Pediatric Decision Making: Consensus Recommendations

Erica K. Salter, PhD,[a] D. Micah Hester, PhD,[b,c] Lou Vinarcsik, BS,[a] Armand H. Matheny Antommaria, MD, PhD,[d,e] Johan Bester, MBChB, PhD,[a] Jeffrey Blustein, PhD,[f] Ellen Wright Clayton, MD, JD,[g] Douglas S. Diekema, MD, MPH,[h] Ana S. Iltis, PhD,[i] Loretta M. Kopelman, PhD,[j,k] Jay R. Malone, MD, PhD,[l] Mark R. Mercurio, MD, MA,[m] Mark C. Navin, PhD,[n,o] Erin Talati Paquette, MD, JD, MBe,[p,q] Thaddeus Mason Pope, JD, PhD,[r] Rosamond Rhodes, PhD,[s] Lainie F. Ross, MD, PhD[t,u]

Despite apparent disagreement in the scholarly literature on standards of pediatric decision making, a recognition that similar norms underpin many of the dominant frameworks motivated a June 2022 symposium "Best Interests and Beyond: Standards of Decision Making in Pediatrics" in St Louis, MO. Over the course of this 3-day symposium, 17 expert scholars (see author list) deliberated on the question "In the context of US pediatric care, what moral precepts ought to guide parents and clinicians in medical decision making for children?" The symposium and subsequent discussion generated 6 consensus recommendations for pediatric decision making, constructed with the primary goals of accessibility, teachability, and feasibility for practicing clinicians, parents, and legal guardians. In this article, we summarize these recommendations, including their justification, limitations, and remaining concerns.

For most pediatric health care decisions, children are presumed to lack decisional capacity and the legal authority to be their own decision makers. Although the concepts of the child and childhood have evolved over time,[1] in the 21st-century children are defined as individuals below the age of majority, which is 18 years of age in most jurisdictions in the United States,[2] unless legally emancipated (or conditions such as marriage or military conscription). As such, a central ethical question is: how should others make decisions for pediatric patients?

This is a fundamental ethical concern in pediatrics, and various decision-making norms have been used to formulate ethically justified decision-making frameworks to guide parents and clinicians. For the purpose of this paper, parent is defined as an individual engaged in a personal relationship with a child and bearing the moral and legal responsibility to provide for the child's basic needs and interests. The American Academy of Pediatrics, for example, identifies 4 "standards for surrogate decision making in pediatrics":[3] the Best Interest Standard,[4] Diekema's Harm Principle,[5] Ross's Constrained Parental Authority,[6] and Shared Family Centered Decision Making.[7] Although the relative merits and shortcomings of these and other frameworks have been debated for >25 years,[5,6,8–16] scholars have failed to generate a clear normative consensus.

Despite apparent disagreement, however, similar norms underpin many of the dominant frameworks. The possibility that these similarities could permit productive discussion and consensus motivated a 2022 symposium addressing the question, "In the context of US pediatric care, what moral precepts ought to guide parents and clinicians in medical decision making for children?" Symposium participants were selected by the organizers (EKS, DMH, and LFR) first by reviewing the past 3 decades of literature by authors writing on US-focused moral norms regarding pediatric decision making. From that review, a final invite list was created by prioritizing authors who have been key participants in the debate about the guiding principles

abstract

[a]Saint Louis University, Saint Louis, Missouri; [b]University of Arkansas for Medical Sciences, College of Medicine, Department of Medical Humanities & Bioethics, Little Rock, Arkansas; [c]Arkansas Children's Hospital, Little Rock, Arkansas; [d]Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; [e]University of Cincinnati College of Medicine, Cincinnati, Ohio; [f]City College of New York, New York, New York; [g]Vanderbilt University Medical Center & Vanderbilt University, Nashville, Tennessee; [h]University of Washington School of Medicine, Seattle, Washington; [i]Wake Forest University, Winston-Salem, North Carolina; [j]East Carolina University, Greenville, North Carolina; [k]Georgetown University, Washington, District of Columbia; [l]Washington University, Saint Louis, Missouri; [m]Yale School of Medicine, New Haven, Connecticut; [n]Oakland University, Rochester, Michigan; [o]Corwell Health East, Southfield, Michigan; [p]Northwestern University, Chicago, Illinois; [q]Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, Illinois; [r]Mitchell Hamline School of Law, St Paul, Minnesota; [s]Icahn School of Medicine at Mount Sinai, New York, New York; [t]University of Chicago, Chicago, Illinois; and [u]University of Rochester, Rochester New York

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Address correspondence to Erica K. Salter, PhD, 3545 Lafayette Ave, St Louis, MO 63104. E-mail: erica.salter@slu.edu

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that underlie pediatric decision making, such as the "best interest standard." We deliberately included experts from different academic fields of scholarship and with different viewpoints, as well as early career scholars with a demonstrated interest and investment in the application of decision-making principles. Over 3 days, using pre-readings (Supplemental Information), plenary presentations, and large and small group discussions of theory and cases designed to identify key concepts, the participants clarified points of agreement and located remaining points of disagreement.

The symposium and subsequent discussion generated 6 consensus recommendations (Table 1). These recommendations assert a set of 6 intersecting principles that govern the moral dimensions of pediatric decision making which represents significant progress in an area in which there has been sustained disagreement for decades. These principles exist independently in the literature, but this statement affirms, connects, and expands on them. These 6 recommendations were constructed with the primary goals of accessibility, teachability, and feasibility for practicing clinicians, parents, and legal guardians. Given the complexity of the topics at hand, the group limited the scope to clinical decision making for children in infancy through primary school, intentionally excluding decision making in the research setting and for neonates and adolescents.

CONSENSUS RECOMMENDATIONS

1. Parents Should Be Presumed to Have Wide, but Not Unlimited, Discretion to Make Health Care Decisions for Their Children

A fundamental principle of modern-day bioethics is that adults with decisional capacity have the right to accept or refuse all, including lifesaving, medical care. Children, in contrast, are presumed to lack the capacity to make medical decisions for themselves, and their parents have presumptive decisional authority on their behalf. This is supported by considerations related to the interests of the child, the parents and family unit, and society.[17]

Justifications for parental authority based on the interests of the child are grounded in features parents typically share:[18] parents have privileged knowledge of their child and, thus, of their child's interests,[12,19] parents are motivated to advance their child's interests,[12,20] and parents know or can ascertain their child's perspectives.[6,21,22] Parental authority is also justified because parents are typically responsible for their child and bear the consequences of medical decisions.[6,12,21] Additionally, given their role in the family unit, parents are best situated to assess competing interests that might be at stake for other family members and for the family unit as a whole.[6,12] Finally, parental authority is necessary to allow families to fulfill the important functions they serve in society.[23,24]

To accommodate a wide range of cultural, social, and religious values, parents must have sufficient space and freedom from intrusion by others and the state. A lack of broad parental discretion and decisional authority hinders many important functions of childrearing performed by and within families.[16,23,24]

However, parental authority is appropriately limited both by the state's role in protecting children from significant harm (Recommendation #5) and by the clinician's role in determining what medically reasonable options are available (Recommendation #6).

When a child lacks a parent, efforts are normally made to find adults who can fulfill some or all parental functions (eg, case workers and foster parents), and state-appointed guardians may act in loco parentis.[25]

2. Parents Should Protect and Promote the Health Interests of Their Children While Balancing Practical Constraints and/or Other Important Obligations and Interests

Children have interests that are morally significant and not wholly subsumable under those of their parents, and parents are broadly obligated to protect and promote those interests. When a child's interests are provided for, they can flourish, and when a child's interests are thwarted, their wellbeing is at risk or even set back. Health interests, as a subset of the broader interests of the child, are of fundamental importance to the child's development and wellbeing. Insults to the child's health interests will impact various other domains of the child's wellbeing (eg, behavioral,

TABLE 1 Consensus Recommendations

Consensus Recommendations
1. Parents should be presumed to have wide, but not unlimited, discretion to make health care decisions for their children.
2. Parents should protect and promote the health interests of their child, while balancing practical constraints and/or other important obligations and interests.
3. A clinician's primary responsibility is to protect and promote their pediatric patients' health interests. Clinicians' recommendations should be informed by professional judgment and the best available evidence.
4. To respect children and promote their wellbeing, clinicians and parents should inform pediatric patients of salient information and invite their perspective to the degree that doing so is developmentally appropriate.
5. In addition to state mandated reporting requirements, clinicians should seek state intervention when all less-restrictive alternatives have been exhausted and a parental decision places the child at significant risk of serious imminent harm or fails to meet the child's basic interests.
6. Clinicians and parents should collaborate in a shared decision-making process to promote the child's interests.

relational, and spiritual), and may lock in disadvantage, suffering, and lack of flourishing.[26–28]

Because children usually grow up in family environments and are uniquely vulnerable and dependent on others for their wellbeing, parents must safeguard their health interests.[6,26,29,30] A critical duty of the parent, therefore, is to protect and promote the health interests of their child. Parents should provide for the health needs of their child, which include preventative and curative medical care, as well as adequate nutrition within a safe and secure environment. Parents should also facilitate appropriate medical care, including preventive and treatment care, guided primarily by the health interests of their child. As presumptive decision makers for their child (see Recommendation #1), parents should engage in health care decisions, typically choosing treatment options that are most likely to promote and protect their child's health interests.

However, parental obligations to protect and promote the health interests of their child are only prima facie; although these obligations should typically be met, there may be compelling reasons to not meet them to the fullest extent.[4,13] Parents must balance these obligations against other existing obligations (eg, obligations to other family members) and consider practical constraints. Health care decisions for a single child do not exist independent of the complex and dynamic features of family life, wherein many competing interests must be negotiated. This reality is one of the justifications for the wide discretion afforded to parental decision-making authority (Recommendation #1). For example, a parent is not obligated to choose the most effective treatment option for their child if that option would bankrupt the family and an alternative, reasonably effective, treatment option exists that is less burdensome.

3. A Clinician's Primary Responsibility Is to Protect and Promote Their Pediatric Patients' Health Interests. Clinicians' Recommendations Should Be Informed by Professional Judgment and the Best Available Evidence

Clinicians' obligations to their patients emerge from the special nature of the patient-clinician relationship, in which a patient seeks medical care and a clinician professes to have the competence, knowledge, skills, and willingness to provide that care.[31] The codes of ethics of numerous professional societies acknowledge the importance of a clinician's obligations to their patients.[32–36]

In addition to physicians, many health care professionals participate in medical decision making related to pediatric patients (eg, nurses, nurse practitioners, physician assistants, psychologists, pharmacists, and child life specialists).[37,38] There is typically an asymmetry of medical knowledge and resources between patients and clinicians, and patients enter clinical relationships with varying degrees and types of vulnerability. Unlike commercial business relationships, in which each party is allowed to maximize personal interests, the vulnerability of patients and the asymmetry of the medical relationship obligate clinicians to prioritize their patients' interests ahead of their own.[31,39–41] This relationship gives patients reason to trust clinicians and rely on them to respond to their health needs or expressed health interests. This relationship also requires clinicians to demarcate the range of clinical options available to protect and promote their patients' health interests. Of course, the health interests of patients are influenced by personal values, and clinicians should elicit and appropriately incorporate the priorities and preferences of the parent(s) and pediatric patient into clinical decisions (Recommendation #4).

In addition to placing patients' interests ahead of their own, clinicians should maintain and advance their own professional competency. This duty encompasses awareness and critical assessment of relevant literature, familiarity with advances in biomedical knowledge, facility with technological advances, and assurance of capacity to provide clinical care within their scope of practice. Thus, when clinicians make recommendations, they should be informed by professional judgment and the best available evidence.

4. To Respect Children and Promote Their Wellbeing, Clinicians and Parents Should Inform Pediatric Patients of Salient Information and Invite Their Perspective to the Degree That Is Developmentally Appropriate

Although decision-making authority usually lies with at least 1 parent (in consultation with clinicians), the decisions are about, and directly affect, the pediatric patient. It is a fundamental ethical norm in medicine to respect persons, and so, as individuals who are directly affected by decisions, some basic respect is owed to the pediatric patient. Respecting a child can be operationalized in at least 2 ways: (1) providing them with information about their health care, and (2) soliciting their perspectives.

Making a child aware of their condition and what is happening to them is one component of demonstrating respect.[42] Providing information treats the pediatric patient as a person, not as an object, allows the child to understand their situation more fully, and better equips them to participate in their care. What constitutes respect differs depending on the particular child's age and stage of cognitive, psychological, emotional, and social development. To respect the child by giving information, the language used in the discussion must be developmentally appropriate and directed at the level of the child's ability to understand and appreciate the information.

A second component of respect, soliciting the child's perspective, better directs and individualizes decisions for the particular pediatric patient whose health care is being determined. Additionally, engaging the child serves a pedagogical function, both expanding their knowledge of their own health care and developing their skills and abilities as participants in important processes that directly affect them.

Inviting a child's perspective does not necessarily require a robust assent process, which typically requires an assessment of the pediatric patient's understanding of the relevant medical information and an expression of willingness to accept the proposed care.[43] Instead, this recommendation encourages clinicians and parents to talk directly with the pediatric patient about their feelings, hopes, and worries, whether related directly to a treatment decision, or just the general experience of illness. Expressions of emotion should be acknowledged and validated, and expert resources (eg, psychology, psychiatry, and child life) should be consulted when beneficial. Finally, when available and appropriate, the pediatric patient should be given real choices, even if only about small decisions (eg, what time of day to receive a medication or in which arm to place an intravenous line).

It is important to note that despite this commitment to involve the pediatric patient in the decision-making process, parents may object to their involvement, and parents have the authority to do so (Recommendation #1) as long as the decision would not present a significant risk of serious imminent harm to the child (Recommendation #5). The clinician should have conversations with parents about the anticipated benefits of involving their child in decision making and address concerns parents might have about their child's involvement.

5. In Addition to Fulfilling State-Mandated Reporting Requirements, Clinicians Should Seek State Intervention When All Less-Restrictive Alternatives Have Failed and a Parental Decision Places the Child at Significant Risk of Serious Imminent Harm or Fails to Meet the Child's Basic Interests

Although parental discretion is wide, it is not unlimited (Recommendation #1). A clinician's duty to protect and promote their pediatric patient's health interests may be complicated when they disagree with parents about what those interests are or how best to promote them. Disputes can typically be resolved by good communication about health care goals and values (Recommendation #6). In some cases, the involvement of additional parties, such as an ethics consultant or patient advocate, may contribute to a satisfactory resolution. In addition, there are rare cases when a dispute is intractable, and it may be appropriate for the clinician to end the clinical relationship respectfully after identifying an appropriate alternative to address the child's health needs. However, if a clinician believes a pediatric patient is significantly endangered by a treatment delay or refusal, the clinician's obligation is to safeguard the pediatric patient's welfare, which may require recourse to child protective services or the legal system.

When parents refuse recommended treatments, their discretion is limited. In clinical emergencies, it is justified for a clinician to implement immediately needed treatment, even over parental objections. In other parental refusal scenarios, it is appropriate to seek intervention from state agents, including child protective services or the courts, if the refusal (1A) causes a significant risk of serious imminent harm[5] or (1B) fails to meet the child's basic interests[6] and (2) the proposed medical treatment and the interventions necessary are likely to be effective. However, state intervention should be considered an option of last resort, and thus, 5 factors should be confirmed before reporting: the harm must be serious and imminent, the risk must be significant, the treatment being refused must be necessary to prevent the serious harm and of proven efficacy, projected benefits of the intervention must outweigh the projected burdens, and less-intrusive but similarly beneficial alternatives must be exhausted.[5] For example, parental refusal of surgery for a ruptured appendix would typically satisfy these conditions, justifying a decision to seek emergency state intervention, but the refusal of surgical reconstruction of a clubfoot would not.

6. Clinicians and Parents Should Strive to Collaborate in a Shared Decision-Making Process to Promote tthe Child's Interests

Parents and clinicians may be informed by different moral values, perspectives, and information (Recommendations #2, #3, and #5). As such, their interactions are best if guided by evidence and shared experience as well as certain norms and values. In addition, the process of decision making should be shared, a process typically characterized by (1) the involvement of at least 2 parties, (2) all parties sharing information, (3) parties developing a shared understanding of the available treatment options, and (4) all parties bringing their knowledge and priorities into the decision-making process.[44]

For decision making to be collaborative and shared, both parents and clinicians must weigh sufficiently the child's interests, share relevant information, explain their preferences, and respect the perspectives of other stakeholders.[11] Given the power asymmetry inherent in these exchanges, a clinician should elicit and encourage the sharing of values, concerns, and questions from parents and make recommendations to parents when appropriate. Similarly, parents should share specific information relevant to the decision (eg, family's values and goals and the pediatric patient's medical history, preferences, and personality). Clinicians should share all materially relevant information about the child's condition (eg, nature and prognosis) and treatment options (eg, risks, benefits, and alternatives) with the family. Although some decisions may not warrant clinician recommendations (eg, in the "informative model" or "informed non-dissent" model of decision making)[45] if clinician recommendations are warranted, these should be informed by the values of the family and available medical evidence.[46] Because effective shared decision making relies heavily

on clinician skill, self-awareness, and judgment, it requires intentional training and practice.

Shared decision making aims at bidirectional, substantive communication between clinicians and parents while maintaining the authority of the parent as decision maker (Recommendation #1). Of course, in some circumstances, parents may not be able to participate fully because of emotional or practical constraints. When possible, institutions and clinicians should mitigate these circumstances. In addition, some parents may exercise their decisional authority by deferring much of the decision making to the clinician. Also, a robust shared decision-making process cannot guarantee that the parties will come to a common decision, and in such cases, it will be important to find another way forward, whether to appeal to policies and procedures of the clinic or institution to break the deadlock, or to notify state authorities if there is a serious risk of significant imminent harm (see Recommendation #5).

Although the American Academy of Pediatrics endorses a similar model of "collaborative communication and the exchange of information between the medical team and family" for pediatric decision making,[3] shared decision making in pediatrics is particularly complex because the relationship includes clinicians, parents, and the patient. The decision-making process should be personalized according to the family's preferences and the unique clinical situation.[45] To the extent the pediatric patient is able, willing, and permitted to participate (Recommendation #4), the process should be flexible enough to provide the pediatric patient with salient information and include the pediatric patient in decision making in a developmentally appropriate manner.[47]

It may be necessary for a clinician to employ varying degrees of directiveness when engaging in decision-making interactions with parents.[48] When a decision involves multiple appropriate medical choices and parents wish to make decisions relatively independently, the clinician may be less directive, simply presenting options and answering questions. A greater degree of directiveness is justified, however, when it aligns with the child's health interests or with the family's preferences regarding the clinician's role in decision making.[49] Additionally, a greater degree of directiveness may be appropriate when one option has a significantly more favorable benefit/risk ratio. In such situations, the clinician may use defaults or nudges[50] to encourage the family to make the medically preferred choice.

REMAINING CONCERNS

These 6 recommendations represent a consensus among the authors. The authors recognize consensus reports may raise questions "about a particular group's composition, its deliberations, and its substantive recommendations."[51] That we could achieve consensus on these 6 recommendations speaks to the willingness of the participants to challenge their own assumptions, beliefs, and values and be willing to listen and compromise. At a minimum, then, this document should be viewed as a starting point for further deliberation about the underlying guiding principles for pediatric decision making.

Still, there remain several questions that require additional consideration.

1. Under what circumstances should health care professionals or the state limit parental authority, and what mechanisms should be used in such situations? There are at least 3 types of disagreements: (1) what kinds of interests and harms warrant limiting parental authority (eg, child's interest in survival and avoiding morbidity, public health interests, psychological harms), (2) what specific thresholds/boundaries must be crossed or what conditions must be present to warrant limiting parental authority (eg, the degree of imminence, likelihood of risk, and magnitude of harm), and (3) what is the appropriate response when a clinician believes that parental authority should be limited (eg, persuasion, nudging, or appeals to state authority)?
2. When should a clinician be permitted to unilaterally withhold or withdraw potentially inappropriate treatment and what should be the limits around such decisions (eg, Simon's Law[52])?
3. What is the proper scope of pediatric medical practice, and when might certain procedures or interventions be considered by some to constitute inappropriate medicalization (eg, growth attenuation, feminizing genitoplasty, or gender-affirming care)?[53–57]
4. Regarding the involvement of the child, what types of clinical information (eg, diagnosis or prognosis) or what level of child participation (eg, notification or deliberation), if any, should be required for decision making?
5. Do these recommendations need to be modified for neonates or adolescents?[42,58–60] Moreover, do these recommendations need to be modified for children who lack a parent if state-appointed agents are asked to make decisions for them?[25,61]

CONCLUSIONS

Despite coming from different philosophical traditions and disciplinary perspectives, this group of pediatric bioethicists was able to come to a consensus on 6 recommendations for pediatric decision making. Although members of this group have written extensively on these issues and have decades of experience in clinical settings that inform these recommendations, it remains critical to test these newly developed recommendations in real-world conditions to determine their validity and utility in the specified population. The next steps will be to determine if these principles apply to neonates, teenagers, and wards of the state, or whether modifications are necessary.

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