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Pediatric Participation in Medical Decision Making: Optimized or Personalized?

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Olszewski and Goldkind (2018) argue that children's participation in medical decision making should be "the default position" and that a stepwise approach is needed to ensure that children are routinely given a voice. They suggest a systematic approach for optimizing such pediatric participation and apply it to two cases concerning terminally ill children: Mary, a 15-year-old girl, and Joe, a 7-year-old boy. The style of argument highlights a generalized problem in bioethical analyses. Authors' framing of case vignettes is often stylized to illustrate the authors' central arguments and to support their conclusions. But other facts or emphases might lead us in different directions. Thus, we believe that there is a need to question whether children's participation in medical decision making is always an unqualified good. As an alternative, we suggest a more flexible approach that we call "personalized decision making."

Autonomy is a fraught concept, particularly for teens, and especially when families' cultural background does not hold autonomy as a fundamental value. Cases involving such families expose gaps between the liberal philosophical values and the legal, ethical, and cultural values that inform families from different traditions.

Scholars have long debated the extent to which children and adolescents should participate in medical decisions relating to themselves. Although parents are generally considered to be the best decision makers on behalf of their child, the Western culture's overwhelming emphasis on autonomy has led to an international trend in law and policy toward recognizing the role of children in such decisions. The adoption of the Convention on the Rights of the Child (1990) played a key role in this shift: It

was the first "hard law" instrument that explicitly acknowledged not only children's vulnerability and need for protection but also children's agency. Article 12 of this convention requires States Parties to assure that a child capable of forming her own views has the right to express them freely, given due weight in accordance with her age and maturity. As the drafting process of the convention and subsequent authoritative interpretations of it demonstrate, this provision was intended to encompass medical and research settings (Sabatello 2009). This understanding has been since incorporated in regional (i.e., European) and national laws and policies. In the Netherlands, for example, physicians are legally obliged to communicate with children older than 12 years old the therapeutic prospects and options that are available to them, and to follow their wishes, with specific regulations governing conflicts between parents and children ages 12 and 16 years (as would have applied to Mary).

As a starting point, Olszewski and Goldkind's call for pediatric participation in medical decision making as the "default position" is consistent with the international trend and professional guidelines (Katz and Webb 2016). It is also supported by empirical research showing that, when given child-friendly information and time to reflect on the issues, adolescents' medical decision-making capacity is comparable to that of adults (Steinberg 2013). The mandate to include children in decisions also reflects an appreciation of the key role of life experiences for children's evolving decision-making capacities. Children with long-term conditions, such as Mary and Joe, often know far more about their own disease than do people who have acute or emergency conditions. They understand the seriousness of

their condition and can evaluate potential treatment options (Alderson 2007). These factors all tip the scale toward an approach to decision making that includes children's voices. Indeed, some scholars charge that forgoing the default position merely reflects adults' anxieties about losing their powers to decide for children (Alderson 2007).

But all is not so simple. It is one thing to endorse the empowerment of children. It is another to operationalize it. And this is a first challenge for pediatric participation in medical decision in the United States, the only country in the world that has not ratified the Convention on the Rights of the Child. Unlike some other countries, the U.S. Constitution contains no explicit protection for children's rights. This legal landscape has significant implications. Children are not recognized as independent subjects of the law but are primarily embedded within nuclear families. With some exceptions, parents have the prerogative to consent for or refuse medical treatment of their child. Thus, Olszewski and Goldkind's advocacy for the default position may appear as an unacceptable effort to replace parental preferences with physicians' liberal political philosophy about children, which is not universally endorsed.

The issue is further complicated because physicians' efforts to implement the default position may exacerbate tensions between parents, children, and the medical team, and may not result in decisions that follow the child's preferences. The authors discuss their discomfort with Mary's decision to delegate decisions to her parents. They also express frustration at not being able to convince Joe's parents that his preference for dying at home was the preferable choice. Thus, although the goal of developing a stepwise approach to pediatric participation in medical decisions is laudable, its implementation may result in situations in which none of the stakeholders are satisfied with the outcomes.

Rethinking the role of *personalized* medical decision making and its relevance for families and children across medical scenarios may be helpful in moving the discussion forward. Specifically, four interrelated issues merit consideration.

First, the traditional Western bioethical paradigms for medical decision making may not be the most suitable for pediatric (and other) patients. These paradigms prioritize individuals as independent decision makers, emphasize rational logic as the mobilizer of human conduct, and focus on how decisions *ought* to be made in an ideal world rather than how they *are* made by most people in the real world (Lantos 2015). These paradigms are inadequate for many adults. They are even more problematic for pediatric patients, including adolescents whose participation inherently depends on their relationships with (and decisions of) adults.

Children's brain development, readiness to assert their autonomy, and preferences regarding participation in medical decisions—regardless of their decisional capacity—are not monolithic (Alderson 2007; Grootens-Wiegers et al. 2017). Children differ in which decisions and how

much decision making they defer to parents. Many children, especially adolescents, want to be involved in medical decisions, but they often prefer shared—not autonomous—decision making. They generally trust their parents and seek support. Some children prefer taking a passive role and leave the decision to their parents or health care professionals. Still other children, especially adolescents, value autonomy differently from their parents. Further complicating is that little empirical research exists on children's preferable voice in end-of-life decisions. The feminist and disability constructs of relational autonomy—that is, autonomy *with* others—may thus better fit the needs of pediatric patients. Rather than optimizing autonomous decision making, which children may neither have nor desire, relational autonomy acknowledges that boundaries and power relations between children and parents or other adults are an ongoing dynamic process of negotiation that needs to be tailored to the particular child, family, and circumstances of the case (Sabatello 2009).

Second, the prevalent expectation in the United States for individualized decision making is not universally shared. In many cultures, the family, rather than the individual, is thought of as the primary moral agent (Betsch et al. 2016; Cochran, Saleem, and Khawaja-Punjwani 2017). Children like Mary may hold such cultural values as well, even if their preferences reflect core values of other adults whom they trust, rather than being based on independent perspectives (Katz and Webb 2016). And although such preferences may change over time as pediatric patients (and their families) engage in the process and adjust to new circumstances, a personalized approach that recognizes these fundamental value differences is more flexible and may thus be a better model.

Third, the justifiability of physicians' efforts to implement the default position requires contextualization. Olszewski and Goldkind draw on guidelines in pediatric research and on studies of assent of adults with intellectual disabilities to deduce that children and adolescents should (always) participate in medical decisions relating to them. However, these contexts may not be analogous to the situation of children and teens who need end-of-life care, nor comport with the unique issues in research.

Finally, the authors' acceptance of assent—rather than consent—as a sufficient bar in these decisions is in and of itself morally fraught (Sabatello and Appelbaum 2016; Iacono 2006). Assent can mean many things. Sometimes it is identical to consent, but without the binding legal authority. At other times, it is sort of "consent-lite," a process that makes doctors, lawyers, and bioethicists feel better without truly empowering children to participate in decisions.

All these problems lead to our recommendation on personalized decision making. This approach does not rely on one-size-fits-all philosophical paradigms but requires providers to adjust the decision making to the specific child, family, and the circumstances of the decision itself. Children should be encouraged, and supported as needed, to participate in the decision-making processes when a

treatment regimen requires their long-term commitment (e.g., compliance with medications or long-term follow-up after a finding of BRCA genetic mutations). In cases where the prognosis is poor, the key issue is to act on the child's interests and to provide supportive and holistic palliative care. This may include a teen's preference to delegate decisional authority to the parents.

The personalization of pediatric participation in medical decision making recognizes that autonomy for both children and many adults is fundamentally relational. We all make decisions within the psychological domains of our families and the sociocultural contexts in which we are embedded. Western bioethical paradigms are one such sociocultural context. But cultural humility would require us to recognize that ours is not the only, or not even necessarily the best, way to think about the ideal process of decision making for medical treatment, especially end-of-life care.

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