

**A Critique of the Relational Potential Standard and the Need for Pluralism when
Evaluating Best Interest Decisions for Cognitively Impaired Infants**

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Requests by parents for treatment to prolong the life of minors with disorders of consciousness can be ethically challenging for physicians and nurses caring for these patients. These patients lack the ability to have certain experiences that seem to many to make life worth living, so it seems difficult to reconcile requests for life-prolonging treatment with the application of the best interest standard. If someone lacks any positive experiential quality to their life, then how could living longer be good for them?

Some commentators have proposed what they call the *relational potential standard*, the view that the capacity to form relationships with others is of central importance to a minor patient's interests.¹ Recently, some proponents of the relational potential standard have argued that parental requests for life-prolonging treatment for minors with profound disorders of consciousness should be accommodated, not because the requests are in the best interests of these patients, but instead because they support the family and honor the parent-child

¹ John D. Arras, "Toward an Ethic of Ambiguity," *Hastings Center Report* 14, no. 2 (1984), 25-33; Arras, "Ethical Principles for the Care of Imperiled Newborns: Toward an Ethic of Ambiguity," in *Which Babies Shall Live? Humanistic Dimensions of the Care of Imperiled Newborns*, edited by Thomas H. Murray and Arthur L. Caplan (Clifton Park, NJ: Humana Press, 1985), 83-143.

relationship.² In this paper, I argue that this approach is misguided. Specifically, I argue that the relational potential standard contains an underlying ambiguity, and so either collapses into a more plausible approach for pediatric decision-making captured by the best interest standard or else amounts to the morally unappealing view that pediatric patients may be used as a means to promote their parents' interests.

Two Relational Potential Standards

John Arras formulated the relational potential standard in 1984 in response to the “Baby Doe” case and the subsequent decision by the Reagan administration (later codified into US law) which barred discrimination on the basis of cognitive disability in the provision of life-sustaining and life-prolonging treatment. In the original Baby Doe case in Bloomington, IN, parents of a child born with Down Syndrome refused (on the advice of their physician) surgery to correct a congenital defect in the connection between the child’s trachea and esophagus. This led to the child’s death days later. The surgery itself was likely to be effective and to restore normal functioning to the child, so the parents’ grounds for refusing was that the child would be cognitively impaired.³ While today many would view Down Syndrome as compatible with a rich life worth living, and so not the basis to withhold life-saving treatment out of consideration for the future child’s welfare, other conditions such as spina bifida, microcephalus, neural tube defects, and serious cases of Trisomy 13 and Trisomy 18 often result in profound cognitive defects that might lead us to question the extent to which the child will live a life worth living.

² Aaron Wightman, Jennifer Kett, Georgina Campelia, and Benjamin S. Wilfond, “The Relational Potential Standard: Rethinking the Ethical Justification for Life-Sustaining Treatment for Children with Profound Cognitive Disabilities,” *Hastings Center Report* 49, no. 3 (2019): 18-25; Jenny Kingsley, Jonna Clark, Mithya Lewis-Newby, Denise Marie Dudzinski, and Douglas Diekema, “Navigating Parental Requests: Considering the Relational Potential Standard in the Paediatric Intensive Care Unit,” *Journal of Medical Ethics*, online first (2023).

³ Kathleen Kerr, “Reporting the Case of Baby Jane Doe,” *Hastings Center Report* 14, no. 4 (1984): 7-9; Jack Resnik, “The Baby Doe Rules (1984),” *Embryo Project Encyclopedia* (2011), available at: <https://embryo.asu.edu/pages/baby-doe-rules-1984>.

When we ask parents to apply the best interest standard in deciding whether to accept life-prolonging care for these infants, in what sense can we say that it is in their interest to continue living, given their limited appreciation of the kinds of things that make life worth living?

According to Arras's formulation of the relational potential standard, a normal human life depends on two capacities to make life worth living: the capacity for self-consciousness and the capacity to form relationships with others. When responding to the view that any life is worthwhile for a severely cognitively impaired minor so long as they are not in pain, Arras writes:

The presence or absence of such characteristics as the ability to think, to communicate, to give and receive love, seems to be highly relevant from a moral point of view. Indeed, in the absence of these capacities, it is problematical in the extreme how we can attribute any human interests to the child on which the best-interest standard might operate. When confronted with such cases, one wants to ask, not whether treatment will further the infant's best interests, but rather whether the child's impoverished level of existence is worth sustaining.⁴

In other words, a *necessary condition* for applying the best interest standard to an infant—and to attribute any human interests at all—is that they possess one (or both) of these conditions. When an infant is so cognitively impaired that they lack both (or either) of these conditions, then it becomes difficult to say that it can be *in their interest* to continue living. This is the *negative formulation* of the relational potential standard: without the capacity to form relationships with others (or for self-consciousness), it is not appropriate to apply the best interest standard. Some cognitively impaired minors, in virtue of their cognitive impairments, lack the ability to form

⁴ Arras, "Ethical Principles for the Care of Imperiled Newborns," 121. Cf. Arras, "Toward an Ethics of Ambiguity," 32.

relationships with others and therefore cannot have human interests to which the best the standard can be meaningfully applied.

Arras's approach was influenced by Robert McCormick's analysis of quality of life in the context of the ordinary/extraordinary means distinction. In the Catholic medical ethics tradition, patients with life-limiting or life-threatening conditions are permitted to forego extraordinary means for prolonging life, but not ordinary means (often thought of as nutrition and hydration).⁵ It is difficult, however, to draw a principled distinction between ordinary and extraordinary means. What is ordinary in the descriptive sense depends on what kinds of medical treatments are commonly available: it is quite common to ventilate patients in ICUs or to perform an operation on a newborn baby with Down Syndrome to repair the connection between their trachea and esophagus. Instead, the distinction can be understood in terms of the burdens imposed on the patient: while a patient *can* be kept alive on a ventilator for some time, such a condition might be perceived as excessively burdensome to them, qualifying that intervention as extraordinary in the normative, rather than descriptive, sense. (It is too much to ask of someone to live life on a ventilator for the purpose of keeping themselves alive.) But quality of life judgments can be problematic, especially for cognitively impaired infants, because their cognitive impairments are plausibly thought of as diminishing the quality of their lives. McCormick argues that the idea of quality of life should be understood relative to the remaining potential for good left in a person's life. When the life they face has exhausted (or achieved) all of the potential human good it had, then it would be extraordinary to expect them to continue to live. According to McCormick, when a human life no longer contains the potentiality for human relationships—because it can only be continued in a ventilation facility, or in a neonatal ICU

⁵ Richard A. McCormick, "To Save or Let Die: The Dilemma of Modern Medicine," *Journal of the American Medical Association* 229, no. 2 (1974): 172-76.

under minimal consciousness—then it is no longer providing value to the one living it and may be permissibly ended.⁶ Again, on this view, while the capacity to form human relationships is one of the things that makes life worth living, McCormick’s view is a negative formulation of the relational potential standard because that capacity is presented as a necessary condition for one to have an interest in continuing to live it.

In the 40 years since Arras’s article, the ability of medicine to sustain the lives of infants born with congenital disabilities has greatly expanded. While the first Baby Doe case involved a patient with Down syndrome (a condition that is both non-lethal and compatible with what many would regard as a robust quality of life that would clearly satisfy Arras’s formulation of the relational potential standard), recent advances in treatment have made it possible to keep patients with trisomy 13 and trisomy 18, which are much more severely physically and cognitively impairing, alive for several years. This has led some researchers to no longer regard these as lethal conditions. While life-saving treatment is *possible* in many of these cases, many providers caring for these patients have reservations about keeping this patient population alive.⁷ This reluctance, combined with increasing awareness of the availability of treatment to extend the lives of these infants, has led to the rise of parent advocacy organizations, which accuse providers of “genetic discrimination” if they express reservations about providing life-saving care to these patients. Whereas Arras’s formulation of the relational potential standard anticipated a case where parents wanted to withhold care from their children on account of a cognitive disability and providers or hospitals being unsure whether this was appropriate, a major locus of conflict today involves parental *requests* for a high-level of life-saving care (often involving weeks or months in a neonatal intensive care unit) with providers expressing reservations.

⁶ Ibid., 175.

⁷ John C. Carey, “Management of Children with the Trisomy 19 and Trisomy 13 Syndromes: Is There a Shift in the Paradigm of Care?” *American Journal of Perinatology* 38, no. 11 (2021): 1122-25.

Wightman et al. have proposed what the authors call an “expanded and reformulated” version of the relational potential standard.⁸ Unlike Arras’s formulation, according to which the capacity to relate to others was a necessary condition (or part of a pair of jointly necessary conditions) for living longer to be good for them, their version of the relational potential standard “honors the *capacity* for a caring relationship to flourish.”⁹ Notably, here, the “capacity” in question can be a wholly extrinsic feature of a cognitively impaired newborn: according to the authors, “the caring relationship between parent and child remains morally meaningful even if the child has limited or no observable ability to reciprocate and the relationship may appear one-directional to an outside.”¹⁰ Many relationships, the authors point out, *are* one-sided: even non-impaired infants don’t reciprocate the affection their parents show. They may, to some extent, lack the relevant conceptual schemata to love in the same way that older children or adults do, since they lack the ability to cognize categories or relations like “parent” or “child.” According to Wightman et al., there is moral value in honoring the relationship between parents and children that is irreducible to the value it produces for either party, since it “cannot be broken down into individual gains and losses for the members of the relation.”¹¹ The relationship between parent and child has final value because it “manifests the values and virtues,” such as love and attentive concern, “we take to be integral to a good life.”¹² This value should play a role in clinical decision-making, the authors argue. In some cases, it would support honoring parents’ requests for life-prolonging treatment for a minor patient even when an assessment of benefit to that patient would not favor doing so.¹³

⁸ 20-22.

⁹ *Ibid.*, 20. Emphasis added.

¹⁰ *Ibid.*

¹¹ *Ibid.*

¹² *Ibid.*, 21.

¹³ *Ibid.*, 22.

Jenny Kingsley et al. have explicitly defended the application of Wightman et al.'s reformulated relational potential standard to end-of-life care decisions in pediatric intensive care units. They consider a case in which a toddler is faced with a grim prognosis and is imminently dying of multi-system organ failure. The patient's care team believes that it would be in the best interest of the patient to transition her to comfort measures. Specifically, the authors claim that intubation and cardiopulmonary resuscitation would not be medically beneficial to the patient. The patient's family, on the other hand, are unwilling to let the patient go and request everything be done to keep the patient alive. Although the patient eventually expires, the family in this case appreciates the efforts the care team made to keep the patient alive. The authors argue that applying the best interest standard to cases such as this is challenging, both because the standard leaves parents substantial latitude to determine what constitutes a patient's best interest (i.e., the standard is indeterminate) and because it is difficult to weigh the value of a longer life against perceived suffering and the assault to a patient's dignity for patients who will not live for very long regardless of the care they receive. Kingsley et al. argue that the relational potential standard can be used as a "complementary framework" to the best interest standard, advocating that "clinicians should seek to prioritise the family's values and create conditions that honour the relationship between families and their children, while incorporating provisions to minimize harm to the child."¹⁴ They interpret the two criteria constituting Arras's formulation of the relational potential standard—the capacity for cognition and the capacity to relate to others—as "motivating factors in [clinical] decisionmaking," rather than, as Arras understood the standard, a minimum threshold a patient must meet to *have* interests.¹⁵

¹⁴ Kingsley, et al., 4.

¹⁵ Ibid., 4.

Notably, both Wightman et al. and Kingsley et al. endorse the constraint that the relational potential standard not be applied when doing so would cause significant harm to the patient. Wightman et al. argue that even if clinicians are obliged to respect the familial relationship between parent and child, they still have an obligation to respect the child qua patient. Even in cases of profound cognitive disability, this requires “limiting pain, preventing or removing burdens when possible, and providing the child with the best possible experience of life.”¹⁶ They qualify this claim, however, noting that it does not extend to the putative “burdens” of life-sustaining treatment in the context of cognitive impairment, such as a persistent vegetative state, since whether or not extending a patient’s life in this way is determined in part by the nature of the caring relationship in which they are involved. Kingsley et al. likewise note that the relational potential standard is limited by the harm principle and by a clinician’s duty of nonmaleficence: interventions that are not beneficial to the patient and cause greater than “transient and manageable discomfort” to the patient are not permitted for the sake of the patient’s family.¹⁷

The positive formulation of the relational potential standard, then, can be understood as the following: it is sometimes justifiable to provide life-prolonging treatment to patients with profound cognitive disabilities (including, possibly, permanent unconsciousness) on the grounds that doing so respects their relationship with their families, including supporting the emotional wellbeing of family-members, even when doing so is not in the best interest of the patient. Whereas, on the negative formulation, the ability to form relationships with others was a necessary condition (or one of two jointly necessary conditions) for someone to have human interests, on the positive formulation, it is sufficient: the relationships newborns are a part of

¹⁶ Wightman, et al., 22.

¹⁷ Kingsley, 4.

ground the value their lives have even in the absence of recognition of those relationships or the potential for robust self-consciousness.

Conceptual Issues for Both Formulations of the Standard

Arras positions the relational potential standard as an alternative to the best interest standard. On his view, the best interest standard is limited in its application to severely cognitively impaired newborns and so is an inappropriate standard in their case. But the two standards are not “standards” in the same sense. The best interest standard is a standard for clinical decision-making: it holds that decisions should be made in accordance with the patient’s best interests (as identified by the patient’s decision-maker). Arras’s formulation of the relational potential standard is a “standard” in the sense that it establishes a threshold individual patients must meet in order to have human interests at all. It does not provide guidance regarding which values should be applied when making decisions on behalf of patients who lack the capacities for self-consciousness and to relate to others. It simply requires that, whatever those values are, they cannot be that an extended biological life is good for the patient because the patient lacks the capacities necessary for a longer life to be better for them. Avoiding inflicting suffering is a desideratum for clinical decision-making that Arras endorses even for patients who do not satisfy the relational potential standard, but without satisfying the standard their lives do not have positive value on his view.¹⁸

By contrast, the positive formulation of the relational potential standard is not a threshold view. It *is* a decision-making standard, since it articulates a set of values that may be appealed to

¹⁸ Arras, “Ethical Principles,” 122. Similarly, for McCormick, human life understood as a biological process does not have final value according to his understanding of Judeo-Christian ethics. Instead, that life is valuable insofar as it possesses potentiality for the realization of human goods such as the potential to form relationships with others. See McCormick, 175.

in clinical decision-making. But because it is not a threshold view, it does not really depend on the *potential* on the part of the patient to relate to others. While neither Wightman et al. nor Kingsley et al. define “relationship” for the purpose of applying their version of the relational potential standard, it is clear that the kind of relationship they have in mind can sometimes be a largely one-way affair, primarily consisting of parents having affection for the patient and exhibiting behavior such as caretaking or expressions of love. It’s unclear what, if any, capabilities the patient must actually possess in order to be a part of this (mostly) one-way relationship. For example, it is not clear whether the patient needs to be able to recognize their parents, or even that they are conscious or have the capacity for conscious experience. Certainly, it is unlikely that significantly cognitively impaired minors (or any infants, impaired or otherwise) possess concepts of social roles like “parent” or “family,” so this is presumably unnecessary to be part of a relationship in the sense in question. There does not appear, therefore, to be any definitive cognitive hurdle a patient must clear to be part of a relationship in the sense described by the relational potential standard. It does not even appear that the patient must recognize that they are in a relationship. Wightman et al. do allow that some cognitive impairments might be so severe that the patient is entirely unable to relate to others. In these cases, the authors note, any relationship “would be absolutely one-sided (like that between a parent and a corpse).”¹⁹ But even in these cases, Wightman et al. argue that it can be difficult for outsiders to ascertain whether the relationship is truly one-sided, or what meaning it holds to its members. So while the patient must possess *some* characteristics in order to be part of a loving relationship—they must not be a corpse, or so impaired that their ability to relate to others is the same as a corpse’s—it seems that clinicians will rarely be in a position to say that a relationship

¹⁹ Wightman, et al., 23.

does not qualify for applying the relational potential standard, since it will always be difficult for an outsider to know that the relationship in question is truly one-sided.

It is unclear that Arras's negative formulation of the relational potential standard is even compatible with the positive formulation offered by Wightman et al. and Kingsley et al. For Arras, if a patient has the capacity to relate to others, then it *is* appropriate to apply the best interest standard. The capacity to relate to others is part of what makes life worth living, so prolonging the life of someone who can relate to others can be good for them. There is no need, in such cases, for an alternative to the best interest standard. Conversely, if a patient *lacks* the capacity to relate to others, then it would *not* be appropriate (on Arras's view) to apply the best interest standard, but it would also not be appropriate to apply the relational potential standard, since the patient cannot be part of a relationship in the relevant sense. The negative formulation of the relational potential standard leaves no room to apply the positive formulation advocated by Wightman et al. and Kingsley et al.²⁰

Arras most likely understood the capacity to relate to others in a narrower sense than do advocates of the positive formulation of the relational potential standard. For this reason, the negative version of the relational potential standard seems to be premised on the idea that it can be in the interest of the patient to honor or preserve their relationships with others (and so subject to the best interest standard), since the capacity to relate to others is part of what gives life value. Conversely, the positive version of the relational potential standard only has space as an alternative to applying the best interest standard when we *cannot* say that it is in the best interest

²⁰ What about the capacity for self-consciousness? Recall that this was the other component of the relational potential standard. It is unclear that Arras intended the capacity for self-consciousness and the capacity to relate to others as either individually necessary or individually sufficient conditions for one's continued biological life to be good for oneself. His exact wording is: "In the absence of certain distinctly human capacities—for self-consciousness and relating to other people—the usual connection between biological life and our notion of the good is effectively severed." See Arras, 32. Does he mean the "in the absence of *both*" or "in the absence of *either*"? I suspect, since Arras calls these capacities "distinctively human," that he didn't anticipate them as coming apart in very many cases. One either has both or has neither.

of the patient to prolong their life, but we *can* say that they are part of a relationship with others that should be honored.

The Argument against the Positive Formulation

According to the positive formulation of the relational potential standard, it can sometimes be appropriate to honor requests for life-prolonging treatment for a minor patient with profound cognitive impairment because doing so honors the loving relationship that the patient is a part of. But there is an important ambiguity in this proposal. Should clinical decisions be made that honor the familial relationship because, ultimately, doing so is in the interest of the patient? Or should these decisions be made because, even if the relationship is of no value *to the patient*, it is still valuable—either in an impersonal sense (it “cannot be broken down into individual gains and losses for individual members of the relation”) or because it is valuable to the patient’s parents rather than to the patient?

The former possibility, I think, is at least plausible. Pre-theoretically, I think most readers will have the intuition that it is in one’s interest to be part of a loving relationship, and that others can advance one’s interest by paying respect to that relationship. It would be a helpful intervention to the literature on the ethics of caring for children with profound cognitive impairments to center being part of loving relationship to an account of these children’s interests and to elucidate how it can play a role in clinical decision-making.

This approach, however, is less ambitious than how Wightman et al. and Kingsley et al. present their proposal, viz., as a new standard for decision-making. Honoring the loving relationship a patient is a part of because doing so would be good for the patient is compatible with applying the best interest standard. On this view, a child’s participation in a loving

relationship simply is one interest they have, alongside other interests like the avoidance of pain and suffering or the restoration of normal bodily function. What this approach is missing is an account of *why* being a part of a loving relationship in the sense that severely cognitively impaired infants are—a sense which does not, apparently, require recognition or appreciation on their part—is in these infants’ best interest.

The second interpretation of the relational potential standard—that it favors clinical decisions that are of no value to the patient even if they promote the value of the relationship—is morally unappealing. To show this, it is worth considering what the best interest standard is and what it requires as a clinical decision-making standard. A decision-making standard includes at least a general description of the kinds of reasons that might favor one decision over another within a given domain. For example, according to the best interest standard, things that would characteristically be in a patient’s interest, such as prolonging life or the avoidance of pain, might favor one clinical decision over another. I will call these *deliberative criteria*. Decision-making standards—insofar as they articulate an actual standard one can fall short of—also contain *exclusionary criteria*: an accounting of what sorts of considerations should *not* count in favor of one decision over another. For example, according to the best interest standard, the fact that one clinical decision would be in the financial interest of the provider does not favor one clinical decision over another. “How much money would this procedure make me?” is one thought too many if anything is.²¹

²¹ The notion of exclusionary criteria that I have used here is similar to Joseph Raz’s idea of exclusionary reasons. See Raz, *Practical Reasons and Norms*, 2nd ed. (Princeton: Princeton University Press, 1999) and N. P. Adams, “In Defense of Exclusionary Reasons,” *Philosophical Studies* 178 (2021): 235-53. An exclusionary reason is a second-order reason an agent has not to take another reason into account in practical deliberation. For example, promises generate exclusionary reasons: if I promise to take your interests into account when making a decision, then, in virtue of promising, I have an exclusionary reason to ignore other reasons I might have for making the decision (e.g., my own financial interests, considerations of social wellbeing, etc.). Fiduciary relationships involve exclusionary reasons: a fiduciary has an obligation to act only in the interests of the principal, and so has exclusionary reasons to ignore other values. I use the language of exclusionary *criteria* rather than exclusionary *reason* because I am

The motivation for both the negative and positive formulations of the relational potential standard is that the best interest standard is limited. It seems to have nothing to say in the case of severely cognitively impaired infants beyond advising that exposing them to unnecessary suffering should be avoided. Otherwise, for these patients, it seems as though we do not have a good account of what their interests *are*, and so it seems that, when applying the best interest standard, we have no way to decide whether one clinical course is better than another so long as it avoids unnecessary suffering. This argument emphasizes the function of the best interest standard in applying a set of deliberative criteria to decision-making. But there's no reason why we should assume, if Wightman et al. and Kingsley et al. are right about the importance of human relationships to a person's life, that these relationships cannot be a part of a person's interests in a broader sense. There is no reason to assume that the interests we appeal to when applying the best interest standard include only one's non-relational interests, such as one's experiences (pleasure, absence of pain, abstract cognition).

But the critique of the application of the best interest standard even to severely cognitively impaired patients ignores the exclusionary criterion at the core of the best interest standard: that no one's interests *other than the patient's* should count in favor of one clinical decision over another (except insofar as promoting their interests would thereby promote the patient's interests).²² I suggest that this exclusionary criterion is a deeply morally appealing aspect of the contemporary practice of medicine. It expresses the sense in which doctors and

discussing how the best interest standard says we should deliberate on behalf of a patient. Its exclusionary criteria give us exclusionary *reasons* (to ignore considerations not relevant to the patient's interests) when we have reason to apply the best interest standard.

²² Here, it may seem that I am advancing a conception of the best interest standard that Erica Salter calls an *individualistic* theory rather than a *relational* one, since this standard is exclusively patient-focused. In fact, however, the analysis here is compatible with, and suggestive of, a restricted relational model, in which others' interests may be considered in a limited way, so long as they ultimately benefit the patient. Unrestricted relational models, in which there are not limits on whose interests may be considered in clinical decision making, are not really versions of the best interest standard at all. See Salter, "Deciding for a Child: A Comprehensive Analysis of the Best Interest Standard," *Theoretical Medicine & Bioethics* 33 (2012): 185-86.

surrogates have a fiduciary duty to their patients when they are tasked with making decisions in the interests of patients. Much as it would be a breach of professional duty for a lawyer to provide legal advice that would help their client's associates but would in no way advance their client's interests, doctors frequently bristle at the notion of "treating the family" rather than making clinical decisions with their patients' best interests in mind. If the positive formulation of the relational potential standard is understood as favoring life-prolonging treatment for some patients for the sake of their family members, or their relationships with their family-members, but not for the sake of the patient, then it is incompatible with the exclusionary criterion embedded in the best interest standard, and so incompatible with doctors' fiduciary role for their patients.

The motivation for looking to the family for a set of values to promote in clinical decision-making appears to be this: we can't say exactly what is in a severely cognitively impaired patient's best interest, or even that anything would be in their interest, so we have to let some other value guide our clinical decision-making. Wightman et al. and Kingsley et al. have identified an important source of value close to the patient: the familial relationship they are a part of. Honoring the relationships a patient is a part of ends up being a moral consolation prize: we can't promote the patient's interests, because we can't say what those are or even if the patient has any real *human* interests, so we may as well make clinical decisions that promote some other value, viz., the value of the familial relationship the patient is a part of.

Once we are in the business of looking for other values to promote besides the patient's own interests, why stop there? Arras suggests another source of value we could use to make clinical decisions for this patient population when he writes that keeping them alive "is pointless

and burdensome to parents and society.”²³ We could also use considerations of overall social utility when determining whether to provide life-prolonging care to patients with profound disorders of consciousness. Perhaps we could refuse to do so (as Arras appears to be urging) because it is costly for society. Or we could refuse to do so when the patients in question have tissue or organs that might be donated so as to keep others alive.

Another source of value which might be considered is the emotional wellbeing of the physicians, nurses, and other allied professions who care for dying patients with severe cognitive impairments. For many providers, watching a trisomy 18 baby gasp for air while they have to increase vent settings because their parents insist on keeping the baby alive as long as possible is deeply distressing. It may be a cause of burnout in the profession.²⁴ Once we have given up on the project of locating the rationale for clinical decisions in the patient’s best interest, it seems that we should be open to considering how these decisions affect the patient’s other caregivers as well.

Wightman et al. and Kingsley et al. do not propose allowing considerations of social utility or the interests of providers to drive clinical decision-making. I suspect they would not accept the social utility standard or the provider wellbeing standard as competing alternatives to the relational potential standard and the best interest standard. But to rule out these standards, they would have to acknowledge at least the partial appeal of the best interest standard’s exclusionary criterion: health care providers should *not* be thinking of what is good for society rather than the patient, or what would promote their own wellbeing, when making clinical decisions.

²³ Arras, “Toward an Ethics of Ambiguity,” 32.

²⁴ See Lyndsay Mackay, Karen Benzies, Chantelle Barnard, and Shelley Raffin Bouchal, “Health Care Professionals’ Experiences of Providing Care to Hospitalized Medically Fragile Infants and Their Parents,” *Journal of Pediatric Nursing* 53 (2020): 18-19.

One could argue that considerations of familial wellbeing are more important than social utility or clinician wellbeing. But it seems unlikely that this would be true either in all cases or even generally speaking. In cases where medical resources such as neonatal ICU beds are scarce, sparing one family from the distress of having less time to spend with their baby may mean that another family spends less time with theirs, or even that another patient dies who might have lived. Moral distress can be quite harmful to providers much as feeling like doctors did not do everything they could to keep one's baby alive can be traumatic for parents. Furthermore, the loss of doctors who burnout may worsen the care for future patients, creating new tragic cases and new traumas.

One might also argue that what is different about the familial relationship is that it is characterized by a relationship of love and care, and that this has distinctive moral value that should be honored beyond its instrumental value to the patient's wellbeing. But the relationship doctors and nurses have with dying infants is also characterized by care and, if not love, strong attachment to the wellbeing of the patient. Even social institutions, if they are functioning well (at least according to proponents of the ethics of care), are characterized by relationships of mutual care.

The best interest standard's exclusionary criterion articulates a powerful norm of medicine: that clinical decisions should be directed at promoting their patients' best interests, *not* the interests of others (except insofar as doing so promotes their patients' interests). This is an important ideal with moral value, and it's one that is not compatible with the relational potential standard on the interpretation under consideration here. So clinical decision-making should not be aimed at supporting the patient's family or paying respect to the relationship the loving relationship the patient is a part of, unless doing so would be in the patient's best interest.

In the remainder of this section, I will add some points of clarification that (hopefully) head-off objections to the argument I have given.

First, it may seem that the argument I have given has the form of a slippery slope fallacy: we should not consider the interests of a patient's family because, if we do, then we would have to admit considerations of social utility and provider wellbeing in clinical decision-making, and everyone agrees that this would be morally unappealing. This is not the argument I am making. Instead, I think it's easier to see why the practice of withdrawing care from a patient because doing so would save society money, or because doing so would ease provider distress, would at least be morally troubling. I think the best reason for *why* this is morally troubling is that contemporary medicine is committed to what I have called the exclusionary criterion embedded in the best interest standard. Once we see that we are committed to the exclusionary criterion, I think it becomes easier to see why the interests of family members or the impersonal value of the family also should not be applied to clinical decision-making as well.

Second, the exclusionary criterion as I have described it may seem too severe. For example, there seem to be cases in which it would seem too strident, even inhumane, to not consider the interests of family members. Suppose a patient's code status has been changed to "comfort measures only" and now it is time to extubate him. His mother, however, is traveling to the hospital and won't be at bedside until tomorrow. Suppose that staying intubated until tomorrow is, in no sense, in the patient's best interest: it provides him no medical benefit; and suppose that he was born without the capacity to recognize or interact with others, and so never once in his life recognized his mother or appreciated her love. It would seem harsh, perhaps monstrous, to insist on principle that the patient must be extubated *now*, because the decision to

wait would in no way serve the patient's interests but only his mother's. But, surely, seems that we must consider the patient's mother's interests in order to support waiting.

On my account, the exclusionary criterion does favor not considering the patient's mother's interest in being at the bedside when deciding whether to extubate now. According to a strict application of the best interest standard, only the patient's interests should be taken into account, and the case stipulates that waiting would not be in the patient's interest. In the next section, I suggest that this stipulation may not be correct, and that we should defer to the patient's mother if she asserts that it would be in her son's interest to remain alive a day longer so that she can see him even if he is not aware of her presence. But for the purposes of responding to this objection, I will assume that this is not the case, and that it would be wrong to say that waiting is in any way in the patient's interest. I would concede that this is harsh and an unappealing consequence of strict adherence to the best interest standard. But it arises from the *strict application* of the standard. Nearly any standard or principle, if strictly adhered to, can produce unappealing consequences. Most would endorse the standard that people shouldn't take what is not rightfully theirs, but they would also acknowledge that this standard should be bent in cases like Jean Valjean's, who steals a loaf of bread to feed his family in *Les Misérables*. It is important, however, that such decisions *are* cases of bending the standard to make it less rigid in practice. In the case of waiting a day to extubate (if the patient truly has no interest in his mother seeing him one last time) still represents a deviation from an ideal of patient-regarding care. The exclusionary criterion captures an important aspect of what it is to make clinical decisions well, but there may be times when it making clinical decisions well is not the only important consideration, especially when the decision in question would probably not make very much difference to the patient. Instead of attempting to list what must be many possible exceptions—

should we only consider the patient's interests in cases of acute scarcity? What about a natural disasters or wars, when health care workers must evacuate?—it is better to leave the exclusionary criterion in its exceptionless form and to say that sometimes it can be all-things-considered justified to accept a minimal infringement on the patient's interests when there is some powerful competing consideration.²⁵

Third, it may seem as though the argument I have given emphasizes potentially conflicting interests between minors and their parents. Proponents of the positive formulation of the relational potential standard locate the view within the ethics of care more broadly, and a central insight of care ethics is that standard normative ethics portrays ethics as a clash between competing individual interests or rights. Instead, on this view, the caring relationship itself is a source of value and represents a space in which the interests of parties in this case align. I do not have a response to the general critique of normative ethics, except to say that in some cases it *is* possible for patients and their families to have competing interests, and that if considering such a possibility is inconsistent with the care ethics approach then so much the worse for care ethics. When the interests of a patient and their family conflict, the best interest standard favors basing clinical decisions on the patient's interest. If the care ethics critique of traditional individualistic ethics is understood as being the claim that sometimes individuals do, generally speaking, have an interest in their relationships with their families and caregivers being respected, then I agree

²⁵ The view offered here is similar to Lorraine Koppelman's negative version of the best interest standard, which requires decision-makers to first establish what would maximally promote the patient's benefits and minimize their burdens, establish that as a *prima facie* duty, and then to interpret what their all-things-considered duty is in light of moral and legal duties persons have toward incompetent individuals. See Koppelman, "Rejecting Baby Doe Rules and Defending a 'Negative' Analysis of the Best Interests Standard," *Journal of Medicine & Philosophy* 30 (2005): 347. It also conforms to the overall normative structure of exclusionary reasons. Recall that promising to only act to serve another person's interests generates exclusionary reasons not to consider factors not relevant to the principal's interests. Still, we would tolerate deviations from this norm if the stakes were sufficiently high: if, e.g., somehow by being committed to only serving your interests I have committed myself to assisting you in egregiously harming someone else. Sometimes it is all-things-considered justifiable to break a promise because promise-keeping isn't always more important than other conflicting values.

with that insight. If this insight is correct, however, that would seem to be a problem for the positive formulation of the relational potential standard, because it would remove the motivation for accepting the standard: if we can say that it is in a patient's *interest* to have their relationship with their families or caregivers respected, then the best interest standard can justify honoring those relationships and we would not need a separate decision-making standard to explain why respect for familial relationships is important.

Finally, it may seem that I have given a version of the mere means objection: that applying the relational potential standard would involve using minors as mere means, which is ethically objectionable. Kingsley et al. respond to this objection in their paper. This is not the objection I am making. The mere means objection is generally understood to be associated with Kantian ethical theory. This is how Wightman et al. and Kingsley et al. understand it.²⁶ My argument is not grounded in Kantian ethics, nor is it an objection to using people as mere means in cases outside of medicine. (These issues lie outside of the scope of this paper.) The exclusionary criterion I have articulated is part of a standard for making clinical decisions in medicine. The justification for applying this standard in clinical decision-making need not be Kantian. Consequentialists could endorse the principle because, a consequentialist might argue, when every doctor pursues the good of their patient, the medical system produces the most good overall. Or one could hold the view that medical professionalism is really an account of the virtues characteristic of a good doctor, since a good doctor puts their patients first. The objection can be articulated without appealing to any particular moral theory.

Respect for Parents and Respect for Pluralism

²⁶ Of course, one could also object to treating others as mere means without accepting much of the rest of Kant's ethical theory.

In the previous section, I suggested that we either accept that severely cognitively impaired minors can nevertheless have an interest in being part of a loving relationship with others—even if they are incapable of recognizing that they are in such a relationship or appreciating most aspects of it—in which case we should reject the relational potential standard because its contribution to clinical decision-making is already captured by the best interest standard; or we reject the relational potential standard because it applies the wrong kinds of reasons to clinical decision-making. If we do not take the first approach, then we are left with Arras’s conclusion from his 1984 paper: whatever we are doing when we prolong the lives of these patients, we are not promoting their interests, so we should therefore stop prolonging their lives. This is a conclusion I believe some providers entertain after having encountered tragic cases in which minimally conscious children are kept alive because their parents cannot, from these providers’ perspective, let go. It would also be a highly revisionist account of our clinical practice, with potential implications outside of pediatric ethics. Pediatric patients are not the only patients who lack cognitive capacities we normally associate with self-consciousness and the ability to relate to others, nor are they the only patients for whom the best interest standard is applied. An unrepresented adult patient with a devastating brain injury may have no family and no known advance wishes. It would seem to follow that we have no basis to say that we are promoting this patient’s interest by keeping them alive, either.²⁷

In this section, I attempt to pursue an alternative approach. One insight from the positive formulation of the relational potential standard is that we should take requests by parents to prolong the lives of cognitively impaired patients more seriously. I think this is, practically speaking, the right result. But, on the view I will outline, the reason we should do so is not

²⁷ Notably, even adherents to the positive formulation of the relational potential standard would lack resources to help here, since this person in the case described is not part of a loving relationship.

because that would be good for the parents or the familial relationship, but rather because we are trying to promote the best interests of the patient.

First, whatever one's favored position on the question, there is a great deal of uncertainty as to what gives life meaning and value. Axiology falls short of being an exact science. One candidate proposal is that, for something to be in someone's interest, whether they have it or whether it occurs must either (a) potentially make a difference to their conscious experience, or else (b) be something that they antecedently desired. (a) and (b) seem to explain why many find it hard to see how they, or someone else, could have an interest in being kept alive on ventilatory support in a persistent vegetative state, and so devoid of conscious experience, unless they had an antecedent desire to be kept alive in this way. Since (a) and (b) require certain forms of cognition, I will call this the *cognitive constraint* on what is in a person's interest.²⁸

The cognitive constraint is plausible, but it is neither obvious nor universally accepted. Wightman et al. quote an exasperated nurse exclaiming to the patient's mother: "Some people here don't think he has a soul."²⁹ Perhaps this indicates an alternative conception of what might be good for a person: if the child has a soul, then their time in this life is a gift to be cherished even if the patient lacks conscious experience, since the soul will persist after the death of the body and still derive meaning and value from the person's experiences in life. Contemporary medicine does not appeal to the soul to explain why a patient is in pain or why a patient has died, but neither does it deny that souls exist. Many health care providers, in fact, believe in souls,

²⁸ One might argue that the cognitive constraint can be supported because interests are psychological attitudes one might have toward a state of affairs. This would imply that some degree of cognition—indeed, higher-order cognition, such as the ability to imagine some possible state of affairs and to take on the attitude that it would be desirable—is necessary in order for anything to be in one's interest. But this seems like an unduly narrow conception of a person's interests. First, we routinely talk about entities that lack this kind of representational capacity as having interests: animals, infants that are not severely cognitively impaired, institutions, nations. Second, even if one favors this conception of what it is to have an interest on conceptual or philosophical grounds, it is clearly subject to reasonable disagreement.

²⁹ Wightman, et al., 21.

something that could potentially be a source of value to someone independently of their subjective desires or experiences. While many would no doubt be skeptical that there is a soul—or, at least, if there is one, that it has a kind of disembodied existence independent of the body and can form the basis of the interests a person has independently of their experience—the objections to the soul theory are generally only to perceived deficiencies of it as an explanatory theory: substance dualism has a problem explaining how the soul interacts with the body; positing a soul is unparsimonious because we don't need it to explain natural phenomena. These are arguments against believing in or positing a soul, not affirmative reasons to deny that there is as soul. Many people use their religious beliefs to understand the world and their place in it, and the soul may be indispensable to *their* belief systems. Consequently, it may be part of their conception of what a good life is and a basis for determining what is in a living person's interests.

The point is not that we should honor parental requests for life-prolonging care because the patient might have a soul. Rather, it is that while the cognitive constraint is a plausible view about what must be true for something to be in someone's interest, there are other competing views that might form the basis of an account of what is in a person's interest. In most societies, we allow parents wide latitude in interpreting what is in their children's best interest. This is not because parents are experts about philosophical questions such as what makes life worth living, or because they never make grievous mistakes. Instead, it is because we don't have a social or expert consensus around what gives life meaning, so it is unclear that anyone else has the requisite insight to do a better job. It is far from clear that attempting to settle the question of what is in a child's best interest is something administrative agencies, experts, or doctors (some of whom believed, when Arras was writing, that Down syndrome patients had no interest in

living, either) are likely to do better than parents. The best approach to making decisions that will be in a patient's best interest is to allow someone who cares for them and is motivated to make a good decision, no *worse* than other candidate decision-makers (such as doctors or ethics committees) at determining what might make their life worth living. The appropriate way to respect parents in a clinical decision-making context is not to make treatment decisions for their benefit rather than for the patient's. Instead, it is to exhibit epistemic humility when they assert that living longer as part of a loving relationship is good for their child and to be open to deferring at least in some cases to their judgment.

This approach to applying the best interest standard is pluralistic. It requires providers generally to defer to parents' conceptions of what gives their cognitively impaired children's lives value. This approach may seem unsatisfying, both philosophically and as a decision-making standard. Arras considers and rejects what may seem like a similar result. He points out that the question of how to treat cognitively disabled infants really involves two distinct issues: the procedural question of who gets to decide and the substantive (or first-order) question of what they should decide (i.e., under what conditions is it permissible to treat or withhold treatment on the grounds of cognitive disability?).³⁰ Borrowing a concept from John Rawls, Arras claims that many conceive of questions of care for impaired minors as a kind of *pure procedural justice*: so long as the correct procedure is followed—the parents decide—then whatever outcome results—i.e., whatever the parents decide—is appropriate.³¹ It may seem that the pluralistic approach that I am urging here is a kind of pure procedural justice.

But this is not the case. *Pure* procedural justice for Rawls is the view that any outcome of a just (or correct, in this case) procedure is just in virtue of being the outcome of that procedure.

³⁰ Arras, "Ethical Principles," 84.

³¹ *Ibid.*, 84-85.

Fair competition for sport is an example of pure procedural justice: if someone were to ask which team should win a match, the right answer is whichever team scores the most points in a fair match. The fairness of the procedure is what makes the outcome fair, and there is no independent criterion of fairness to which to compare the outcome. Applying this idea to parental decision-making for cognitively impaired newborns would be to say that the fact that the parents decided on some course of treatment is what *makes* it right for their child: there is no more to what is in the interests of a child (at least, a sufficiently cognitively impaired child) except for what their parents want. On this view, the interests of children are imputed to them by their parents. This is actually similar to the positive version of the relational potential standard, in which the attitudes constitutive of a relationship such as love and affection are imputed by the parents onto the child, who may lack any ability to know love.

On the pluralistic account that I am proposing, parental decision-making is instead analogous to what Rawls calls *imperfect procedural justice*. In imperfect procedural justice, there is some independent standard according to which some outcome is just or unjust, and the procedures we use to realize that outcome do not perfectly yield that result.³² If we were to ask, returning to the competition analogy, not which team should be declared the winner (whichever scores the most points, of course), but which team *deserves* to win, we see that fair competition only imperfectly tracks deservingness to win. Sometimes, a competitor deserves to win—they worked harder, endured more adversity than the other competitors, exhibited greater excellence in play—yet they still lose due to bad luck. Sometimes competition seems to yield the unjust result that the lucky rather than deserving team wins, and this seems unfair. In this sense, competition can be understood as exhibiting imperfect procedural justice. On the pluralistic approach to decision-making for cognitively impaired minors, there may well be a fact of the

³² Rawls, *A Theory of Justice*, rev. ed. (Cambridge, MA: Harvard University Press, 1999), 74-75.

matter regarding whether it is in an infant's interest to live longer or to be spared the pains of medical intervention that might lengthen their lives for a few months or a few years. And there is no guarantee that parental decision-making according to their conception of the child's best interest will arrive at the right answer. The case for respecting parental decision-making in these cases does not rest on the ability of parents to reliably determine what is in the best interest of their cognitively impaired children, but rather on the weakness of the claim of anyone else's ability to do a better job.

This point of clarification illustrates how the pluralism of parental decision-making might be constrained. Unconstrained pluralism is unjustifiable in parental decision-making. As Arras points out, we would not feel comfortable deferring to parents who say that it is not in the interest of their otherwise healthy baby to get a surgery needed to sustain their life so that the parents can be spared the burden of raising the child or because they really wanted a girl.³³ Pluralism should still be reasonable. Reasonableness is, however, an amorphous concept and difficult to use as a practical constraint on parental decision-making. Much as we lack a consensus on what features of a life lend it meaning, we also lack a consensus regarding which requests by parents are reasonable. We do, however, have a consensus that certain things are in any child's interest. For example, there seems to be a consensus that even severely cognitively impaired infants have an interest in not being subjected to unnecessary suffering. This suggests widespread agreement that suffering is a bad-making feature of any human life, regardless of how capable that person is of complex cognition. We also have a general consensus that, where possible, the quality and complexity of experience a person has can be a good-making feature of their life, the richness of the relationships. While it would be difficult to provide a set of necessary and sufficient conditions for a judgment about what is in a child's best interest to be

³³ Arras, "Ethical Principles," 85.

reasonable, one requirement is that the judgment not radically discount one of the good-making features of a human life about which there is a reasonable overlapping consensus. Someone who, for example, insists on life-extending treatment at all costs, regardless of the pain they inflict on their child, in order to sustain as long as possible the relationship they have with that child, is radically discounting the importance of avoiding pain to that child's interest and so is insisting unreasonably. (This is a position Wightman et al. and Kingsley et al. would agree with, given that they reject honoring requests for care that might harm a newborn for the purpose of upholding the familial relationship.) Similarly, the parents of an otherwise healthy child are choosing unreasonably if they decide that the quality and richness of that child's future experience count for nothing against the incidental discomfort that the procedure might cause.

Conclusion

In this paper, I have argued that the relational potential standard suffers from an underlying ambiguity: whether promoting a patient's family's interest is understood as part of a patient's interests or not. I have argued that neither side of this ambiguity supports accepting the relational potential standard, and so we should therefore reject it. I have also attempted to provide a defense of what I take to be the positive contribution of the view, that we should accept that being part of a loving relationship may be of value to severely cognitively impaired minor patients even if they lack the ability to recognize that they are in such a relationship. We should do so not because this would be good for parents or the relationship as such, but because we should be open to a wide degree of pluralism in parents' determinations of what is in the best interest of their children.