



Perspective

Autonomy and Best Interests in Pediatric End-of-Life Decision-Making

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ABSTRACT

Pediatric end-of-life decision-making sits at the unresolved intersection of three imperfect authorities: the child, the parents, and the clinical team.

This perspective examines how the best-interests standard, developed originally for family-law disputes, functions once transplanted into intensive-care decisions about withdrawing or withholding life-sustaining treatment.

It traces the limits of parental authority, the uneven application of the mature minor doctrine to end-of-life refusals by adolescents, and the procedural mechanisms -- ethics consultation, second opinions, and judicial review -- available when parents and clinicians cannot agree.

Recent literature converges on a layered model in which no single actor holds unilateral authority and the weight given to the child's own voice should rise with developmental capacity and fall with the irreversibility of the decision, but this model is harder to operationalize than any single framework it replaces.

We argue that defensible practice requires treating capacity assessment as a genuine clinical task, engaging ethics consultation early enough to slow contested decisions without displacing the family, and giving more institutional weight to what dying children and adolescents themselves report wanting.

Keywords: pediatric bioethics; end-of-life care; best interests standard; mature minor doctrine; parental authority

Citation: Brenner K, Wisniewski K and Larsen K (2023) Autonomy and Best Interests in Pediatric End-of-Life Decision-Making. *Bioethics*. 1(1):01-05.

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Article History: Received 6 January 2023 | Accepted 3 April 2023 | Published 22 June 2023

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INTRODUCTION

A dying adult's wishes are, in most jurisdictions, close to dispositive: a competent patient can refuse a

ventilator, decline a feeding tube, or choose hospice over another round of chemotherapy, and clinicians are expected to comply even when they disagree with the choice. A dying child occupies no comparable

position. The law and the ethics literature both treat the child's own voice as one input among several, weighed against parental authority, clinical judgment, and a "best interests" standard that nobody has ever managed to define with much precision [1]. That gap between how end-of-life autonomy works for adults and how it works for children is not an oversight; it reflects a genuine and unresolved disagreement about how much weight a child's stated preferences should carry when the stakes are irreversible.

The standard framework asks three questions that do not always point in the same direction: what does the child want, so far as the child is able to say; what do the parents, as the child's presumed best advocates, believe is right; and what does the clinical team judge to be in the child's medical interest [2]. When these three align, the framework works quietly and well. When they diverge -- an adolescent who wants to stop treatment her parents are not ready to give up on, or parents requesting continued intensive care that clinicians consider harmful rather than merely futile -- the apparatus that is supposed to resolve the disagreement turns out to be much less settled than professional guidelines suggest [3]. This piece examines how the best-interests standard actually functions in pediatric end-of-life care, how much room it leaves for a child's own developing capacity for judgment, and what happens, procedurally and ethically, when the people around the bed cannot agree.

BEST INTERESTS AS A LEGAL AND ETHICAL STANDARD

The best-interests standard was never designed to answer end-of-life questions with any precision; it was designed for custody disputes and child-welfare decisions where the range of acceptable outcomes is wide and mostly reversible. Transplanted into intensive care, it has to do something much harder: weigh a small number of irreversible options against a value system that, for a young child, is largely the parents' own value system, since the child has not yet formed one independently. Recent bioethical and medico-legal commentary describes this transplant as leaving a persistent "gray zone" between clearly beneficial treatment and clearly futile treatment, a zone that most hard pediatric end-of-life cases actually fall into rather than at either extreme [4].

Table 1 lays out how three commonly invoked decision frameworks -- parental proxy consent, the best-interests standard, and the harm principle -- differ in whose judgment controls and how disputes are meant to be resolved under each. None of the three was built specifically for end-of-life care, and each imports assumptions from a different area of law and ethics: proxy consent from ordinary medical decision-making, best interests from family law, and the harm principle from child protection. Recent proposals for reframing pediatric decision-making

default to what dying children themselves say they want, arguing that clinicians and ethics consultants have historically underweighted the child's own account of their situation in favor of parental and clinical judgments that feel more legally comfortable [5].

Table 1. Three decision-making frameworks invoked in pediatric end-of-life care, compared by whose judgment controls and how disputes are resolved.

Framework	Primary decision-maker	Role of child's voice	Typical dispute-resolution route
Parental proxy consent	Parents/guardians	Advisory, weight varies informally by age	Renewed discussion with clinical team; ethics consultation if impasse persists
Best-interests standard	Shared: parents and clinical team, courts if needed	One factor among several in a broader welfare assessment	Ethics committee review; judicial review as a last resort
Mature minor doctrine	Adolescent, if capacity is established	Potentially decisive once sufficient understanding is demonstrated	Formal capacity assessment; courts may still intervene on state-interest grounds

THE LIMITS OF PARENTAL AUTHORITY

Parents are granted very wide latitude to make medical decisions for their children, on the reasonable assumption that they know the child best and have the strongest motivation to act in the child's interest. That latitude is not unconditional, and end-of-life care is one of the settings where its limits are tested most directly. When parents request continuation of treatment that the clinical team judges to be causing suffering without offering a realistic chance of benefit, professional guidance increasingly treats this as a situation requiring structured ethics review rather than automatic deference to parental wishes, while stopping well short of treating parental requests as presumptively wrong [6]. A recent systematic review of physicians' attitudes toward withholding and withdrawing life-sustaining treatment in pediatrics found wide variation across countries and specialties in how much independent weight clinicians give their own judgment relative to parental preference, with no clear convergence even within single health systems [7].

The harder cases are not the ones where a family clearly wants something unreasonable; they are the ones where a family's request is a defensible reading of ambiguous prognostic information, made under conditions of grief and hope that most ethics frameworks are honest enough to acknowledge distort judgment without necessarily invalidating it. A widely discussed case report and ethical analysis of a parental request to withdraw life-sustaining care in a seriously ill child illustrates how quickly the apparent

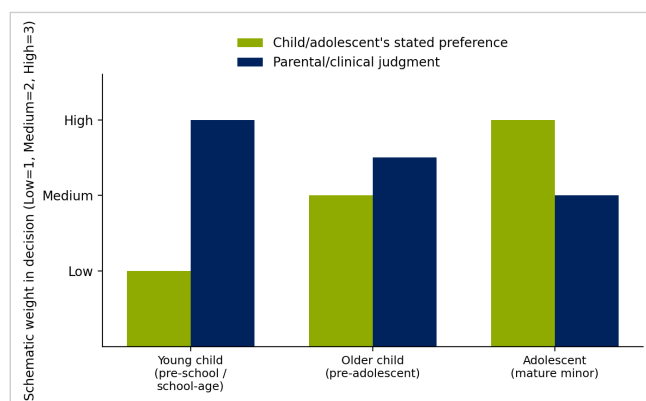
clarity of "the family's wishes versus the medical facts" collapses once the actual prognostic uncertainty is taken seriously [3]. Custody disputes complicate the picture further: when separated or divorced parents disagree about end-of-life decisions for a shared child, institutions have had to build ad hoc, multi-stakeholder processes for resolving disagreement that ordinary consent frameworks simply do not anticipate [8].

ADOLESCENT VOICE AND THE MATURE MINOR DOCTRINE

Nothing in the best-interests framework requires that a child's own preferences be ignored, and as children move into adolescence, most clinicians and ethicists agree those preferences should carry increasing, though rarely decisive, weight. The mature minor doctrine, developed originally outside the end-of-life context, holds that an adolescent who demonstrates sufficient understanding of a decision's consequences may be treated as capable of consenting to, or refusing, medical treatment independent of parental authorization [9]. Its application to refusal of life-sustaining treatment specifically has been far more contested than its application to routine consent, since the consequence of getting the capacity assessment wrong is not a suboptimal outcome but an irreversible one [10].

Courts applying the doctrine have generally required more evidence of mature judgment as the stakes of the decision rise, effectively creating a sliding scale in which the same adolescent might be treated as capable of consenting to a minor procedure but not of refusing a life-saving one [11]. Commentary aimed at clinicians has long noted that a minor's refusal of a life-saving therapy triggers a different, more cautious institutional response than a minor's refusal of a routine one, even when the underlying capacity evidence is identical [12]. Cases involving adolescents whose refusal of treatment is grounded in religious conviction have proven especially difficult, because they force courts to separate two questions that are easy to conflate: whether the adolescent understands the medical consequences of the choice, and whether the state has an independent interest in preventing that choice regardless of how well it is understood [13]. A recent account of "the weight of assent" in adolescent end-of-life care argues that clinical teams often treat assent as a formality to be documented rather than a genuine input to be weighed, which understates how much moral work an adolescent's stated preference is actually doing in defensible decisions [14]. Figure 1 offers a schematic illustration of how much practical weight a child's or adolescent's stated preference tends to receive across three broad developmental bands, relative to parental and clinical input -- illustrative rather than derived from a single empirical study, since no dataset tracks this consistently across settings.

Figure 1. Schematic illustration of how much practical weight a child's or adolescent's stated preference tends to receive relative to parental/clinical judgment across three broad developmental bands (illustrative, not derived from a single empirical study).



WHEN PARENTS AND CLINICIANS DISAGREE

Most pediatric end-of-life decisions never reach the point of formal disagreement; families and clinical teams typically converge, sometimes slowly and painfully, on a shared plan. The interesting ethical work happens in the minority of cases where they do not. Ethics consultation exists precisely for this reason, but recent commentary on paediatric intensive care disagreements argues that consultation is most useful not when it identifies a single correct answer -- often there is none -- but when it slows the process down enough for the actual sources of disagreement (differing risk tolerance, differing views about quality of life, differing trust in the prognosis) to be named explicitly rather than argued past each other [15].

A now-classic report on pediatric palliative and end-of-life care catalogued the range of formal mechanisms -- ethics committees, second medical opinions, and, as a last resort, judicial review -- available when disagreement cannot be resolved at the bedside, while cautioning that reaching for these mechanisms too early can itself damage the family-clinician relationship the mechanisms are meant to protect [16]. Cases involving suspected abuse or neglect add a further complication, since the presumption of parental good faith that underwrites ordinary best-interests reasoning is precisely what is in question, and end-of-life decisions in that context cannot be evaluated by the same procedural default [17]. A moral-distress case study from pediatric palliative care describes how prolonged disagreement, even when eventually resolved in a defensible way, leaves a residue of distress among nursing and medical staff that institutional ethics processes rarely have a mechanism for addressing afterward [18].

TOWARD A LAYERED MODEL OF DECISION-MAKING

The literature converges, unevenly, on a picture in which no single actor -- parent, clinician, or child --

holds unilateral authority over pediatric end-of-life decisions, and in which the correct allocation of weight among the three shifts with the child's developing capacity, the reversibility of the decision, and the degree of genuine prognostic uncertainty involved [19]. That picture is more honest than any of the individual frameworks it draws from, but it is also harder to operationalize, since it gives clinical teams a set of considerations to balance rather than a decision procedure to follow. Some recent work frames this explicitly as a call to give dying children's own accounts of their situation more standing than institutional practice currently affords them, without pretending this resolves the deeper tension between a child's stated wishes and a family's grief-shaped judgment about what is best [5]. Broader ethical treatments of end-of-life decision-making, largely developed with competent adults in mind, offer a useful comparison point precisely because so much of their reasoning about autonomy and beneficence does not transfer cleanly once the patient is a child whose capacity is itself the thing in question [20].

CONCLUSION

Pediatric end-of-life decision-making sits at the intersection of three imperfect authorities -- the child, the parents, and the clinical team -- and none of the standard frameworks for resolving disagreement among them was built with this setting specifically in mind. Best interests supplies a vocabulary rather than an algorithm; parental authority is wide but not unconditional; and the mature minor doctrine gives adolescents a real, if uneven and stakes-dependent, claim to a voice in decisions about their own dying. What recent scholarship adds is less a solution than a sharper insistence that these three sources of authority be balanced explicitly, case by case, rather than resolved by defaulting reflexively to whichever one is procedurally easiest to invoke. A defensible practice likely means treating capacity assessment as a genuine clinical task rather than a formality, building ethics consultation into difficult cases early enough to slow decisions down without displacing the family, and taking seriously the growing body of work suggesting that dying children and adolescents understand more about their own situations, and deserve more say in them, than institutional habit has generally allowed.

DECLARATIONS

Acknowledgements

The authors are grateful to colleagues in their respective bioethics departments for discussions that helped clarify the scope and structure of this review.

Funding

This review received no external funding.

Conflict of Interest

The authors declare no conflicts of interest relevant to

this work.

Author Contributions

Kasper Brenner conceived the review and drafted the initial manuscript. Kasper Wisniewski performed the literature synthesis on parental authority and disagreement resolution and critically revised the manuscript. Katrin Larsen contributed the sections on adolescent capacity and the mature minor doctrine 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 reports, and legal 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.

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