

A Push for Progress With Shared Decision-making in Pediatrics

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Shared decision-making (SDM) is a decision-making model in which “both parties share information...take steps to build consensus about the preferred treatment, and [reach an agreement] on the treatment to implement.”¹ It exists on a continuum between 2 extremes (decision-making driven solely by the patient or by the physician) and represents a balance between patient and physician decisional responsibility that is guided by the patient and calibrated to the clinical context.² At its inception, SDM was proposed to be the “ideal for the physician–patient relationship” as medicine pivoted from paternalism.³ It is now the standard decision-making model in medicine.

Despite SDM’s prominence, however, problems linger. The evidence to support the purported benefits of SDM (increased patient understanding and satisfaction, improved adherence, and better health outcomes) is equivocal.⁴ Physicians are also struggling with how to practice SDM.⁵ In addition, little is known about how SDM should be applied in the pediatric setting.

The gap in our understanding of SDM in pediatrics exists in part because initial frameworks used to develop the concept of SDM were based on the clinical context of a competent adult patient facing an acute, one-time intervention for the treatment of disease. This single, simplistic dyadic scenario has also served as the basis for subsequent analyses of SDM, its features, and tools to facilitate it. Analyses of SDM for scenarios common in pediatrics, such as decisions that occur with a surrogate decision-maker, in the absence of disease, and longitudinally over several encounters, are comparatively scarce.

I worry that this gap has created confusion among pediatricians about when and how to use SDM. My own practice may be representative. When talking with parents in the newborn nursery about several routine interventions that comprise the cornerstone of pediatric preventive care, such as supine sleep position, breastfeeding, newborn screening, and immunizations, I find that I approach these interventions in different ways despite each having a common core: all are universally recommended, evidence-based, offer substantial benefit with minimal risk, and constitute the standard of care. For some of these interventions, I operate from the patient-driven end of the SDM continuum by inviting

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parents to participate in the decision-making process (eg, “Do you plan to breastfeed?”), communicate their preferences, share information about risks and benefits, and reach agreement about the plan. For others, I operate from the physician-driven end and simply tell parents the plan in a way that limits their ability to provide much input at all (eg, “He’ll get a heel poke before you leave as part of the newborn screen.”).

Although some of this variability may be based on differences that do exist between these interventions, I think it is also due to confusion about SDM itself. Consider the SDM process of building consensus about a preferred treatment; how should this look with a surrogate decision-maker? Fundamentally, this process involves exploring and incorporating patient values, preferences, and beliefs to ensure patient decisions match their preferences.¹ However, in pediatrics, patients generally cannot participate in the decisions that affect their interests. As a result, additional factors become relevant to building consensus, such as the expectation that parents adhere to the best interest standard. Eliciting parents’ preferences to ensure they match their decision, in fact, generally occurs in conjunction with a scrutiny of whether those preferences serve the child’s best interests. This can yield a process for building consensus that not only looks different from that used with a competent adult patient, but may even undermine the ability to build consensus (and, therefore, SDM) at all. It seems that the degree to which we endorse SDM is dependent, to some extent, on the decision-making capacity of the patient involved.

Inherent constraints on parental decision-making also seem to impact when it is appropriate to use SDM in pediatrics in the first place. For instance, a prerequisite for SDM is that a decision have more than 1 medically acceptable

option.⁶ Though competent adult patients always retain the option to do nothing, regardless of the risk of harm it may pose to them, parents do not. Parental requests for options that put their child at significant risk of serious harm, in fact, are superseded. As such, there may be a more restricted set of decisions in pediatrics in which SDM is appropriate. Confounding this, however, is an inherent subjectivity regarding what constitutes an option that poses “significant” risk or “serious” harm to a child, and therefore little consensus about which decisions in pediatrics have only 1 option. Providers are often left to make their own determinations. What follows is variability in when SDM is and is not used.

Lastly, the suitability of SDM for decisions that have consequences for the health of others has been overlooked. This is not a feature of decisions unique to pediatrics, but is one that potentially represents SDM’s greatest threat: providers have obligations toward the communities within which they practice, but acting on these obligations can encroach on patient involvement in the decision-making process and undermine SDM. In pediatrics, the paradigmatic decision with this public health feature is the childhood immunization decision. Interestingly, current recommendations for communicating with parents about immunizations favor a SDM approach.⁷ Motivational interviewing, a patient-centered communication framework similar to SDM in its emphasis on collaboration and patient autonomy, has also been encouraged.⁸ In analogous situations, however, such as with patients who have tuberculosis, SDM regarding therapy is not recommended. This apparent decision-making discrepancy may be contributing to confusion surrounding SDM in pediatrics.

To advance the concept and practice of SDM in pediatrics, therefore, I propose 3 tasks as the basis for a SDM research agenda. First, we need to conduct conceptual work to assess how current SDM frameworks can accommodate common decision-making scenarios in pediatrics, such as those involving interventions that are longitudinal, prevent disease, and include surrogates. Newborn screening represents a potential starting point for this work because it includes each of these features, its decision-making has been extensively deliberated, and its consensus approach is a mandatory offer.⁹ We also need to map these common decisions on the SDM continuum to additionally conceptualize how physician and patient responsibility for each decision should be balanced; if a physician-driven SDM approach to newborn screening is appropriate, what justifies a different approach to breastfeeding?

Second, we need to develop a transparent and deliberative process involving pediatric providers and policy-makers to determine what constitutes a decision with real choice. As parents continue to request alternatives to universally recommended, evidence-based, minimal risk interventions that constitute the standard of care, practice guidelines that specifically address the reasonableness of these requests are needed. Third, it is unclear how providers should balance public and individual health within SDM. With the immunization decision as a reference point, we need to partner with colleagues in public health and decision science to explore new models or versions of SDM that are better able to accommodate physician obligations to protect public health while recognizing the importance of parent participation in decision-making.

Progress with SDM in pediatrics is needed. It is needed to address paradoxical approaches to

decisions with similar features, such as newborn screening and immunizations. And it is needed to ensure that we don't deprive parents of choice when it exists or create the illusion of choice when it does not.

ABBREVIATION

SDM: shared decision-making

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