Features

Disagreement and Ethical Decision Making in Pediatric Emergency Care

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ABSTRACT

Disagreements between parents and healthcare providers over plans of care are common and unavoidable in pediatric medicine. Few places are these trends more pronounced than in the pediatric emergency room, where parents and providers have no established relationship and their encounters are pressured by time constraints and clinical acuity. Unfortunately, appropriate ethical guidance is sorely lacking for this unique clinical environment. Instead, one finds an assortment of traditional principles taken from general pediatrics or adult emergency medicine that are applied haphazardly to an ill-suited context.

In this article we aim to take the uniqueness of pediatric emergency care seriously and develop an ethical framework that is better suited to its distinctive context. First, we analyze several major features of pediatric emergency medicine (PEM) that distinguish it from both general pediatrics and adult emergency medicine. Then we critically evaluate the limitations of the two dominant principles of pediatric bioethics when applied to this realm. Here we argue that the best interest standard is impracticable due to the difficulties in navigating value uncertainty within a highly constrained time frame, while the harm principle functions only as an intervention and not as a guidance principle. Finally, we conclude by defending a reasonable interest standard as a unifying pragmatic framework for pediatric emergency care that has the potential to improve the consistency of care and to decrease moral distress among pediatric emergency providers.

INTRODUCTION

Disagreement between parents and clinicians over care plans is a familiar and unavoidable feature of pediatrics. Consider three examples:

- A father, fearful of hospitals and concerned about costs, seeks outpatient versus recommended inpatient care for his teenage daughter's new-onset type 1 diabetes.
- Parents object to part of a critical diagnostic process for a febrile neonate due to concerns that it is invasive and unnecessary.
- A mother refuses admission for her moderately ill four year old because her newborn requires care at home.

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Cases like these abound throughout pediatrics, sometimes driven by disagreements about facts and at other times by differences in values, priorities, or cultural and political identities. However, such conflicts often are more frequent and pronounced in emergency rooms, where parents and providers have no established relationship and encounters are pressured by time constraints and clinical acuity.

Unfortunately, the standard tools that bioethicists use to manage and resolve conflicts generally are ill-suited to this unique context. The best interest standard (BIS) is impracticable due to time constraints and difficulties navigating value uncertainty in emergency conditions. The harm principle (HP), meanwhile, functions well as an *intervention* principle but provides no guidance for the far-more-common conflicts that involve no significant risk of imminent, serious harm. As such, neither of the two most prominent principles of pediatric ethics provide compelling guidance for pediatric emergency care.

In contrast, we argue that a reasonable interest standard (RIS) provides a unified framework for PEM because it integrates a pragmatic condition with intervention and guidance principles. While the BIS and the HP can function as square pegs in a round hole, the RIS is well suited to the unique contours of PEM. Moving between cases and general analysis, we argue that this framework can improve the consistency of care and decrease moral distress within the pediatric emergency setting.

PEDIATRIC EMERGENCY CARE IS UNIQUE

Several unique features of pediatric emergency care distinguish this clinical environment from general pediatrics, on the one hand, and adult emergency medicine, on the other. Moreover, these unique features change interpersonal dynamics and ethical considerations when parents or guardians disagree with clinicians about a recommended care plan, when compared with similar practice scenarios in general pediatrics or adult emergency care.

Some differences between PEM and general pediatrics relate to the features of the patient populations they tend to serve. In the United States, patients who are seen in the emergency care context are more likely to be socioeconomically vulnerable (for example, uninsured or underinsured) and the emergency department (ED) often serves as their primary point of contact with the healthcare system.[1]

However, the most salient differences between PEM and general pediatrics derive from the intrinsic nature of "emergency" care. Perhaps most obvious are the constraints imposed by limited time frames, high acuity, unbounded ranges of pathologies, unscheduled round-the-clock care visits, and the lack of an established long-term relationship between providers and the patient and family. Often, emergency visits permit only a narrow window for clinical decision making, as the relevant interventions require immediate or expedited execution to be effective (for example, cardiopulmonary resuscitation or intubation). Moreover, emergency rooms are traditionally structured such that providers have limited total time to dedicate to each patient. Complex or high-acuity situations can take a more significant proportion of a provider's time, but there is a practical limit to this redistribution and the inevitable exacerbation of time constraints for other patients. Additionally, all types of pathology and levels of patient acuity are seen in pediatric emergency care. Providers may move back and forth between highly dissimilar patient cases throughout the course of an average work shift. Furthermore, by their very nature, EDs can't schedule a patient's visit to their unit. Almost every patient seen is unscheduled and unplanned for. Emergency providers are unable to bundle all cases of a certain kind on a certain day for maximum efficiency or to time the sequence of patients in a certain way that furthers some value; they are forced to continually triage whoever shows up, when they show up, and make decisions in real time about which patients will get how much of their time for what purposes and in what order.

Finally, and perhaps most consequentially, there usually is no established relationship between patients and families and the emergency clinicians who provide care for them. This lack of relationship has profound effects for each

party's understanding, expectations, and trust *vis*-à-*vis* the other party.

The significance of these intrinsic constraints from an ethics perspective is that many of the traditional strategies to prevent and resolve conflicts, such as relationship building, exploration of interests, second opinions, social work involvement, or ethics consultation, may be less possible in the ED. The nature of a given patient's emergency needs, or the limited availability of certain services or consultations, may not permit their employment within the needed time frame to render effective care.

AN ANALYSIS OF RELEVANT FRAMEWORKS

The unique features of pediatric emergency care call for a coherent ethical framework to guide surrogate decision making. We will review some of the best established frameworks in pediatric bioethics and assess their utility for navigating disagreements in PEM. For our purposes, we will delineate between appropriate *guidance principles*—frameworks that provide substantive direction toward achieving an ideal outcome—and *intervention principles*—frameworks that identify when authority should be transferred from the hands of the presumptive decision makers (that is, parents).[2]

Complex or high-acuity situations can take a more significant proportion of a provider's time, but there is both a practical limit to this redistribution and the inevitable exacerbation of time constraints for other patients.

Turning to the contrast between pediatric and adult emergency medicine, the most striking difference between the two contexts is their divergent presumptions about decision-making authority. The presence of a surrogate decision maker is standard for all patients under 18 years of age in PEM. It is the exception for pediatric patients to make their own decisions. In contrast, it is the clinical and ethical default that adult patients make their own decisions. A surrogate decision maker is a possibility but is relatively rare.

The ethical significance of these divergent presumptions is profound. While patient autonomy is a well-established and overriding ethical principle to resolve the majority of conflicts in adult emergency settings, no equivalent overriding principle exists for PEM. Instead, principles like the BIS and the HP compete for priority with appeals to parental authority. This structural feature of PEM renders it vulnerable to more frequent, more intense, and more entrenched disagreement while depriving it of a widely agreeable way to resolve differences.

The BIS

The BIS calls for decision makers to follow whatever course of action will maximally promote a child's well-being.[3] When parents and providers disagree, the BIS recommends that providers use available means to override parents when their medical decisions don't promote their child's well-being to the greatest extent. This is referred to as the *best interest threshold*.[4]

Although it often is regarded as the default ethical framework for pediatric medicine, the BIS has been widely debated. Critics characterize it as poorly defined, inconsistently applied, unreasonably demanding, and lacking an appropriate consideration of family interests.[5] Moreover, many authors assert, and we agree, that whatever its merits as a guidance principle, the best interest standard is inadequate as an intervention principle.[6] We will argue further

that it is an inappropriate guidance principle in the PEM context.

Navigating value uncertainty is a common challenge when one attempts to apply the BIS. Determining best interest involves assigning weight to possible outcomes. It is not possible to make this assignment in a value-neutral way.[7] In an ideal application of the BIS, providers build trust and understanding with families and patients in an extended encounter or across multiple encounters. Listening to patients and building rapport with them are essential to understand a family's values and to establish consensus around a care plan. Such labor- and time-intensive activities are difficult to execute in the best of situations; they are all but impossible in the short, pressured interactions of PEM. While emergency providers usually can assess what likely will best serve a patient's medical interests, they often are constrained from conducting a careful and comprehensive analysis of a child's full set of interests through conversation and negotiation with parents or guardians. This renders the most defensible version of BIS as impractical in the PEM context.

Consider the following case.

A 13-year-old girl, Kate, is evaluated for abdominal pain, increased thirst, and frequent urination. Initial labs are consistent with a diagnosis of new-onset type 1 diabetes (DM1). There are no signs of diabetic ketoacidosis (DKA). The patient has a normal bicarbonate level and no ketones in her urine. Her most recent blood glucose is 265 mg/dl. The endocrinologist on call recommends admission for initiation of insulin overnight as well as diabetes education as an inpatient tomorrow. Her father refuses. He explains that he is fearful of hospitals and finds the prospect of admission traumatic because his father died one year ago last week at the nearby adult hospital. Additionally, he is worried that he won't be able to afford the financial costs of an inpatient admission. He requests to return his daughter to care as an outpatient the following morning. This request is relayed to the endocrinologist on call, who states that it would be logistically impossible for the outpatient endocrinology team to accommodate the family for teaching the patient about diabetes within the next two days. The endocrinologist further advises that if the family doesn't consent to admission, he recommends the ED provider make a report to Child Protective Services (CPS) due to the higher risk of DKA following a first-time diagnosis of DM1.

The medical recommendation is for an overnight admission for observation and teaching in a relatively low-risk scenario (new-onset diabetes without acidosis or ketosis). From a purely medical perspective, this is probably in the child's best interest. However, there are financial and psychosocial factors that make this a more challenging situation. It is possible, if not likely, that family financial constraints and past trauma weren't addressed in the initial history taking, and, without an established relationship with the ED physician, the family may be hesitant to explain their situation. Balancing medical concerns and social needs is a common challenge in much of medicine, but the ED presents a particularly difficult situation in which to navigate it. Thus, while a comprehensive version of the BIS may seem laudable in principle, it simply is not a practicable standard for pediatric emergency care.

The HP

Commonly cited as an alternative to the BIS, the HP states that parental decisions should be accepted unless their decisions place their child at significant risk of imminent serious harm.[8] Diekema, the architect of the modern bioethical conception of the HP, clarifies that the likelihood of serious harm must be compared to the risk associated with other options. To aid in the practical application of the HP, he proposes eight conditions that should be met to justify the use of state intervention to override parents' decisions.[9]

Critics often raise two primary objections against the HP. First, they argue that the concept of harm is as indeterminate as the concept of best interests to which it is contrasted. Second, critics argue that the focus of the HP is too narrow and insist that a comprehensive approach to medical decision making for children must go beyond harm alone.[10] Diekema acknowledges some indeterminacy in the HP but points out

that it's less indeterminate and more easily understood by the legal system, parents, and providers than the BIS. He answers the narrowness critique by pointing out that the HP was put forth as an intervention principle only, and its scope doesn't need to be expanded.[11]

In the context of pediatric emergency care, we believe that the HP is an ideal intervention principle. In ED encounters, when surrogate decision makers and providers have an intractable disagreement about the plan of care, the logical question becomes, "Does the parent's decision significantly increase the likelihood of serious harm when compared to viable alternatives?" While the issue of indeterminacy remains, it's more easily addressed when the scope of available clinical decisions and resources is narrowed, as is the case in the ED.

In an ideal application of the BIS, providers build trust and understanding with families and patients in an extended encounter or across multiple encounters.

Take, for example, the following case of a febrile neonate.

A 12-day-old boy, John, is brought in with fever for one day. He is febrile to 38.7 degrees Celsius, measured by a rectal thermometer in the ED. He appears well, with normal vital signs and no concerning findings on physical examination. The physician recommends a full work up for serious bacterial infection, including urine, blood, cerebrospinal fluid cultures, and hospital admission for intravenous antibiotics observation until the culture results are available. The family agrees to urine and blood cultures and one dose of antibiotics but refuses to consent to a lumbar puncture or hospital admission. They insist that the procedure is dangerous and unnecessary.

The risk of serious bacterial infection (urinary tract infection, bacteremia, or meningitis) for a febrile neonate less than 28 days of age is often estimated at 5 to 10 percent, with the risk of invasive bacterial infection (bacteremia or meningitis) estimated at 0.3 percent to 3 percent.[12] Bacteremia and bacterial meningitis are often fatal if not treated in a timely fashion. An emergency provider who exhausts all attempts at persuasion with John's family has only two options: seek state intervention to force admission or discharge home. Discharge requires accepting the uncertainty of illness severity and patient follow up. We contend that the HP requires the provider seek state intervention, as a 3 percent risk of a potentially fatal acute illness represents a significant risk of serious harm.

However, consider a variant of this same case: The parents refuse lumbar puncture and request discharge, but the child is a newborn in a hospital nursery when his fever is identified. In contrast to the ED setting, the nursery setting offers a variety of interim clinical and social interventions. Simpson and colleagues present a similar case and review varying measures, such as ongoing nursery observation, antibiotics administration without a lumbar puncture, social work (SW) consult, the involvement of CPS without removal of the child, or transfer to a new medical provider.[13]

The pediatrician in the nursery has a chance to delay disposition, build rapport with the family, and marshal resources (SW, CPS) in an attempt to reach consensus. In the ED, the limited availability of interim measures makes it more challenging to determine whether there is a substantial risk of serious harm, compared to the risks associated with other options. Put simply, the HP often is applied with greater clarity in the emergency room than it can be in an inpatient or outpatient setting.

The RIS

We have established the HP as an ideal intervention principle for pediatric emergency practitioners to fall back on, but is there a framework that may perform this function while it also provides a guidance principle? In response to the ongoing debate over the BIS, the HP, and the related model of constrained parental autonomy, Micah Hester defends the RIS as a cohesive ethical framework for decision making for children. The RIS holds that decision making for children should be (1) aspirational (aims for best interests) and (2) pragmatic (recognizes contextual differences and limitations), but also (3) constrained by a threshold for intervention.[14] All three conditions are critical to an ethically satisfactory standard in pediatrics. The aspirational condition highlights the need for clinicians to facilitate a shared decision-making process with more than a minimal threshold of mere harm avoidance. All pediatric clinicians can, and should, aim for an outcome that exceeds this low bar. Meanwhile, the pragmatic condition holds that decisions should be reasoned through to account for unique features of the child's life, which could include culture or family values as well as financial, social, or psychological circumstances. The RIS acknowledges that parents are the appropriate persons to incorporate these factors into decision making. Finally, the threshold condition, which is congruent with the HP, stipulates that there must be a lower limit for decisions that significantly increase the risk of imminent serious harm. It establishes a basic floor for decision making, below which decisions must be appropriately resisted and contravened.

While it may well provide better guidance for all pediatric decision making, the RIS is an especially promising ethical framework for PEM. An encounter in the pediatric emergency room should start at an aspirational place. Parents and providers presumably desire what is in the best interest of the child. Providers make a clinical assessment and propose what they believe is in the child's medical best interest (this more limited task usually is possible in the ED even if a more comprehensive analysis of best interests is not). Parents should be given room to modify their decisions to account for their family's unique circumstances and values. Ideally, their modification is a dynamic, consensus-building process. If that falls short, which it often does in the emergency room, providers should only interfere with parents' authority by invoking state intervention as a last resort. Such interference can only be justified when every other practicable alternative has been ineffective and when a significant risk of imminent serious harm precludes any less-intrusive measure to mitigate that risk. As Hester states, "It is laudable to want all parents for all children to shoot for the stars, but it is morally acceptable that they choose within the realm of reason."[15]

To evaluate the RIS in context, consider a third case.

A four-year-old girl, Laila is being treated in the ED for an asthma exacerbation. Serial examinations determine that she requires albuterol treatments approximately every two to three hours. In accordance with national guidelines, the ED physician recommends she be admitted to the hospital.[16] The mother requests to continue treatment at home. She states she has another young child at home she needs to supervise and believes it would be traumatic for Laila to stay in the hospital alone. She expresses that she feels very comfortable administering albuterol treatments every two hours and accurately articulates signs and symptoms that would cause her to return her daughter to the hospital.

From a purely medical perspective, the best interest of this patient would seem to be admission to the hospital for frequent albuterol. When administration of albuterol is required every two hours, hospitalization is thought to decrease the burden on caregivers, ensure the accurate administration of medication, and allow prompt escalation of care in the case of decompensation.[17] However, this mother has valid concerns about admission. She states that being in the hospital with Laila would prevent her from supervising her other child, and she feels Laila is not mature enough to stay in the hospital alone. She expresses a preference based on her understanding of Laila's emotional de-

velopment and her family's interests as a whole. Ideally, this provider would attempt to resolve these issues, potentially by helping Laila's mother to identify childcare solutions (such as finding an available family member) or working with child life and nursing to explain how Laila would have companionship and supervision throughout her hospital stay were the mother unable to remain at her bedside.

If Laila's mother can't be convinced to consent to admission, then the provider would need to evaluate whether this clinical condition poses a significant enough risk of serious and imminent harm to the child that state intervention (and all the disruption that entails for the child and family) is justified.

Although the clinical severity of this case is debatable (as are most cases), there is a feasible alternative to admission (at-home albuterol treatments combined with close follow up with the child's primary caregiver), so state intervention would not be justified. Were the clinical team to allow discharge at this point, they may not have achieved the absolute best medical treatment plan, but they have appropriately worked with, and ultimately deferred to, the child's mother to achieve a reasonable outcome for the child.

CONCLUSION

In summary, it isn't uncommon in pediatric emergency care for parents to challenge or refuse recommended treatment. A thoughtful, ethical approach to such disagreements offers the potential to improve care and prevent provider distress. The most defensible version of the BIS (which would require a comprehensive assessment of a child's full set of interests) is impracticable for PEM, while the HP is too narrow in its scope and function. Instead, we identify the RIS, with its inclusion of a pragmatic condition and an intervention threshold, as a more appropriate ethical framework for pediatric emergency care. We should aspire to the best possible outcome for every child in the ED, but when there is disagreement about what is "best," it's ethically permissible to accept what is "reasonable."

BLINDING OF THE CASES

Details in the cases have been altered to protect the identities of patients and their parents.

NOTES

1. M.B. Greenwood-Ericksen and K. Kocher, "Trends in Emergency Department Use by Rural and Urban Populations in the United States," *JAMA Network Open* 2, no. 4 (5 April 2019): e191919. *https://doi.org/10.1001/jamanetworkopen.2019. 1919.*

2. A. Buchanan and D.W. Brock, "Deciding for Others," *Milbank Quarterly* 6, no. 64 (1986): 17-94, doi:10.2307/3349960; E.T. Paquette and L.F. Ross, "Pediatric Decision Making Requires Both Guidance and Intervention Principles," *American Journal of Bioethics* 18, no. 8 (2018): 44-6, doi:10.1080/15265161.2018.1485777.

3. L.M. Kopelman, "The best-interests standard as threshold, ideal, and standard of reasonableness," *Journal of Medicine and Philosophy* 22, no. 3 (1997): 271-289, doi:10.1093/jmp/22.3.271.

4. D. Wilkinson and T. Nair, "Harm isn't all you need: Parental discretion and medical decisions for a child," *Journal of Medical Ethics* 42, no. 2 (2016): 116-8, doi:10.1136/medethics-2015-103265.

5. E.K. Salter, "Deciding for a child: A comprehensive analysis of the best interest standard," *Theoretical Medicine and Bioethics* 33, no. 3 (2012): 179-98, doi:10.1007/s11017-012-9219-z.

6. D.S. Diekema, "Decision Making on Behalf of Children: Understanding the Role of the Harm Principle," *The Journal of Clinical Ethics* 30, no. 3 (Fall 2019): 207-12; L.F. Ross, "Better than Best (Interest Standard) in Pediatric Decision Making, " *The Journal of Clinical Ethics* 30, no. 3 (Fall 2019): 183-95; D.M. Hester, K.R. Lang, N.A. Garrison, and D.S. Diekma, "Agreed: The Harm Principle Cannot Replace the Best Interest Standard . . . But The Best Interest Standard Cannot Replace the Harm Principle Either," *American Journal of Bioethics* 18, no. 8 (3 August 2018): 38-40, *https://doi.org/10.1080/15265161.2018.1485759*; T.M. Pope, "The Best Interest Standard: Both Guide and Limit to Medical Decision Making on Behalf of Incapacitated Patients," *The Journal of Clinical Ethics* 22, no. 2 (Summer 2011): 134-8, PMIC: 21837885.

7. Wilkinson and Nair, "Harm isn't all you need," see note 4 above.

8. D.S. Diekema, "Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention," *Theoretical Medicine and Bioethics* 25, no. 4 *(*2004): 243-64, doi:10.1007/s11017-

004-3146-6.

9. Diekema proposes eight conditions: (1) By refusing to consent are the parents placing their child at significant risk of serious harm? (2) Is the harm imminent, requiring immediate action to prevent it? (3) Is the intervention that has been refused necessary to prevent the serious harm? (4) Is the intervention that has been refused of proven efficacy, and therefore likely to prevent the harm? (5) Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents? (6) Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents? (7) Can the state intervention be generalized to all other similar situations? (8) Would most parents agree that the state intervention was reasonable? Ibid.

10. G. Birchley, "Harm is all you need? Best interests and disputes about parental decision-making," *Journal of Medical Ethics* 42, no. 2 (February 2016): 111-5, doi: 10.1136/medethics-2015-102893, Epub 23 September 2015, PMID: 26401048, PMCID: PMC4752625; J.C. Bester, "The Best Interest Standard Is the Best We Have: Why the Harm Principle and Constrained Parental Autonomy Cannot Replace the Best Interest Standard in Pediatric Ethics," *The Journal of Clinical Ethics* 30, no. 3 (Fall 2019): 223-31, PMID: 31573966.

11. Diekema, "Decision Making on Behalf of Children," see note 6 above.

12. E.C. Powell et al., "Epidemiology of Bacteremia in Febrile Infants Aged 60 Days and Younger," *Annals of Emergency Medicine* 71 (2018): 211-6.

13. E. Simpson, M. Moon, and J.D. Lantos, "When Parents Refuse a Septic Workup for a Newborn," *Pediatrics* 128, no. 5 (2011): 966-9, doi:10.1542/peds.2010-3375.

14. D.M. Hester, "Offering the "Reasonable Interests Standard in Response to Ross's Analysis of the Best Interests Standard," *The Journal of Clinical Ethics* 30, no. 3 (Fall 2019): 196-200; D.M. Hester and E.K. Salter, "Reasonableness as a Relational Principle: An Integrated Framework for Pediatric Decision-Making," *Journal of Pediatrics* 251, no. (December 2022): 30-5, *https://doi.org/10.1016/j.jpeds.2022.06.002.*

15. Hester, "Offering the "Reasonable Interests Standard in Response to Ross's Analysis of the Best Interests Standard," see note 14 above.

16. National Heart, Lung, and Blood Institute, "Guidelines for the Diagnosis and Management of Asthma, Expert Panel Report 3," 2007, *https://www.nhlbi.nih.gov/health-topics/guidelines-for-diagnosis-management-of-asthma,* p. 440.

17. Ibid.