



Policy Analysis

Parental Refusal of Recommended Pediatric Treatment: Ethical and Legal Tensions

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ABSTRACT

Parental refusal of recommended pediatric treatment sits at the intersection of parental authority, child welfare, and, at times, third-party interests, and the frameworks used to resolve it are more differentiated than a simple parental-rights-versus-intervention framing suggests.

This analysis surveys the best interests and harm-principle standards used to justify overriding parental refusal, narrower doctrines of medical tolerance and second-best accommodation used to avoid escalation, and considerations distinctive to religious refusal, withdrawal of life-sustaining treatment, and refusal of preventive care such as vaccination.

It also examines the mature minor doctrine and adolescent decision-making capacity, which increasingly treats the adolescent as a party to the refusal rather than only its subject.

Across these scenarios, the harm threshold justifying intervention and the weight given to parental values shift depending on whether harm is immediate or probabilistic, borne by the child alone or by others, and whether adolescent capacity is implicated.

We conclude that no single doctrine resolves these disputes, and that defensible policy calibrates the intervention threshold to each scenario's harm profile rather than applying one uniform standard.

Keywords: parental refusal; pediatric ethics; best interests standard; informed consent; mature minor doctrine

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INTRODUCTION

Pediatric medicine rests on a legal fiction that mostly works: because children cannot consent for

themselves, parents consent on their behalf, and the law treats that substituted judgment as if it were the child's own. The fiction holds up reasonably well when parents and physicians agree about what a sick child

needs. It comes under real strain the moment they do not, and recommended-treatment refusal is where that strain shows most clearly -- a parent declining chemotherapy, blood products, vaccination, or continued life support that a clinical team believes the child needs. Diekema's influential formulation frames the question not as whether parents may ever refuse recommended care, since some refusal is an ordinary and legitimate exercise of parental discretion, but as where the harm threshold sits above which the state may override that discretion [1]. That threshold has never been fixed by statute in any precise, portable way; it is worked out case by case, informed by a body of case law and commentary that has grown considerably since the classic religious-refusal disputes of the mid-twentieth century.

What makes the topic harder than a simple parental-rights-versus-child-welfare framing suggests is that the "best interests of the child" standard invoked to justify overriding a refusal is itself contested, both in what it means and in who gets to apply it. Sheldon has argued that debates over pediatric decision-making frequently skip past a prior question -- not what is in a child's best interest, but who holds legitimate authority to decide that in the first place, parents, physicians, courts, or the state acting through child protective mechanisms [2]. That question of legitimate authority runs through nearly every scenario examined below: refusal grounded in religious conviction, refusal of life-sustaining treatment judged futile or nearly so, refusal filtered through an adolescent's own emerging capacity to decide, and refusal of preventive care such as vaccination that implicates other people's health as much as the child's own.

THE BEST INTERESTS STANDARD AND ITS LIMITS

The best interests standard is often presented as though it supplies a determinate answer once the relevant medical facts are known, but in practice it functions more as a threshold for state intervention than as a formula for resolving disagreement. Diekema's harm principle reframes it explicitly this way: intervention is warranted not whenever a court could imagine a marginally better option than the parents chose, but when parental choice imposes a risk of serious harm the child cannot be expected to accept for themselves, and when the treatment being demanded actually works, carries acceptable risk, and no less intrusive option achieves comparable benefit [1]. That four-part test deliberately sets a high bar, precisely because a lower one would authorize routine second-guessing of ordinary parental medical judgment, most of which involves genuine trade-offs rather than clear right answers.

The limits of the standard become visible once care teams are asked not just whether to override parental refusal, but whether to accommodate parental demands for something less than the clinically optimal

option. Nair and colleagues examine this inverse problem directly: when should physicians agree to a "second-best" treatment a parent will accept, rather than escalate to legal override in pursuit of the first-best option [3]. Their answer turns on much the same proportionality logic as Diekema's harm principle, but applied to accommodation rather than override -- the acceptability of settling for less depends on how much benefit is actually lost, not merely on whether the parents' preferred option is technically inferior. Table 1 summarizes how several of the standards discussed in this review differ along the two dimensions that drive most of the disagreement in the literature: how serious the anticipated harm must be before intervention is justified, and how much weight is given to parental values once a plausible, if imperfect, treatment option exists.

Table 1. Selected standards invoked in pediatric treatment-refusal disputes, compared by the harm threshold each requires and the weight it gives to parental values once a plausible treatment option exists.

Standard	Harm threshold for intervention	Weight given to parental values	Primary source
Harm principle	Serious, preventable harm from a treatment that works, is low-risk, and has no comparably effective alternative	High, below the threshold; parental discretion governs ordinary trade-offs	Diekema (2004)
Second-best accommodation	Loss of benefit from the parent-preferred option, not mere technical inferiority	High, provided the accepted alternative is not clearly harmful	Nair et al. (2017)
Medical and social tolerance	Deviation large enough to threaten the therapeutic relationship or child welfare	Moderate; some deviation absorbed without escalation	Guadarrama-Orozco et al. (2015)
Best interests (court-applied)	Best-interests determination by a court, typically in life-sustaining-treatment disputes	Low once litigation is underway; court substitutes its own judgment	Wilkinson (2020); Charlie Gard line of cases

Guadarrama-Orozco and colleagues, writing from a Latin American clinical-ethics perspective, describe a related but distinct concept: a threshold of "medical and social tolerance" within which physicians accept a degree of parental deviation from the recommended plan without pursuing legal escalation, precisely because pushing every disagreement toward court intervention would itself damage the therapeutic relationship and, with it, the child's overall care [4]. This tolerance threshold is rarely written into policy, but it does a great deal of the practical work that formal best-interests doctrine leaves unspecified.

RELIGIOUS AND PHILOSOPHICAL OBJECTIONS TO TREATMENT

Religiously motivated refusal remains the paradigm case in both legal doctrine and public perception, not because it is statistically the most common form of pediatric treatment refusal but because it presents the harm-versus-autonomy tension with unusual clarity: a sincerely held, constitutionally protected belief on one side, and a child's survival or health on the other. Courts in the United States and comparable jurisdictions have converged on a now-familiar distinction, traceable to mid-century case law, between an adult's right to refuse treatment for religious reasons and a parent's much more limited right to make that same refusal on a child's behalf -- religious liberty protects the believer, not a third party who has not chosen the belief and bears the medical consequences of it.

De Vos and colleagues examine a harder variant of this problem: parents who wish no further treatment for their child, not necessarily from religious conviction but from an assessment -- sometimes aligned with clinical opinion, sometimes not -- that continued treatment causes more suffering than benefit [5]. Their findings complicate any simple story in which parental refusal is reflexively treated as a threat to be managed; some refusals track the same proportionality judgments physicians themselves would endorse, and distinguishing those from refusals driven by denial, distress, or belief requires more than a fixed doctrinal rule can supply on its own.

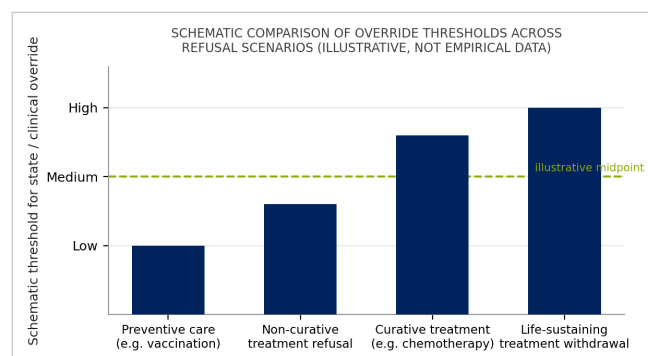
The most widely cited illustration of the stakes involved remains the case of Billy Best, an adolescent with Hodgkin lymphoma who ran away from home in 1994 rather than continue chemotherapy his parents supported but he personally refused, and who ultimately survived after pursuing alternative treatment -- an outcome that has been invoked ever since on both sides of the refusal debate. Marron and colleagues revisit the case twenty-five years later and note how selectively it gets deployed: as proof that conventional oncology recommendations can safely be second-guessed, or, just as often, as a case whose favorable outcome was fortunate rather than representative, and whose real lesson concerns adolescent voice in treatment decisions rather than the wisdom of refusal itself [6]. Read against Diekema's harm principle, the case is less a counterexample to state intervention than a reminder that intervention decisions are made prospectively, under uncertainty about which patients will do well despite refusing recommended care.

LIFE-SUSTAINING TREATMENT, FUTILITY, AND THE LIMITS OF PARENTAL AUTHORITY

A separate and in some ways more difficult category concerns refusal not of curative treatment but of its

withdrawal -- parents insisting that life-sustaining treatment continue against a care team's judgment that it is futile, or, in the mirror-image dispute that produced the Charlie Gard litigation, parents seeking to pursue further treatment a hospital and courts judged to offer no realistic benefit and a meaningful risk of prolonging suffering. Wilkinson's analysis of the Charlie Gard case argues that its most consequential and least discussed feature was not the underlying best-interests determination, which was relatively uncontroversial among treating clinicians, but the international attention that turned a difficult clinical-ethics dispute into a referendum on whether courts should ever obstruct parents from transferring a child abroad for experimental treatment at their own expense [7]. That question, Wilkinson suggests, deserves a more cautious answer than the case's public framing implied: obstructing international transfer is a significant restriction on parental authority that requires its own justification, distinct from the justification for the original treatment-withdrawal decision.

Figure 1. Schematic, illustrative comparison of how far a refusal scenario tends to sit from a state or clinical override threshold, from routine preventive-care refusal through to disputes over withdrawing life-sustaining treatment. The scale is qualitative (Low/Medium/High) and is not derived from a single empirical study.



Pope, Ruck Keene, and Chandler examine a related and increasingly contested procedural question: whether parental consent is required before brain-death testing is performed on a child, given that families sometimes object to the testing itself rather than only to its implications [8]. Their analysis illustrates how far these disputes now reach beyond the classic refusal-of-treatment scenario into the diagnostic process that precedes any treatment decision at all, and how unsettled the answer remains across jurisdictions.

Cicero-Oneto and colleagues' qualitative study of therapeutic futility decisions among Mexican adolescents with cancer adds an empirical dimension often missing from doctrinal analysis: clinicians, patients, and family members frequently disagree not about the facts of prognosis but about what counts as an acceptable burden to bear for a given probability of benefit, and futility determinations that treat this as a purely clinical judgment tend to obscure the values

question actually driving the disagreement [9]. Paquette and Vinarsik extend the authority question into an institutional setting the classic parental-refusal literature rarely addresses: children in state custody, for whom no parent is available to consent or refuse at all, and for whom the state itself occupies the decision-making role the best-interests standard was designed to check [10]. Figure 1 sets out, schematically rather than empirically, how the practical threshold for state or clinical override tends to shift across several of the scenarios surveyed in this review, from routine refusal of a preventive intervention through to withdrawal-of-care disputes where courts have shown the greatest willingness to act.

ADOLESCENT CAPACITY AND THE MATURE MINOR DOCTRINE

Much of the analysis above treats the child as the object of a decision made about them, but a growing body of literature asks instead when the child should be a party to the decision, or its principal author. The mature minor doctrine, recognized in varying forms across jurisdictions, allows an adolescent judged to possess sufficient understanding and appreciation of a treatment decision to consent to or refuse it largely on their own terms, independent of parental wishes. Diekema's account of adolescent brain development urges caution about applying this doctrine too broadly, noting that the neurocognitive capacities relevant to medical decision-making, particularly under emotional stress and time pressure, continue developing well into the twenties, which complicates any bright-line age threshold for treating adolescent refusal as fully autonomous [11].

Nemetz, Huang, and Das push back against an overly paternalistic reading of that caution, arguing that excluding adolescents from medical decision-making on developmental grounds alone risks treating a genuinely heterogeneous population as uniformly incompetent, when the more defensible approach evaluates the specific decision, its stakes, and the individual adolescent's demonstrated understanding [12]. Spencer's earlier analysis of children's competency to consent frames the underlying dilemma in terms that still apply: competency assessment inevitably imports adult judgments about what counts as a "good" decision, which risks treating disagreement with the recommended treatment as evidence of incompetence rather than as a legitimate, if unwelcome, exercise of the adolescent's own values [13].

The doctrine's edge cases are instructive. Turnham, Binik, and Wilkinson examine the unusual situation of parents who are themselves minors, asking whether a minor parent's legal capacity to refuse treatment on their child's behalf tracks their own contested capacity for autonomous decision-making, or whether it should instead default to a more protective standard given the added layer of dependency involved [14]. Vrouenraets

and colleagues study a different capacity question in the context of puberty-suppression treatment for transgender adolescents, finding that clinicians, parents, and adolescents themselves frequently assess decision-making competence differently, with parents tending to weight long-term uncertainty more heavily than the adolescents whose bodies and futures are actually at stake [15]. Fishman and colleagues' broader review of surrogate decision-making for children situates both disputes within a single unresolved question -- who should decide, and on what basis -- that the field has not settled so much as developed increasingly sophisticated frameworks for managing case by case [16]. Goldstick and Peled-Raz's analysis of contraceptive prescribing to minors without parental consent illustrates how the same capacity question recurs even for interventions far removed from life-threatening illness, wherever an adolescent's interest in confidentiality and autonomous access collides with a parent's presumptive authority over their medical care [17].

VACCINATION REFUSAL AND THE PUBLIC HEALTH DIMENSION

Vaccination refusal occupies a distinct category within this literature because the harm at issue is not confined to the child whose parent declines the recommended immunization; unvaccinated children contribute to community transmission risk that falls disproportionately on infants too young to be vaccinated and on immunocompromised patients who cannot be. Calandrillo's long-standing analysis of vaccine exemption law traces how broadly worded religious and philosophical exemptions, originally intended as narrow accommodations, expanded over subsequent decades into a much larger opt-out mechanism whose public health costs became visible only once vaccination rates fell far enough, in certain communities, to permit outbreaks of diseases the vaccines were specifically designed to prevent [18].

A recent case discussed by Basu Roy and colleagues sharpens the analysis considerably: parental refusal of hepatitis B vaccination at birth for an infant born to a hepatitis B-positive mother, where the intervention exists specifically to prevent vertical transmission and where the harm of refusal, unlike many other vaccine-refusal scenarios, is neither probabilistic nor deferred but immediate and substantial [19]. Their discussion of when this particular refusal crosses the threshold for state override illustrates how much the harm-principle analysis depends on the specific epidemiology of the intervention being refused, rather than on any general rule that vaccination refusal either always or never justifies intervention. Brusa and Barilan take the underlying authority question in a different direction, arguing that where an adolescent has the relevant capacity, direct clinician engagement with the adolescent's own vaccination preferences

may be more appropriate than routing the decision exclusively through parental consent, particularly for vaccines, such as those against sexually transmitted infections, where parental refusal sometimes reflects discomfort with the underlying health topic rather than a considered risk-benefit judgment [20].

CONCLUSION

No single doctrine covers the full range of situations this review has surveyed, and that is not really a gap in the literature so much as an accurate reflection of how different the underlying disputes actually are. A parent declining a preventive vaccination, a parent refusing chemotherapy on religious grounds, a parent contesting withdrawal of life-sustaining treatment, and an adolescent refusing a parent's chosen treatment for themselves each raise the best-interests and harm-threshold questions in a different configuration, with different weight given to probabilistic future harm, immediate certain harm, third-party risk, and the child's own emerging voice. What holds across all of them is Diekema's basic insight that state intervention needs a threshold higher than mere disagreement with parental choice, paired with Sheldon's reminder that the harder question is often not what serves the child's interests but who has the standing to decide that in a given case. The clinical and legal frameworks reviewed here have gotten more sophisticated at managing that question case by case; they have not, and probably cannot, reduce it to a formula that removes the need for judgment.

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Conflict of Interest

The authors declare no conflicts of interest relevant to this work.

Author Contributions

Sylvie Benitez conceived the review, coordinated the literature synthesis, and drafted the initial manuscript. Eleni Nagy contributed the sections on adolescent capacity and vaccination refusal and critically revised the manuscript for intellectual content. Mette Lefevre contributed the sections on life-sustaining treatment and the best interests standard and provided final approval of the submitted version. All authors read and approved the final manuscript.

Ethics Statement

As a literature review synthesizing previously

published, publicly available research, case law commentary, and policy analysis, this article did not involve new data collection from human participants and did not require institutional ethics committee approval.

Data Availability

No new data were generated or analyzed for this review. All sources discussed are cited in the reference list and are publicly available through their respective publishers.

REFERENCES

1. Diekema DS (2004) Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics*, PMID:15637945.
2. Sheldon M (2004) Medical decision-making for children and the question of legitimate authority. *Theoretical Medicine and Bioethics*, PMID:15739285.
3. Nair T, Savulescu J, Everett J, et al. (2017) Settling for second best: when should doctors agree to parental demands for suboptimal medical treatment? *Journal of Medical Ethics*, PMID:28947505.
4. Guadarrama-Orozco JH, Garduño Espinosa J, Vargas López G, Viesca Treviño C (2015) Informed consent and parental refusal for medical treatment in childhood. The threshold of medical and social tolerance. Part II. *Boletín Médico del Hospital Infantil de México*, PMID:29421149.
5. de Vos MA, Seeber AA, Gevers SK, et al. (2015) Parents who wish no further treatment for their child. *Journal of Medical Ethics*, PMID:24917616.
6. Marron JM, Mithani Z, Meyer EC (2021) The Case of Billy Best: 25 Years Later. *Pediatrics*, PMID:34413248.
7. Wilkinson D (2020) The Charlie Gard Case, and the Ethics of Obstructing International Transfer of Seriously Ill Children. *Pediatrics*, PMID:32737233.
8. Pope TM, Ruck Keene A, Chandler J (2024) No consent for brain death testing. *Journal of Medical Ethics*, PMID:38154918.
9. Cicero-Oneto CE, Valdez-Martinez E, Bedolla M (2017) Decision-making on therapeutic futility in Mexican adolescents with cancer: a qualitative study. *BMC Medical Ethics*, PMID:29228962.
10. Paquette ET, Vinarsik L (2024) Pediatric Decision-Making for Children in State Custody. *Perspectives in Biology and Medicine*, PMID:38828605.
11. Diekema DS (2020) Adolescent Brain Development and Medical Decision-making. *Pediatrics*, PMID:32737228.
12. Nemetz ETA, Huang RS, Das S (2023) No adults

allowed: Adolescents and Medical Decision Making. Paediatrics & Child Health, PMID:38827364.

13. Spencer GE (2000) Children's competency to consent: an ethical dilemma. *Journal of Child Health Care*, PMID:11858414.
14. Turnham HL, Binik A, Wilkinson D (2020) Minority report: can minor parents refuse treatment for their child? *Journal of Medical Ethics*, PMID:32060211.
15. Vrouenraets LJ, de Vries ALC, Arnoldussen M, et al. (2023) Medical decision-making competence regarding puberty suppression: perceptions of transgender adolescents, their parents and clinicians. *European Child & Adolescent Psychiatry*, PMID:36115898.
16. Fishman M, Paquette ET, Gandhi R, et al. (2020) Surrogate Decision Making for Children: Who Should Decide? *The Journal of Pediatrics*, PMID:31708154.
17. Goldstick O, Peled-Raz M (2022) Prescribing Contraceptives to Minors Without Parental Consent. *Harefuah*, PMID:36578244.
18. Calandrillo SP (2004) Vanishing vaccinations: why are so many Americans opting out of vaccinating their children? *University of Michigan Journal of Law Reform*, PMID:15568260.
19. Basu Roy R, Paulus S, Kelly DF, et al. (2025) A vaccine emergency -- when to overrule parental refusal of vaccination at birth for prevention of vertical transmission of hepatitis B virus? *Archives of Disease in Childhood*, PMID:40921482.
20. Brusa M, Barilan YM (2024) No Need for Parental Involvement in the Vaccination Choice of Adolescents. *Journal of Bioethics Inquiry*, PMID:37477842.