

Competence or Experience: The Missing Voice in Pediatric Decision-Making

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INTRODUCTION

One night in 2016, I fell sound asleep, then awoke to painkiller-induced, nightmarish hallucinations in the ICU. Despite being unable to identify myself or surroundings, I can clearly remember the discordant beeping of hospital monitors, acrid smell of saline wash, and taste of sickly sweet orange amoxicillin syrup. I was unaware that, the morning after I'd fallen asleep, I'd skied off an unmarked 30-foot cliff, breaking my legs, jaw, eye socket and nose, rupturing my right ear canal, and shattering nearly all of my teeth. Over the years that followed, I was fortunate enough to receive care from skilled, compassionate physicians. This not only allowed me to return to ski racing, but to dream of becoming a surgeon. Having grown older and thus more aware throughout my years as a pediatric patient, I've developed a nuanced understanding of what treatment made me feel heard.

In fact, I found the most radically varying aspect of my care to be the degree to which I was addressed as a conscious, capable individual versus an extension of my parents. This is unsurprising as the proper amount of authority lended to pediatric patients persists as highly disputed in bioethics. Over the course of this paper, several perspectives will be considered in order to evaluate the current position of the pediatric patient in medical decision-making. First, the ambiguity of maturity and reactions to pediatric autonomy will be considered through the Mature Minor Doctrine, especially important in the refusal of life-saving therapies. Next, the need for improved pain management, rooted in the misalignment of experienced and perceived pain in pediatric patients. Finally, this paper will prove, through the lenses of communitarianism and mosaic decision-making, the need for a more nuanced approach to pediatric care that structurally accounts for the patient's voice without neglecting their place within a greater network. Therefore, there exists a great need for a more direct, balanced integration of pediatric patients' as well as revisiting prevailing notions of where pediatric patients stand in relation to reason and experience.

ANALYSIS

To begin, Fleischman's *Pediatric Ethics* opens with an exploration of what makes pediatric bioethics distinct.¹ Fleischman quickly runs into the most problematic of principles in the treatment of pediatric patients—autonomy. The ethical ambiguity of the degree of autonomy to offer pediatric patients and at

what point in their lives is a central point of conflict. Many in favor of expanded authority point to the neurobiological similarity between young adults and late teenagers.² Furthermore, while parents are treated as natural decision-makers for their children, there are several cases of minors facing pressure to undergo medical treatment against their wishes.^{3,4} In response to these concerns, the Mature Minor Doctrine was created, a common law exception to the parental consent requirement. The doctrine allows a minor “to refuse or consent to medical treatment if [they possess] sufficient maturity to understand and appreciate the benefits and risks of the proposed medical treatment.”⁵ The doctrine has spurred extensive and impassioned bioethical discourse, especially in relation to the refusal of life-saving therapies.

In “Health Care Decisionmaking by Children”, Ross draws a clear distinction between the notion of competence, often cited in psychological justifications of the Mature Minor Doctrine, and sound judgment.⁶ Her points against child liberationists can be simplified as follows: (a) children need time to develop virtues that preserve their life-time autonomy versus their present-day autonomy, (b) pediatric patients possess “limited world experience and so [their] decisions are not part of a well-conceived life plan,”⁷ and (c) it serves parents and children alike for parents to make decisions in line with their view of a good life. I find all three points convincing, but each of them to be uniquely rooted in this same, critical lack of experience possessed by pediatric patients. I can attest to this. There were times where I suffered so desperately that I longed for relief by any means. I even told my mother that I was content only hearing out of one ear, willing to do anything to prevent another surgery. Now, I am fearful to imagine a world where, at my lowest, I had full autonomy.

Hence, the broad aversion to expanded pediatric autonomy is largely rooted in potential misuse, especially in the possibility of a unilateral, misinformed decision in favor of death via refusal of life-sustaining therapy.^{8,9} Yet, one might argue, the desire for death has concrete rationale beyond lack of life experience— pain and suffering. As Foley describes, “The public’s fear of pain and the media’s portrayal that physician-assisted suicide and euthanasia are the only reliable options for pain relief... demand that health care delivery systems commit their efforts to improve pain relief at an institutional level.”¹⁰ Indeed, the issue of insufficient pain management is all too common in pediatrics. One study comparing postoperative pain assessments surveyed 307 patients, 207 of whom were verbal. Across the board, nurses’ pain estimations produced significantly lower pain scores than parents and children, and were consistently closer to estimated pain scores of independent observers.¹¹ In another study, a total of 356 nurses across 22 Japanese PICUs were surveyed, and despite possessing a median of 4 years of experience, a mere 32.6% expressed confidence in their ability to accurately assess pain.¹² It is alarming and telling that even in verbal pediatric patients, pain is significantly underestimated by medical personnel, reflecting a real gap in pediatric patient-professional communication. I can, again, personally attest to this. In the children’s ward, I was offered only Tylenol for severe nerve pain in my legs that kept me awake most nights.

Relatedly, the spirited debate in response to the Mature Minor Doctrine is somewhat disproportionate. Despite the suggestion of various commentators that the law broadly recognizes the doctrine or that states are trending in its direction, only eight states have adopted a mature minor exception, and even these states condition this authority greatly.¹³ With this in mind, a crucial issue is illuminated— an aversion to the pediatric patient voice altogether. As Flesichman writes, “Children should be informed about the nature of their condition, the proposed treatment plan, and the expected outcome... appropriate to their developmental levels.”¹⁴ Hence, it is vital to curtail pediatric autonomy in complex and life-threatening choices, but it is worth seriously considering that the current landscape might excessively minimize or avoid pediatric patients’ expression, merely serving to inform them rather than account for their voice.

The experience that pediatric patients do possess, in the form of knowing their body, past medical experiences, and thus present pain-related needs, is systemically underrepresented. This is a pressing issue. Before considering expansion of the pediatric voice, though, it is first important to consider the manner in which the patient's capacity is further complicated by their role within a larger community. It is worthwhile explicitly mentioning communitarianism, a prevailing school of thought in modern bioethics, defined by Callahan as "a way of... assum[ing] that human beings are social animals... and whose lives are lived out within deeply penetrating social, political, and cultural institutions and practices."¹⁵ Pediatric patients present a uniquely communitarian case as the perspectives of parents and the needs of patients' families are vital considerations in offering care. The pediatric patient's role in a larger family unit and community should be kept in focus so long as the well-being of the patient isn't compromised, such as in potentially life-threatening religious preferences, as the obligation of the physician is, first and foremost, to the patient.

Nonetheless, the status quo demands a more thoughtful and structural accounting of the pediatric voice to ensure that they feel heard and empowered in complex decision-making and regular care alike. Hence, it is necessary to develop and evaluate clinical models and frameworks that directly account for the pediatric voice, that integrate pediatric patients' input as continuous, regular, and required elements of treatment. For instance, there may be promise in a model similar to that of mosaic decision-making, a means of restoring the capacity of reemergent patients following brain injury. Rather than enabling complete surrogate authority, the model would enable a pediatric patient's *emergent* voice to be accommodated but to not "speak beyond its range and capabilities" via group deliberation between surrogate and patient, a medical professional, and a patient advocate.¹⁶ Opting for such a model would enable the active involvement of pediatric input without excessively empowering the patient in a manner that neglects their communitarian role and lack of experience.

CONCLUSION

In the heated response to the largely unenforced mature minor doctrine, one finds the invaluable and lacking factor of experience in pediatric patients, especially in decisions to withdraw or refuse life-sustaining medical treatments. In this same response, however, one finds a sharp aversion to the pediatric voice, reflected in pervasive under-medication. Deficits in pain management must be addressed to more effectively treat discomfort, an effort bolstered by a more structural accounting of the pediatric voice and thus pain-related needs. Finally, frameworks that regularly involve the pediatric patient perspective while valuing their communitarian importance and lacking experience, such as the mosaic model, hold real promise moving forward.

¹ Fleischman, Alan. *Pediatric Ethics: Protecting the Interests of Children*. (Oxford: Oxford University Press, September, 2016), p. 1-16.

² Coleman, Doriane & Rosoff, Philip. "The Legal Authority of Mature Minors to Consent to General Medical Treatment." (Itasca: American Journal of Pediatrics, March 2013), p. 1.

³ Hawkins, Susan. "Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes." (New York: Fordham Law Review, March 1996), p. 1.

⁴ Derish, Melinda & Heuvel, Kathleen. "Mature Minors Should Have the Right to Refuse Life-Sustaining Medical Treatment." (Boston: The

Journal of Law, Medicine & Ethics, January 2021), p. 1-14.

- ⁵ Derish, Melinda & Heuvel, Kathleen. "Mature Minors Should Have the Right to Refuse Life-Sustaining Medical Treatment." p. 7.
- ⁶ Ross, Lainie. "Health Care Decisionmaking by Children. Is It in Their Best Interest?" (Garrison: The Hastings Center Report, November-December 1997), p. 1-5.
- ⁷ Ross. "Health Care Decisionmaking by Children". p. 5.
- ⁸ Penkower, Jessica. "The Potential Right of Chronically Ill Adolescents to Refuse Life-Saving Medical Treatment - Fatal Misuse of the Mature Minor Doctrine." (Chicago: DePaul Law Review, 1996), p. 1-8.
- ⁹ Burk, Josh. "Mature Minors, Medical Choice, and the Constitutional Right to Martyrdom." (Charlottesville: Virginia Law Review, September 2016), p. 1-15.
- ¹⁰ Foley, Kathleen. "Pain Relief Into Practice: Rhetoric Without Reform." (Alexandria: Journal of Clinical Oncology, 1995), p. 1-3
- ¹¹ Hla et. al. "Perception of Pediatric Pain: A Comparison of Postoperative Pain Assessments Between Child, Parent, Nurse, and Independent Observer." (Melbourne: Pediatric Anesthesia. 2014) p. 1-5.
- ¹² Tsuboi et. al. "Nurses' perception of pediatric pain and pain assessment in the Japanese PICU." (Tokyo: Pediatrics International, February 2023), p. 1-3, 10-12.
- ¹³ Coleman, Doriane & Rosoff, Philip. "The Legal Authority of Mature Minors". p. 1-3.
- ¹⁴ Fleischman, Alan. *Pediatric Ethics*. p. 115.
- ¹⁵ Callahan, Daniel. "Principlism and communitarianism." (Garrison: The Hastings Center Report, October 2003), p. 2.
- ¹⁶ Fins, Joseph. "Mosaic Decisionmaking and Reemergent Agency after Severe Brain Injury". (Cambridge: Cambridge University Press, September 2017), p. 6.