## Involving Youth With a Chronic Illness in Decision-making: Highlighting the Role of Providers

Victoria A. Miller, PhD

abstract Decision-making is important in the context of pediatric chronic illness because children and families need to make decisions about burdensome and complex treatments on a regular basis, and children must eventually learn how to make such decisions independently. Research related to children's decision-making in medical settings has been focused primarily on cognitive aspects of decision-making, such as understanding and capacity. The concept of decision-making involvement (DMI) recognizes that children can be involved in decision-making in multiple ways, regardless of capacity, and that parents and health care providers play a critical role in supporting children as they learn to make decisions on their own. Providers can facilitate DMI during medical encounters by asking for the children's opinions and concerns, encouraging turn-taking, soliciting questions, asking for information directly from the children, and checking that the children understand what has been said. Efforts to involve children send the message that the youth perspective is important and set the expectation for increased participation over time. Providers can also support parentchild decision-making about illness management at home by guiding parents as to how best to involve children in decisions about illness management, identifying areas in which more or less parental guidance and support are needed, and assisting youth in planning ahead for decision-making about illness management in high-risk situations. Additional research is needed to identify why children's DMI in medical settings remains low, develop and evaluate strategies to enhance DMI, and test the effects of DMI on health-related behaviors and outcomes over time.

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Children with a chronic illness and their families face numerous decisions related to the ongoing management of complex and burdensome treatment regimens. There are periodic, discrete decisions related to medication changes and other aspects of treatment, but there are also decisions that must be made and tasks that must be completed by families on a daily basis. These include when and how to fit in treatments amid the demands of daily life, determining treatments based on symptoms or other information (eg, whether to take a rescue inhaler for asthma and identifying and responding to low blood sugar in youth with type 1 diabetes), deciding what and how much to eat and adjusting treatment as appropriate (eg, how much insulin to bolus in the case of type 1 diabetes and how many enzymes to take in the case of cystic fibrosis), determining activities based on symptoms or potential health consequences, and whether and how to discuss the illness with others. such as friends and teachers.<sup>1</sup>

Decision-making about chronic illness management occurs in the context of significant developmental change and individual and/or family differences. Developmental factors, which are discussed at length elsewhere,<sup>2,3</sup> include aspects of cognitive development (eg, attention, memory, abstract thinking, and reasoning), psychosocial maturity (eg, future orientation and impulsivity), and decisionmaking and communication skills. In addition, children typically desire more decision-making and behavioral autonomy as they mature. However, the transition to greater independence can be challenging for many reasons, including parental anxiety about nonadherence and disease complications and the children's resistance to the treatment regimen. Individual differences, such as a child's previous experience

with decision-making, health-related goals, and coping style, as well as a family's cultural background, family structure, and parenting style, will also shape how medical decisions are made, including the extent to which the child is involved in the decision.4,5 Recommendations for involving children in decision-making are further complicated by the fact that decisions vary along several dimensions, including urgency, the risk/benefit ratio, the certainty of the outcome, the number of options available, the setting in which the decision is being made, and the extent to which the decision is preference sensitive.

Much of the previous research on children's decision-making in medical contexts has been focused on assent to research or treatment and cognitive aspects of decisionmaking, such as understanding and decision-making skills. This previous work has attempted to answer the question of when children become capable of making medical decisions on their own.<sup>6</sup> Because of the emphasis on children's capacity, the relational aspects of decision-making have been largely ignored.<sup>6,7</sup> A relational approach to children's decision-making is used to address the question of how adults can best support children's involvement in the decision-making process and facilitate independent and effective decision-making as they mature. The concept of decision-making involvement (DMI) captures both the relational and developmental aspects of decision-making and allows for various ways for children to be involved, regardless of capacity. In this article, I propose that (1) there are numerous ways to involve children and adolescents in decisionmaking, and involving children has potential benefits; (2) even as children and adolescents become increasingly involved in decisionmaking, parents continue to play an important role; and (3) the role of the provider is critical when involving children in decision-making during medical encounters and, especially in the case of chronic illness management, providing support and guidance for parent-child decisionmaking at home.

#### THE CONCEPT OF DMI

DMI is defined as the way in which children are engaged in decisions, including both childactive participation (eg, child asks for advice and expresses opinion) and adult solicitation of the views and opinions of the child.<sup>8</sup> This definition is based on a relational model of decision-making,<sup>5,9,10</sup> in which the role of collaborative decision-making in normative development is recognized. It reflects that children can be meaningfully involved in decision-making in multiple ways and that parents and other adults, including health care providers, are an important source of support and advice even as children assume increasing levels of decisionmaking independence.<sup>1,11</sup> The acknowledgment of the role of parents is critical because research has revealed that children and adolescents want parental input about health-related decisions<sup>5,9,12,13</sup> and that decision-making authority, without support or guidance, can be burdensome.<sup>1</sup> Parents are typically in the best position to understand the broader context of a child's or adolescent's values and goals; they can provide emotional support through the process of decisionmaking; they can assist with the steps of decision-making, such as providing information and identifying options and pros and cons of each option; and they can facilitate the implementation of a decision.

DMI is an alternative to the construct of shared decision-making (SDM), which was developed with respect to the adult patient-provider relationship and requires mutuality, shared information giving and decision-making, and agreement about a decision.<sup>14</sup> These qualities do not always apply to child-parent or child-provider relationships in pediatric settings. Parents typically play a significant role in decisionmaking, both legally and practically, and children are in the middle of developing their decision-making and communication capabilities. As such, they are not necessarily equal partners in decision-making and may not be willing or able to express opinions, preferences, and values; share relevant information; and evaluate alternatives. These are behaviors that are necessary, according to a widely cited model of SDM.<sup>14</sup> Unlike in SDM, in DMI, it is recognized that children need to learn about and practice decisionmaking in multiple situations.<sup>7,15</sup> It is hypothesized that DMI is used to teach children the factors to consider when making decisions, the consequences of different options, and the communication skills needed to negotiate and influence decisions. In addition, DMI may be used to enhance self-efficacy<sup>16</sup> and promote adherence and coping skills.<sup>2,17</sup>

Much of the previous research on children's DMI has been qualitative, and researchers have assessed children's preferences for involvement and perceptions of how they were involved in treatment decisions.<sup>12,18–20</sup> There have also been observational studies in which researchers assessed aspects of youth involvement in decisionmaking, but these studies were primarily grounded in the concept of SDM.<sup>21–24</sup> In 1 line of research, researchers have developed a quantitative measure of DMI, called the DMI Scale, in youth with asthma, type 1 diabetes, or cystic fibrosis to assess parent-youth decisionmaking interactions about chronic illness management.<sup>8</sup> In analyses of the subgroup of youth with

type 1 diabetes, the extent to which youth expressed an opinion, shared illness-related information, and engaged in joint decision-making behaviors with parents during decision-making interactions was positively associated with adherence after controlling for age.<sup>25</sup> In a longitudinal study, aspects of DMI changed with age, were associated with adherence consistently across development, and interacted with age to predict glycemic control in youth with type 1 diabetes.<sup>26</sup> Other researchers, although not assessing DMI directly, have found that more collaborative parental involvement in managing diabetes is associated with improved adherence, quality of life, and metabolic control in youth.<sup>27,28</sup> Furthermore, an intervention designed to increase parent-child teamwork around diabetes tasks in youth ages 8 to 17 years prevented the worsening of metabolic control that was seen in the control group after 1 year.<sup>29</sup> Given the rates of nonadherence in pediatric chronic illness, especially during adolescence,<sup>30–32</sup> enhancing children's involvement in illness management decisions may prove to be a fruitful target of intervention.

#### THE ROLE OF THE PROVIDER

There is a rich history of debate about the ethics of decision-making involving pediatric patients, and much of this debate has been centered around whether, when, and how to obtain children's assent (ie, affirmative agreement) to treatment.<sup>33–37</sup> A focus on DMI is consistent with recommendations put forth by the American Academy of Pediatrics (AAP) as far back as 1995<sup>34</sup> in its policy related to informed consent, parental permission, and assent and as recently updated in a 2016 Policy Statement.<sup>35</sup> It is important to note that the AAP policies, as well as an AAP Clinical Report regarding SDM

with children with disabilities and their families,<sup>38</sup> have underscored that decision-making is an interactive process in which information and values are shared and the experiences and perspectives of children are critical. They emphasize that it is important to involve children to the extent that they are able and that involving children may have important benefits, such as fostering trust, enhancing the physician-patient relationship, and influencing health outcomes. Furthermore, in the 2016 policy, the AAP recognizes that children's and adolescents' decision-making should not be expected to be autonomous or voluntary because of the developmentally appropriate influence of parental perspectives. In the 2016 policy, the AAP also asserts that some children, especially those who are older and have more experience because of chronic illness, may have the capacity to engage in the informed consent or refusal process for proposed treatment goals. Although the AAP policies provide a useful framework, additional guidance regarding specific ways to involve children in the process of decisionmaking, beyond simply seeking their assent, is needed.

#### Involving Children During Office Visits

Patient-physician communication is 1 of the primary means by which patients receive information and make decisions about treatment options for chronic health issues. In pediatric settings, physicians also may shape expectations about who should be responsible for healthrelated tasks and decisions. motivate effective self-management and adherence, prepare youth for greater responsibility and the transition to adult health care,<sup>39</sup> and guide communication between parents and youth about health behaviors and treatment decisions. In studies of adolescent preferences, adolescents

with a chronic illness reported that they prefer direct communication to them versus their parents<sup>40</sup> and want either a shared or active role in decision-making.<sup>41,42</sup> Furthermore, aspects of physician communication relevant to decision-making, such as perceived support and a patientcentered style (eg, asking, listening, and taking notice of the adolescent's opinion), have been associated with visit satisfaction,<sup>43</sup> adherence,<sup>44,45</sup> and perceptions of control and competence<sup>46</sup> in adolescents.

Because providers typically have longstanding relationships with patients and their families, they can play a critical role in facilitating DMI during medical encounters as youth mature. Indeed, incorporating ways to involve children early is important because the experience of participation sets the stage for increased participation over time.47 In addition, failure to involve children may contribute to later nonadherence if youth perceive that their preferences and goals regarding treatment decisions have not been taken into account.48,49 Specific strategies to facilitate children's involvement include turntaking (eg, teaching and encouraging the children to take turns when speaking),<sup>50</sup> directly asking the children for information about symptoms or treatment routines, soliciting questions from the children about decisions to be made, asking the children for their opinions or concerns about a proposed treatment change, and checking for the children's understanding about their illness and treatment regimen. Researchers have shown that children's verbal participation in medical encounters is greater when providers engage in these sorts of communication behaviors.51-53

Involving children in these ways may be challenging for multiple reasons, including time limitations,<sup>54</sup> a history of parents being the primary focus of communication,<sup>55</sup> parental

interference,<sup>55–58</sup> and wanting to protect children from upsetting information.<sup>19</sup> In addition, providers may perceive that youth are not interested in such involvement,55 and children and adolescents may not respond to attempts to involve them in discussions or decisions about illness management (eg, the anxious 7-year-old girl who wants her parent to answer for her and the adolescent boy who is distracted by his mobile device). Youth nonresponsiveness or lack of engagement should not be taken as cues to abandon such efforts. When a provider actively attempts to facilitate a child's involvement, it sends the message that the child's voice is important, sets the expectation of participation, and may increase the child's comfort when speaking up in future visits.

Although children have reported feeling more valued when they are included in health-related discussions with providers,<sup>18</sup> there is limited research regarding the ways in which youth-provider decision-making interactions may impact health-related outcomes and behaviors. However, in related research, researcher-child interactions about the decision to enroll in medical research studies have been examined. The findings revealed that when youth perceived that researchers engaged them more in the discussion about research participation (eg, asking for their opinions and soliciting questions), youth reported greater decision self-efficacy after controlling for age.<sup>59</sup> When they perceived that researchers supported their autonomy (eg, indicating that the children were central to the decisions), youth reported that the decision-making process was more fair. Research is needed to determine if these findings are replicable in a clinical care context as well as whether these proximal outcomes lead to the long-term outcome of better health.

### Supporting Decision-making at Home

Office visits are a context in which providers can directly facilitate children's involvement in discrete decisions about illness management. However, they offer only a snapshot of the decisions that children and families need to make on a regular basis, and providers can play an important role in supporting parentchild decision-making about illness management at home. Parentdirected strategies may include suggesting strategies to engage youth in specific decisions, such as asking for their opinions and concerns, providing information and guidance, and soliciting questions. Providers can also guide parents to respond effectively to children's requests for help or information (eg, avoiding overreactions, anxiety, or unnecessary activity limitations in response to children's symptoms) and identify areas in which more assistance or, alternatively, more autonomy might be needed. Such guidance from providers may be critical because decision-making independence before children are ready may contribute to the declines in adherence that are typically seen during adolescence.<sup>30–32</sup> Childdirected strategies include helping children differentiate between decisions and tasks they can manage on their own versus those that require support from parents or other adults and encouraging youth to disclose important symptom- or treatment-related information to parents in a timely manner. Providers can also help youth identify and plan ahead for high-risk situations (eg, situations in which peer pressure or emotional arousal may impact successful decision-making and illness management). Overall, provider facilitation of discussion about illness-related decision-making at home may facilitate treatment adherence by increasing the likelihood that parents and children

are "on the same page" with respect to illness management and that timely and effective decisions are made.<sup>1,48,60</sup>

#### CONCLUSIONS

Involving children in decisionmaking about chronic illness management is an important means through which youth can observe, learn, and practice decision-making skills, and researchers suggest that DMI is associated with favorable views of the decision-making process, self-efficacy, and adherence. An overemphasis on children's capacity (ie, seeking to answer the question of whether a child has the capacity to participate in or make decisions) may result in providers forgoing children's involvement altogether. In other words, when we begin with the assumption that children are incapable, we may not consider how we can guide the development of decision-making skills and provide the opportunity for learning and practice.<sup>7</sup> There are multiple ways in which children and adolescents can be included in decision-making,

regardless of capacity, and the onus is on both parents and providers to facilitate children's involvement. Efforts to facilitate youth involvement send the message that a child's voice is important and set the expectation for increased participation as the child matures. A decision-making process in which the exchange of opinions is emphasized also may be used to contribute to understanding different perspectives, identifying misconceptions regarding the decision at hand, and reaching a consensus.<sup>7</sup> Providers play a critical role not only during medical encounters, when they can directly attempt to involve children in decision-making, but also by supporting the dynamics of decisionmaking about chronic illness management at home, which can be challenging for families.

Despite recognition by the medical profession that children's involvement in decision-making is important, the extent to which children are involved in practice appears to be low.<sup>24,54</sup> For example, observational research has revealed that asking for youth input about asthma management during primary

care visits is infrequent, occurring in only 6% of visits.<sup>21</sup> Research is needed to identify reasons for this gap and examine trajectories of DMI during medical encounters over the course of a chronic illness and across development. Finally, research is needed to develop strategies to enhance provider facilitation of children's involvement in decision-making and to evaluate the short- and long-term effects of such strategies on health-related behaviors and outcomes over time. including the transition to adult health care. Although especially relevant for enhancing chronic illness management in children and adolescents, such strategies are likely to be relevant to a broad range of pediatric medical decisions.

#### ABBREVIATIONS

AAP:	American Academy of
	Pediatrics
DMI:	decision-making
	involvement
SDM:	shared decision-making

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