not (Nagel 1986, p. 167).

One's end-of-life preferences, depending on what they may be, may generate agent neutral reasons that give others a reason to be involved, but they may not.

If the patient did not provide *specific* guidance, we next ask, given what we know about the patient, whether we can feel confident in a judgment about what the patient would want in a specific situation. This type of judgment is obviously more tentative and more difficult because the evidence is less specific. In addition, the standard introduces ambiguity between trying to decide what the patient would *actually* do and what the patient *would have the most reason* to do. The former seems to be what we would want to get at but may be very difficult if the patient tended to make decisions in an idiosyncratic manner. The latter is often more accessible to a surrogate but may not reflect the patient's actual decision. This standard attempts to respect a patient's preference for what happens to his own body but is admittedly in a worse epistemic situation in regards to what this preference actually would be. This standard is often called the Substituted Judgment Standard.

If we cannot feel confident about what a patient would want either because the patient gave us no specific guidance or because we do not have confidence in making such a judgment based on what we know about the patient's values, we then ask what we believe would be in the patient's best interest. The final standard often makes a shift from the perspective of the patient to the perspective of the surrogate in trying to decide what would promote the patient's well-being.⁶ In some situations, when there is not clear knowledge of the patient's preferences or values that would lead one toward a particular judgment, the answer may tend to take the form of what a reasonable person would want in a particular situation.

While there are many questions that can be raised about these three standards, this general hierarchical approach is often what is endorsed in American bioethics. The model itself has an important feature to consider. It does not specify restrictions for making a medical decision. In particular, there are no explicit restrictions on a surrogate regarding the withholding or withdrawal of LST. The model focuses exclusively on the method by which the decision is made, not the outcome.

In our case, Mary's parents are the correct surrogate decision-makers. Because Mary is a minor and has not expressed her thoughts about LST, the advance directive standard would not be applicable. Likewise, given the patient's age the substituted judgment standard would not apply. Mary's parents are left with trying to decide what they think is best for their daughter. Their decision can be rationally reconstructed as follows⁷: Because of Mary's severe injuries her life prospects are very limited. She will be permanently attached to a ventilator without the ability to move or meaningfully interact with others. Based on our best estimations, her

⁶ One might think that there is an overlap in applying the second standard and the third standard. For example, if we had a justified belief regarding *the patient's view* of what constituted his own good (Best Interests Standard), we could couple this with the supposition that the patient would choose the course of action that promoted this view of his good, and arrive at a decision about what the patient would have wanted in the particular situation (Substituted Judgment Standard). Thus, it would seem that a Best Interest Standard would either collapse into a substituted Judgment Standard or would represent an acknowledgement that one is making a judgment not about what the *patient* would necessarily think promotes his well-being but what the *surrogate* thinks would promote the patient's well-being.

⁷ Obviously, the account we offer here is not the only reasonable decision calculus. We are offering a plausible reconstruction of the basis for the decision by Mary's parents. We are neither endorsing this decision nor excluding other plausible decisions/analyses. For more discussion of this point, see Sect. 4.

internal life would vacillate from complete non-awareness to a confused and possibly painful experience. Her parents would not be able to see her often, and she would likely die in an institution. Given these severe limitations, her parents decided that a short peaceful, death is “better” for Mary than continued existence in such a confined and diminished state. Mary’s medical team is in agreement with her parent’s decision.

4 Arguments for Continuing Triggering Conditions

As mentioned above, the North Carolina Right to a Natural Death Act specifically mentions two triggering conditions: (1) the patient “has an incurable or irreversible condition that will result in the person’s death within a relatively short period of time” or (2) the patient “is unconscious and, to a high degree of medical certainty, will never regain consciousness”. Many other states have similar conditions, although some jurisdictions do not use such language, or do use such language and supplement these requirements with additional conditions not applicable in North Carolina (Table 1).

What purpose do such triggering conditions serve? And how should we view them? Certainly, North Carolina could have left out any mention of the triggering conditions and then surrogates would have been free to make whatever decisions they believed appropriate for patients. Physicians would still be ethically obligated to ensure that an ethical decision-making process was followed including acting on the patient’s preferences in so far as they were known or acting in the patient’s best interest even if this conflicted with a surrogate’s decision.

In this section, we will explore public policy reasons supporting the inclusion of triggering conditions within statutes pertaining to the legal withdraw of LST. First, however, we must locate this approach within a spectrum of three possible public policy approaches.

One approach for a legislature would be to allow the medical profession in collaboration with patients and surrogates to decide when and under what conditions LST may be withdrawn. This approach, while curtailing state involvement in the actual decision of when withdrawal of LST is acceptable, would not necessarily eliminate state involvement altogether. For example, there are good public policy reasons to require at law (1) informed consent from the patient or surrogate prior to withdraw; (2) a second opinion and (3) designation of a process for determining a surrogate decision-maker. In addition, in cases of interminable conflict the state would act as the final arbiter. This option, however, would not mandate that any specific triggering conditions must be met prior to withdrawal of LST. The conditions under which LSTs would be withdrawn would be negotiated by the physician and the patient/surrogate, guided by the medical profession’s interest in respecting the liberty interests of patients and in promoting the patient’s overall good.

A second approach for a legislature would be to take the decision of withdrawal of LST completely out of the purview of physicians, patients and surrogates. The state, for example, could simply outlaw withdrawal of LST. This public policy

approach is exemplified by statutes in several states that prohibit withdrawal of LST when a patient is pregnant. This approach would severely restrict the liberty rights of individual patients and possibly compromise the professional integrity of physicians but would maximally promote the state's interest in protecting citizens from premature death.⁸

A third approach for a legislature would be to try to balance the competing interests of avoiding the premature death of citizens and respecting their liberty interests to actualize their own understanding of a good death. To accomplish this balance the legislature might intervene to delimit the conditions under which LST can be withheld. A legislature might be predominately concerned with situations in which the patient cannot make decisions for themselves. It is in these cases that the potential for an unwanted death is highest. If the patient is competent and judges the continuation of LST more of a burden than a benefit, the state has an interest in protecting the liberty rights of citizens against the imposition of medical care by removing legal barriers to the withdrawal of LST.

Over the past several decades in the United States a consensus has developed that a citizen's liberty rights with regards to what happens to his own body at the end of life generally take precedence over the state's interest in protecting the citizen from premature death. However, this is not an absolute hierarchy. Physician assisted suicide (PAS) is still illegal in most states and this illustrates the fact that the state still has a interest in protecting its citizens from premature death—sometimes even if an individual citizen would prefer a premature death. One way to explain the prohibition on PAS is that there is a worry that legalizing such a practice may create an overall environment in which some citizens may feel pressured to end their lives prematurely and the state has an interest in protecting citizens' right not to have their lives ended prematurely.⁹

One way to conceptualize the restrictions in the North Carolina law is as an attempt by its legislature to balance the two interests of protecting citizens' right to avoid the premature cessation of their life and of protecting their liberty rights to determine what happens to their own bodies.¹⁰ The move to legalizing withdrawal of LST is a move toward recognizing the importance of citizens' liberty rights over their own bodies. The requirement of meeting triggering conditions prior to withdrawal of LST is a move towards protecting citizens from having their lives ended prematurely.

The specific content of the triggering conditions in the North Carolina Advance Directives Act can be viewed both as a way of demarcating situations in which

⁸ In addition, the disability rights community has extensively argued that given the widespread devaluation of the capacity for disabled people to live meaningful, flourishing lives, larger barriers to withdrawal of LST for even severely impaired persons must be erected. The disability rights critique of end-of-life discourse within mainstream Western bioethics is extremely important, and a series of recent texts have integrated the critique into bioethical thinking (Ouellette 2013; Scully 2008). The most vocal and visible advocacy group in the US on these kinds of issues is the appropriately named Not Dead Yet. Although this article does not develop a disability bioethics approach, we address some of the key aspects of the disability critique in Sect. 5.

⁹ For a particularly compelling and impassioned analysis of these issues, see Longmore (2005).

¹⁰ By "prematurely" we mean ending the patient's life before he would want it ended or, if the patient's wishes are unknown, ending the patient's life when it is not in the patient's best interest to do so.

patients would likely prefer LSTs to be withdrawn thereby respecting the patient's liberty rights over their own bodies and also as a way of minimizing the harm if a patient's life is ended prematurely. If a patient is likely to die in a short period of time anyway or is unconscious and is not likely to regain consciousness, these are situations in which a rational person may be likely to defer continued LST, especially if the burden of continued treatment is high. Furthermore, if a mistake is made and the patient's life is shortened prematurely, the significance of the mistake is arguably lessened if the patient did not lose a substantial amount of life or if the life that is lost is one devoid of consciousness.

In the situation in which surrogates are making decisions for patients and the risk of causing premature death is higher, in order to decrease this risk the state may want to constrain the conditions under which withdrawal of LST is permitted. There are at least two general strategies the state can use to accomplish this purpose. The first would be the use of triggering conditions. The second would be the specification of the degree of evidence of the patient's preferences required to justify withholding or withdrawing LST.

As to this second strategy, the state could specify that in order to withdraw LST there must be a high degree of evidence supporting that such withdrawal is what the patient would have wanted. By requiring evidence of what the patient would have wanted, one disallows withholding or withdrawing LST on the basis of a best interest standard alone. By requiring a high degree of evidence, the state could disallow any withdrawing or withholding except in the situation in which the patient formally executed a living will or designated a health care power of attorney who could then attest to the patient's explicit wishes. That is, one could set the bar so high that it would be difficult to withdraw or withhold LST on the basis of a substituted interest standard.

Requiring a higher level of evidence about what the patient would have wanted is a way to prevent the premature death of the patient.¹¹ The more certain we are that this is what the patient would have wanted, the more certain we are that the death is not premature. However, requiring high levels of evidence of the patient's actual preferences may also be overly restrictive and may lead to cases in which patients endure LSTs that are burdensome and unwanted. In many cases, even if one could reasonably ascertain based upon facts about the person what they would prefer if they were in a position to form such preferences, the patient may not have actually formed preferences prior to being in that situation.

Generally, continued biological existence is a good thing for people. While some people commit suicide, most do not. Furthermore, most people will go to extreme lengths to avoid death. However, our tendency to avoid death and to value continued life seems to have a lot to do with the type of life we have currently and will have in the future. In cases in which our life is devoid of the things that make life meaningful such as interpersonal relationships, the ability to communicate, the

¹¹ See, for example, the state of Missouri's requirement of an intermediate standard of proof ("clear and convincing evidence") showing that an incapacitated person would wish LST to be withdrawn (MO Rev Stat § 459.010 et. seq 2012). It was this statute and the constitutionality of such a higher burden of proof that was at issue in *Cruzan*.

ability to be self-aware, the absence of constant pain, etc., continued life may not have the same value for us.

However, whether a life has value for an individual is a very subjective thing. Some people find meaning in lives devoid of many of the things that seem to make life meaningful. So in deciding whether and under what circumstances the state will allow a surrogate to withdraw LST for a patient, a policymaker may want to make sure the circumstances are such that there is a great deal of evidence that withdrawal of treatment is really what the patient would have wanted.

The disability critique of mainstream end-of-life discourse is also relevant here (Wardlaw 2010; Gill 2004). This critique flows from two basic points. First, there is overwhelming evidence that the able-bodied are very poor at estimating the quality of life reported even by severely disabled (capacitated) persons. (Kothari and Kirschner 2006; Kothari 2004). Able-bodied people tend to dramatically underestimate the meaning that disabled people—given sufficient resources—are able to make of their lives. Second, disabled persons have historically been among the first class of persons to be deemed “useless bodies” whose lives are disposable, as in the Third Reich’s T4 euthanasia program, where disabled persons were gassed. Of course, the suggestion is not that a surrogate’s decision to withdraw LST embodies the active euthanasia programs of the Third Reich; the point is instead a larger one regarding the need for epistemic humility, even for the most well-intentioned surrogate, when making determinations about the capacity for meaningful life that a severely disabled person can enjoy. This need is especially urgent given the historical tendency to devalue the lives of disabled persons, as well as the enormous consequences of such devaluation in end-of-life decision-making.

Triggering conditions are another strategy that can be used by legislators to attempt to prevent unwanted death. This strategy avoids the requirement of a high level of evidence of the patient’s specific preferences and attempts to constrain the situations in which LST’s can be withdrawn to those that an average person would likely find overly burdensome, in which death would likely not be unwanted, and in which if a mistake was made and the patient’s life was prematurely ended, the significance of the mistake would be less.

There are two types of mistakes that could be made in withdrawal of LST. First, one could withdraw wanted care and cause unwanted death. Second, one could continue unwanted care and prevent death. Triggering conditions can be conceptualized as the answer to the following questions: How can we minimize the first mistake? Under what conditions can we be confident that an average person would likely want LST withdrawn because the burdens outweigh the benefits? That is, under what conditions is it unlikely for death (if it meant continued medical intervention) to be unwanted? Certainly, if one is likely to die very soon despite the LST, one might judge that the burden of the treatment might be too high since it does not pay off in longevity of life. Also, if the type of life one is living is devoid of consciousness, one might quite literally have no interest in continuing it. Triggering conditions are a constraint on individual liberty motivated by the moral appeal to prevent premature death when dealing with the conditions of epistemic uncertainty inherent to surrogate decision-making.

5 Arguments for Eliminating the Triggering Conditions

As mentioned above, one argument for the statutory inclusion of triggering conditions is to protect the patient from premature death that he might not have desired and to minimize the consequences of premature death if a mistake is made. However, the inclusion of triggering conditions also presents several problems.

First, the statutory inclusion of triggering conditions represents an intrusion by the state into the patient-physician relationship. The medical profession has an interest in preventing the premature death of patients—an interest at least as strong as the state’s since preventing the premature death of patients is arguably one of the fundamental, defining goals of the medical profession. Acting in the best interest of patients is a defining characteristic of what it means to be a medical professional and even though it may be difficult to say what constitutes a patient’s best interest in any given case, preventing the patient’s premature death would likely almost always be part of it. Moreover, the medical professional in conjunction with the surrogate decision-maker is in a much better position to make decisions regarding withdrawal of LST because these decisions are often nuanced and depend on particularities that a statute cannot anticipate (Pope 2012). Since the medical profession has a strong interest in preventing premature death and since a morally conscientious medical professional in conjunction with a surrogate is arguably better situated to accomplish this goal, the state should set policies in place that nurture and protect the moral development and professional conscience of physicians so that they can make good, ethically appropriate decisions within the confines of the patient-physician relationship. The thrust of this argument is that triggering conditions are both an unnecessary intrusion into the patient-physician relationship and an inferior way of protecting a patient from premature death when compared to simply allowing the medical profession to perform its appropriate role.

Second, while triggering conditions may reduce the likelihood of prematurely ending the life of a patient, they also may lead to prolonged, unwanted suffering or existence with severely diminished cognitive capacity that many might judge *worse* than a premature death. The North Carolina triggering conditions minimize the effects of one mistake only to increase the odds of a second mistake—a mistake that one might reasonably judge worse than the first.

Third, even if the statutes simply create a legal safe-harbor without criminalizing the withdrawal of LST in situations in which the triggering conditions are not met, they create a potentially powerful misalignment between prudential and ethical decision-making. In a hospital that is risk averse, the most prudent course of action would be to adhere strictly to the letter of the law even when doing so is not the ethically appropriate course of action. Furthermore, by constraining physicians in this way, the state creates a disincentive for physicians to be fully professional. In so doing, the state runs the risk of creating medical technicians, competent in the diagnosis of problems and the coordination of therapeutic solutions, but devoid of a commitment to considering thoughtfully the particular ethical considerations at play in cases and to helping surrogates make the right ethical decision at the right time in the right way for the particular patient with whom they are both concerned.

According to this line of reasoning, triggering conditions are not only an inferior way of protecting patients from premature death but also a corrosive influence on medical professionalism.¹²

5.1 Conflict Between Bioethicists and Risk Managers

Our case also illustrates the potential for conflict that triggering conditions create between risk managers and bioethicists. Defining the respective roles of risk managers and clinical bioethicists is challenging, as both are highly fluid across geography, time, and organizational structure. The American Society for Healthcare Risk Management notes six major functional areas for risk managers: “loss prevention and reduction, claims management, risk financing, regulatory and accreditation compliance, risk management operations, and bioethics” (Sedwick 2009). Traditionally, risk managers overwhelmingly focused on loss prevention and reduction, but their roles have expanded over the past two decades, especially in areas such as patient safety and quality improvement (Sedwick 2009). In spite of the obvious overlap between risk managers and clinical bioethicists, conflicts can arise when a risk manager advocates for a course of action that minimizes risk in a legally ambiguous situation that limits the rights of consenting adults to make decisions that are reasonable and ethically permissible.

These conflicts are a specific example of a more general conflict between prudence and morality. In regards to its ethical character, an act may be ethically permissible but not required, ethically obligatory to do or ethically obligatory to avoid; in regards to its prudential character, an act may be prudent or not. This leads to six possibilities outlined in Table 2.

Prudence gives us a reason for action. Ethical obligation also gives us a reason for action. If an act is ethically permissible, then we are neither obligated to perform the act or to avoid doing the act—ethical reasons are, therefore, not determinative in such cases. Imprudence gives us a reason not to act (it is not in our interest).¹³ We have the most reason to do acts that are ethically obligatory and in our prudential interest. We have the least reason to do acts that are ethically obligatory for us to avoid doing and would be imprudent for us to do

Conflicts arise when a given action is in our prudential interests but is ethically obligatory for us to avoid doing. Similarly, a conflict arises when a given action is not in our prudential interests but is ethically obligatory for us to perform. The state uses coercive force to create powerful, prudential reasons to perform or avoid doing certain acts. And when both ethical and prudential reasons coincide, a strong incentive is in place to do what is right. However, when prudential and ethical reasons pull in opposite directions, the agent must make a decision regarding which set of reasons will trump.

¹² At least some of these problems are also apparent in the debates over the Baby Doe regulations during the 1980s, which attempted to restrict via federal law the conditions under which LST could be withdrawn from severely impaired neonates. We are indebted to an anonymous reviewer for this point.

¹³ One might think that there are also actions that are neither prudent nor imprudent—neither in our interest or against our interest but simply neutral to our interests. Non-prudence in this neutral sense would not give one a reason to act.

Table 2 Interactions between prudence & morality

	Prudent	Imprudent
Ethically permissible	Ethically permissible + prudent	Ethically permissible + imprudent
Ethically obligatory	Ethically obligatory to perform + prudent; Ethically obligatory to avoid + prudent	Ethically obligatory to perform + imprudent; Ethically obligatory to avoid + imprudent

This is the situation that the physicians in our case find themselves—because of the existence of the triggering conditions. In the context of legal ambiguity, at least some risk managers might be understandably expected to advocate for the most risk-averse position. Doing so, after all, fulfills at least some traditionally significant features of the role of the risk manager. However, the most risk-averse decision in this case apparently conflicts with the settled judgment of the physicians and Mary’s parents regarding what ethically ought to be done. Once the decision is made that taking Mary off the ventilator is best for Mary, acting otherwise is to do that which one believes is not best for Mary. And if the physician believes that it is an ethical obligation to take Mary off of the ventilator because this is what the proper decision makers (the physician and Mary’s parents) have agreed is best for Mary after carefully considering the ethical considerations in the case, then the physician must decide whether to fulfill his/her ethical and professional obligations or to act on prudential concerns created by the existence of triggering conditions.¹⁴

6 Conclusion

What conclusions are we to draw from our examination of Mary’s case? We believe there are several. First, the dilemma in the case arises because of a conflict between prudential interests—avoiding the risk of legal liability by acting outside of the legal safe harbor created in part by specific triggering conditions codified within the North Carolina general statutes—and ethical obligations—pursuing what Mary’s family and physicians believe is in her best interest, namely, withdrawal of LST. As

¹⁴ One might argue that it is not ethically obligatory to withdraw LST but only ethically permissible. And if it is only ethically permissible then prudential reasons can trump without acting wrongly. However, this is not the situation in our case. The parents along with the care providers have judged that it is in Mary’s best interest to have her LST withdrawn. To act otherwise, when they have a choice about it, would be to do what they thought was not in her best interest—and as a result to act wrongly. A different pair of parents along with a different health care team may have decided that continuing LST was in fact in Mary’s best interest and then their obligation would have been to continue LST. One might wonder whether there is a fact of the matter about what is actually in Mary’s best interest. We believe that there is such a fact, but that this fact may be difficult (perhaps impossible) to know. As a result, reasonable people may disagree about whether a given act is objectively obligatory (actually in Mary’s best interest) but once this decision is made the subjectively obligatory act (acting to do what one *believes* is in Mary’s best interest) is pretty clear—and pursuing this act is obligatory not simply permissible. For a fuller discussion of these issues see Swinburne (1989).

a general rule, our ethical obligations should trump prudential interests. We take this to be a general property of ethical obligations.¹⁵ In Mary's case, in light of the careful decision reached by Mary's family and physicians, the ethically appropriate course of action would be to withdraw life sustaining treatments.

The bigger questions raised by Mary's case turn on the genesis of the conflict—namely, North Carolina's legislatively-imposed triggering conditions that generate the prudential reasons to keep Mary on LST. In situations in which the care team and the appropriate surrogate decision-makers (in this case the parents of a young child) agree on a morally appropriate course of action, does the state's general interest in preserving life justify intrusion into the decision-making process? And even if one maintains that such an intrusion is justified, the question remains whether a particular level of intrusion is justified given the state's interest.

As shown in Table 1, states can and do regulate the decision-making process in end-of-life scenarios in a variety of ways. The issue presented in *Cruzan*, for example, was whether the state of Missouri could require a certain standard of proof regarding the patient's wishes that must be satisfied before LST could be withdrawn. (Of course, heightened evidentiary standards apply only to scenarios in which substituted judgment or advance directive standards are applicable. In a case which requires the use of the best interests standard, there is by definition no evidence to be gathered on what the patient would have wanted.) Aside from raising or lowering evidentiary standards, states (like North Carolina) can impose triggering conditions that indicate the circumstances under which surrogate decision-makers along with the relevant care teams are legally authorized to withdraw LST.

In terms of public policy approaches, there are some commonalities in how various jurisdictions choose, if at all, to regulate surrogate authority in end-of-life decision-making scenarios. However, there are also marked differences (the proverbial "laboratory of the states"). To some extent, how states regulate contested and difficult questions regarding surrogate authority reflects particular perspectives held by the polity in question on a variety of key factors. Such factors might include

- positions on the value of biological life;
- trust in the medical profession;
- position on the value of self-determination;
- worries about the epistemic gap between able-bodied and disabled persons (i.e., the valuation of disabled life); and
- anxieties regarding the costs of intensive care needed for severely impaired persons.

¹⁵ Certainly if the prudential costs are extremely high then what might otherwise be ethically obligatory may become supererogatory. For example, if you have a seizure and are laying face first in a puddle of water drowning and I can save your life simply by pushing your face out of the puddle, then I would have an obligation to do so even if this meant I got my shoes dirty. However, if you are trapped in a burning building and the only way you could be saved is for me to put my life at great risk to save yours, then even though this would be morally heroic for me to do, it would not be obligatory.

How a particular polity orders these issues is likely to be reflected at least partly in the specific regulatory scheme the state adopts regarding surrogate authority in end-of-life decision-making. For example, in jurisdictions where a critical mass of people are especially concerned with the possibility of ending life prematurely (i.e., either before the patient would have wanted their life to end or when the patient's immediate death is not in their best interest), one would predict the state would implement more extensive constraints on surrogate authority. As we have documented, a variety of legal and policy levers can be deployed in constraining such authority. States can, if they so choose, impose mandates on surrogate decision-makers and care teams that dictate legally permissible and impermissible actions in end-of-life scenarios. An obvious example of this kind of regulation is Texas's outright ban on withdrawing LST from pregnant women.

Jurisdictions can also use legal safe harbors to shield actors from liability in resolving morally and legally ambiguous end-of-life cases. North Carolina's statute creates such a legal safe harbor as long as specific conditions are met. However, it is crucial to note that the very existence of legal safe harbors—which by definition are not mandates—can in at least some situations essentially operate as *de facto* mandates. Recall that loss prevention and reduction is one of the core functional areas that defines the risk manager's role. The operational importance of the immunity that legal safe harbors provide in terms of loss prevention and reduction creates a prudential reason so strong that losing the protection of the safe harbor is a result to be avoided at almost any cost. This possibility has two implications. The first consequence is that as tools of governing surrogate decision-making in end-of-life scenarios, legal safe harbors may in some circumstances create disincentives for action that rival mandates and proscriptions. The second implication is that the disincentives for acting in certain ways created by legal safe harbors may be sufficiently strong to generate conflicts between morally obligatory and prudentially inadvisable actions.

Although we maintain some ambivalence, our ultimate perspective is that state legislatures should disfavor the imposition of triggering conditions for end of life decision-making and favor treating these decisions like any other type of medical decision for which duly authorized surrogates are charged. In a society that historically has devalued disabled life, there are obvious risks to leaving these kinds of end-of-life decisions in the hands of even well-intentioned surrogates and providers. The alternative, however, of endorsing more aggressive state action in restricting such decision-making not only suffers from many of the deficiencies enumerated in this paper, but also carries no small amount of irony given that there has arguably been no greater violator of disabled people's rights in the modern era than nation-states themselves. At least part of what fuels our belief in the justification of a preference away from increased legislative restrictions in Mary's case is the fact that there is bilateral agreement between the moral agents involved in Mary's care. Where surrogates and care teams/administrators do not agree, a much stronger case can be made for state adjudication and increased procedural and substantive restrictions on withdrawal of LST.

Our position reflects a commitment to the idea that ethically attuned physicians in concert with thoughtful surrogates are best left a sphere of privacy from state intrusion to make difficult and nuanced end-of-life decisions. Such a position emphasizes the important role that medical professionals have to play in helping patients balance the equally existentially important goals of preventing premature death and avoiding prolongation of an unwanted dying process. It is in this sphere that end-of-life decisions generally belong with state intervention and adjudication best left for matters of interminable disagreement between physicians and surrogates.

References

- Armstrong, E. M., & Abel, E. L. (2000). Fetal alcohol syndrome: The origins of a moral panic. *Alcohol and Alcoholism*, 35(3), 276–282.
- Bachman, J. G., Alcsér, K. H., Doukas, D. J., Lichtenstein, R. L., Corning, A. D., Brody H. (1996). Attitudes of Michigan physicians and the public toward legalizing physician-assisted suicide and voluntary euthanasia. *New England Journal of Medicine*, 334(5), 303–309.
- Bell, K., McNaughton, C., & Salmon, A. (2009). Medicine, morality and mothering: Public health discourses on foetal alcohol exposure, smoking around children and childhood overnutrition. *Critical Public Health*, 19(2), 155–170.
- Benton, E. C. (1990). The constitutionality of pregnancy clauses in living will statutes. *Vanderbilt Law Review*, 43, 1821.
- Buchanan, A. E., & Brock, D. W. (1989). *Deciding for others: The ethics of surrogate decision-making*. New York: Cambridge University Press.
- Burch, T. J. (1995). Incubator or individual: The legal and policy deficiencies of pregnancy clauses in living will and advance health care directives. *Maryland Law Review*, 54, 528.
- Emanuel, E. J., & Emanuel, L. L. (1992). Proxy decision making for incompetent patients: An ethical and empirical analysis. *Journal of the American Medical Association*, 267(15), 2067–2071.
- Gill, C. J. (2004). Depolarizing and complicating the ethics of treatment decision making in brain injury: A disability rights response to Nelson and Frader. *Journal of Clinical Ethics*, 15(4), 277–288.
- Griffin, J. (1986). *Wellbeing: It's meaning, measurement and moral importance*. New York: Oxford University Press.
- Heilborn, M. L., Brandão, E. R., & Cabral, C. D. S. (2007). Teenage pregnancy and moral panic in Brazil. *Culture, Health & Sexuality*, 9(4), 403–414.
- Jerde, A. L. (1999). Breaking through the silence: Minnesota's pregnancy presumption and the right to refuse medical treatment. *Minnesota Law Review*, 84, 971.
- Kothari, S. (2004). Clinical (mis)judgments of quality of life after disability. *Journal of Clinical Ethics*, 15(4), 300–307.
- Kothari, S., & Kirschner, K. L. (2006). Abandoning the golden rule: The problem with “putting ourselves in the patient's place”. *Topics in Stroke Rehabilitation*, 13(4), 68–73.
- Longmore, P. K. (2005). Policy, prejudice, and reality: Two case studies of physician-assisted suicide. *Journal of Disability Policy Studies*, 16(1), 38–45.
- Meisel, A., Cerminara, K. L., & Pope, T. M. (2013). *Right-to-die: The law of end-of-life decision making*. New York: Aspen Publishers.
- MO Rev. Stat. § 459.010 et. seq. (2012).
- Nagel, T. (1986). *The view from nowhere*. New York: Oxford University Press.
- North Carolina. Gen. Stat. § 14–17 (2012).
- North Carolina. Gen. Stat. § 90–322 (2012).
- Ouellette, A. (2013). *Bioethics and disability: Toward a disability-conscious bioethics*. Cambridge: Cambridge University Press.
- Pope, T. M. (2012). Physicians and safe harbor legal immunity. *Annals of Health Law*, 21, 121.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1982). *Making health care decisions: The ethical and legal implications of informed*

- consent in the patient-practitioner relationship*. Washington, D.C.: U.S. Government Printing Office.
- Scully, J. L. (2008). *Disability bioethics: Moral bodies, moral difference*. Lanham: Rowman & Littlefield Publishers Inc.
- Sedwick, J. (2009). The health care risk management professional. In Roberta Carroll (Ed.), *Risk management handbook for health care organizations* (pp. 31–86). San Francisco: Wiley.
- Stabile, C. A. (1992). Shooting the mother: Fetal photography and the politics of disappearance. *Camera Obscura*, 10(1), 178–205.
- Swinburne, R. (1989). *Responsibility and atonement*. New York: Oxford University Press.
- Wardlaw, M. P. (2010). The right-to-die exception: How the discourse of individual rights impoverishes bioethical discussions of disability and what we can do about it. *International Journal of Feminist Approaches to Bioethics*, 3(2), 43–62.
- Winslade, W., & Goldberg, D. S. (2007). Dying in America: Legal decisions, ethical conflicts, and the kinetics of cultural change. *Annual Review of Law and Ethics*, 13(2), 523–563.
- Wolff, K. B. (2011). Panic in the ER: Maternal drug use, the right to bodily integrity, privacy, and informed consent. *Politics & Policy*, 39(5), 679–714.