

# Supporting Family Decision-making for a Child Who Is Seriously Ill: Creating Synchrony and Connection

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**abstract** The families of children with chronic or serious illness are sometimes faced with difficult decisions never previously imagined. We offer a stepwise approach in building a human connection with these families to support them through the decision-making process. We encourage the clinician to stop talking and to actively listen and find common ground. We suggest that offering open and honest information begins with an invitation. We encourage clinicians to explore concepts with the family, including their fears and hopes. We discuss nurturing an emotional connection between the child and family and describe ways to discover a family's preference for involvement in the decision-making process. Central to supporting a family is to place infinite value on the life of their child. We argue that attention to these matters will help the clinician remain in sync with the family to ensure meaningful and high-quality decision-making during highly vulnerable times for families.



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Supporting a family during decision-making for their child with chronic or serious illness creates unique challenges and opportunities.

Decisions are made and exist within constantly changing contexts: illness trajectory, perception of acceptable quality of life, emotions, age and development of the child, and other life changes in the family (such as loss or change of employment, a move, or death or illness of an older family member or parent). All contribute to a dynamic and active process. These contextual attributes affect family goals, hopes, fears, and preferences for decision-making.

Shared decision-making (SDM) is an accepted standard of collaborative care processes that involves the patient (and family) and the clinician using the best evidence in consideration of the patient's (and family's) values, goals, and preferences related to decisions.<sup>1-6</sup> SDM does not completely address certain unique aspects of decision-making that involve children with chronic and serious illness and their families, whose decision options commonly involve life-limiting consequences, risk of undesirable outcomes, and uncertainty. As a result, supporting the family may take a more longitudinal and evolutionary course.<sup>7</sup>

Evidence suggests that SDM may be a best-matched approach for some families (or for  $\geq 1$  individuals within a family) but not necessarily for all families or all children with illness all of the time.<sup>8,9</sup> SDM was originally designed to represent optimal communication between a physician and a patient to make outpatient treatment decisions.<sup>10,11</sup> The challenge for today's health care team is in building clinician skills, confidence, and flexibility to use diverse approaches tailored for each family as the team navigates how best to solicit family members' preferences for their role in decision-making and how best to maintain

**TABLE 1** Steps on Building a Human Connection

Step	Build a Human Connection	Example
1	Start with an invitation	"Tell me about you today?"; "How does your child look to you?"; "Tell me more."
2	Stop talking	—
3	Actively listen	Eye contact, head nodding, and deliberate focus on the person speaking; repeat back: "What I'm hearing you say..."
4	Exercise in reciprocity: find common ground; go back to step 1	"What is your understanding of your child's current condition?"; "What do you fear?"; "What do you hope for?"; "Is now a good time?"; and then... "We are both hoping for that goal."

respectful attention to their choice. This nuanced partnering between the health care team and the family requires exquisite attention to the family's cues while intentionally establishing a human connection.

Here, we discuss the process of supporting families facing chronic and serious illness during decision-making. Many of the strategies and concepts we present are applicable to less serious conditions in which SDM is more traditionally applied. By focusing on chronic and serious illness, however, we intended to fill the gap in which conventional SDM might fall short. We discuss how to extend an invitation to the family for their involvement and how to implement strategies for getting to know the child and family, anticipating their emotional reactions and their preferences for how much information they need at any given time, and regarding their preferences for how they want and need to be involved in decision-making (or not). We hypothesize that a stepwise approach in engaging the family will be useful. We further believe that central to supporting the family is ensuring that they perceive that members of the health care team are genuinely devoted to their child's best interests and their family's well-being and that their child is valued.

### THE HUMAN CONNECTION STARTS WITH AN INVITATION

Attention to building a human connection is essential to supporting

the family in decision-making. Before even beginning to have a conversation about a difficult decision, a human connection must be established. Contrary to common misconception, a connection can be established or at least initiated in a short period of time. A smile, a warm handshake, and body language that states, "I am here and present; I am dedicated to you right now," will set the right tone. Parents notice when clinicians express sincere interest in the child or the family as valuable individuals,<sup>12</sup> and they expect collaboration and wish to have sincere relationships with their clinicians.<sup>13</sup> Key to establishing these relationships is active listening, empathic statements, and open-ended questions.<sup>14</sup>

A stepwise approach might look similar to the following (see Table 1):

#### Step 1: Start With an Invitation

A genuine question such as "Tell me about you today..." may open a window into the difficulties and joys of this individual's daily experience, and in so sharing, a possible connection may begin. We may find that this parent is frazzled; she's late because her other children had a 2-hour school delay, and her husband cannot possibly miss more work or be at risk for losing his position (ensuring disaster for the family).

An invitation such as "Tell me, how do you see your son?" might lead to insight that the parent knows things are not going as expected (a statement that then can be built on).

If confronted by the cursory and polite responses of “fine” or “ok,” saying, “Tell me more...,” will allow the families more space and reveal to them that the clinician wants to hear more.

### Step 2: Stop Talking

We need to make a bigger effort to listen. Studies have revealed that clinicians do most of the talking during family conferences.<sup>15</sup> The language and context of what the family says provides helpful information about the context of their current situation and gives enormous insight into how to approach the next steps, what their sticking points are, what is not negotiable, and what is valuable. Much of the mystification in how to approach a family and what to say exists in the language they provide, if given the opportunity.

### Step 3: Actively Listen

Eye contact, head nodding, and deliberate focus on the person speaking are all tools to deploy. Clinicians should repeat back what they have heard to avoid or correct misunderstandings and to help foster trust.

### Step 4: Exercise Reciprocity

Exchange ideas that are mutually beneficial. Find a common ground (eg, “We are both hoping for...”). To explore and find that common ground, clinicians should ask family members about their understanding of their child’s current condition, what they fear,<sup>16</sup> and what they hope for<sup>17</sup> all while demonstrating empathic curiosity.<sup>18</sup> The concept can be operationalized by going back to step 1 (invitation): “Is it ok if we talk about...,” “Is now a good time?” “Tell me about...” Such methods have been explored by Back et al<sup>19</sup> in the well-known ask-tell-ask method. If the conversation takes an unexpected turn (and the clinician regrets the wording or delivery), parents might appreciate an honest approach, an

offer of apology, and a request to start over.

Importantly, an invitation may not yield the intended results. It might never be a good time to talk about a laboratory result, a diagnosis, an emotion, or a difficult decision. Although a clinician might be able to have some flexibility and come back later, many situations may call for opening the door when a parent has explicitly (or using body language) made the statement of “not ready.” Awareness of this possibility must be ever present, and the clinician might engage with statements such as “I wish we didn’t have to talk about how sick John is...and talking through some things ahead of time might be helpful if he were to worsen.”

The stepwise approach described here emerged in October 2017 at the intensive workshop on SDM in pediatrics at Children’s Mercy Center for Bioethics in Kansas City, Missouri. Deliberation by leaders in the field led to the unique collaboration of a multidisciplinary group, including physicians, researchers, psychologists, ethicists, nurses, palliative care experts, and others.

The results are our interpretation of the articulated conclusions and summary of this topic. We believe this approach represents the practical strategies and tools based on the group’s collective wisdom, clinical and research experience, interpretation of the literature, and observations of exceptional communicators. We propose that this approach might help clinicians support parents and families, particularly when facing a difficult decision. In future work, researchers might methodically investigate the different components and derive further understanding of its universal applicability.

### Synchrony in Decision-making

Human conversation has a cadence and rhythm that fosters the human

connection. Synchrony can be defined as communication that reflects symmetry and mutuality or a “coordinated movement between individuals in social interactions.”<sup>20</sup> Family-led pacing and seeking synchrony have been associated with positive social responses and intensive experiences of compassion.<sup>21,22</sup> Developing synchrony between team members and the family often precedes a productive and successful conversation. Matching rhythmic and coordinated behavior and movements in individuals increases cooperation and shared intentionality.<sup>20,23</sup> Expressions and body language during synchronous conversations have a matched cadence, as seen with artists in dancing and music. Clinicians who make an effort to assess the family’s reaction while attempting to follow their pace of understanding and information absorption will gain their respect and trust.

Attention to synchrony is more than just kindness or trying to “feel good”; instead, it is an act of mindfully falling into step with the family and trying to meet them where they are. Although synchrony alone does not drive a family in ultimately making a difficult decision for their child facing illness, the human connection that results can yield a powerful understanding of what the family is most worried about (ie, “I know my son would not have wanted to be connected to machines, but I cannot imagine letting him go”). Statements shared in a safe space can help clinicians shape the next steps and help frame statements such as “Based on what you’ve shared with me, is it ok if I give you some recommendations and talk about what that might look like?”

In some cases, we might tap into conflict, pain, grief, and anger and unleash an outpouring of negative emotion. This should not be discouraged or avoided in favor of what feels good. Instead, the

recognition of this dissonance is healthy and sometimes required for a resolution. An astute clinician can remain in step with the family throughout that entire journey. We should possibly seek out this release of emotion and try to illuminate points of contention and find the dissonance. More research is needed to understand how to approach this part of the conversation and to explore and find flexibility in the vast variation of the human experience. We suggest that step 4 should include attention to synchrony and exploration of dissonance.

Synchrony is not achievable with every family. The most experienced clinicians will find parents (and situations) who will resist their best efforts to form an alliance.

Another challenge is in convincing clinicians that this type of skill can be taught. As with other communication techniques, teachability begins with awareness and recognition. We are continuing to explore how to best teach and apply these skills.

### **Nurturing an Emotional Connection Between the Child and Family**

Creating memories with the child and family is extremely important in helping to establish a human connection. Helping the family to be physically present during the child's serious illness is a part of establishing this connection. Most children's hospitals provide for 24-hour parental presence and have staff members dedicated to helping develop and grow meaningful connections with the child.

Parents need to be assured that the clinical team is doing everything possible to help their child, whether the goal is cure or comfort. They also need to know that their child feels loved. Engaging parents in discussion about what it means to them to be a good parent to their child facing illness contributes to enriching and deepening the connection between the clinician and the family member,

permits a deeper understanding of core beliefs,<sup>24</sup> and provides examples of how the team can support parents.<sup>25,26</sup> Using instruments such as *My Wishes* or *Voicing My Choices* with children who can communicate can increase a sense of the child being heard and being emotionally connected in the living and dying experience.<sup>27,28</sup>

### **Acknowledging Emotion and Uncertainty and Inviting Hope**

Parents are physically exhausted from the demands of caregiving and from emotional overload; they are too often overwhelmed and unable to process the information they are being given. Parents want and need emotional support,<sup>13</sup> and clinicians must attend to their shock and emotional distress. Attending to emotions such as anxiety, depression, joy, guilt, and loss is critical to building a trusting relationship and is essential to supporting a family through a difficult decision. Acknowledging uncertainty about their child's condition may also be helpful.<sup>29</sup> When the child's condition is deteriorating, or when the child is near death, parents may not be able to repeatedly talk about how poorly their child is doing,<sup>30</sup> and repeated attempts to engage with them about their child's deteriorating condition may feel like an assault to them.

Maintaining hope is critical to supporting families through any decision.<sup>31,32</sup> Parents can simultaneously understand the reality and seriousness of their child's disease while maintaining hope. Hope is not limited to a cure or treatment response<sup>33</sup>; it can range from the miraculous to the mundane and is adaptable.<sup>17</sup> Even as some hopes die, others emerge, such as hope for freedom from pain, a dignified death, or more quality time together. Families' most bitter complaints have been about physicians who dismiss their hopes.<sup>31</sup>

Clinicians should engage parents in conversations about hope as a means to elicit realistic hopes that can help to focus meaningful treatment plans. And yet, clinicians rarely talk about hope.<sup>33</sup> One example of a way to engage with parents is asking them, "What would you want if things don't go as you hope?"<sup>34</sup> When we ask parents and children about their fears and hopes, we remind them that we value them and wish to know them as people.<sup>35</sup>

### **OPEN AND HONEST INFORMATION SHARING WHEN GIVEN THE GREEN LIGHT**

When a child is ill or injured, parents consistently report a desire for ample information in nontechnical language<sup>32,36,37</sup> (and a realistic picture of the child's condition) with a balanced presentation of risks and benefits.<sup>32,38,39</sup> Even in the face of uncertainty or bad news, parents prefer honesty.<sup>26,31</sup> The team must also carefully attend to parents' responses to information. In certain circumstances, parents will be hearing for the first time that their child has a potentially life-threatening illness, such as cancer, or that their child has suffered an accident that will lead to death or lifelong disability. Parents report that they cannot attend to lengthy discussions or absorb all the information.<sup>30,40-42</sup> Information might be broken up into shorter discussions so that they can begin to accept and understand. Here is another example of synchrony in which clinicians pace with the family's response and adjust the conversation; ask questions such as "Is now a good time to hear about what we know so far?"

Clinicians should carefully consider the language they use when providing information to parents and include expressions of empathy and compassion.<sup>43</sup> A single event, such as receiving bad news in an insensitive



way (via vocal or body behavior), or the feeling of being dismissed can cause parents profound distress<sup>31</sup> and increase anxiety, distrust, and dissatisfaction with care.<sup>44</sup>

The presence of a nurse during family meetings can increase parents' understanding of key discussion points.<sup>45</sup> Along with team members such as social workers, child-life therapists, psychologists, and chaplains, nurses can serve as a voice for families and help inform physicians about parents' wishes.<sup>46,47</sup> After formal meetings are over, the nurse is most often at the bedside, summarizing, clarifying, and managing a broad range of resulting emotions.<sup>40</sup> The bedside nurse is often the person alerting the team and clinician of a change in the family's dynamic. The nurses' assessment that the "parents are in a different place" can help the team distinguish the family's changed understanding and possible acceptance from a previous state in which the family required space and time to come to grips with their child's situation. This sometimes provides a meaningful window for reinitiating the family in discussion and SDM. Therefore, the nurse and other team members should be included in conversations whenever possible, and conversations should be summarized to members of the health care team, ideally including detailed documentation in the chart.

Whenever there is information sharing, a question about prognosis arises. However, physicians are often not fully equipped to give the most accurate understanding of prognosis.<sup>48</sup> Even within similar disease processes, there exists an enormous amount of variability, and the most honest approach could be a "best guess." In addition, clinicians must take great care to avoid value judgments about what defines good quality and a meaningful life.<sup>12</sup> Parents often have a different view of the quality of life for their

children, even in the face of profound disability, and find themselves fiercely advocating for others to find value in the life of their child.

### EXPLORING DECISION-MAKING PREFERENCES

Many parents share that throughout their child's illness trajectory, they did not perceive a choice in treatment.<sup>49,50</sup> They often navigate the complex world of a chronic, progressive illness, including years of experience with multiple subspecialists and a lifetime of medical interventions and medicines. Ups and downs, improvements, and setbacks are more frequently speckled with micro-readjustments in goals and priorities.<sup>51</sup>

When decisions are perceived, parents have differing preferences for involvement in the decision. For example, a high degree of urgency and a high level of required medical expertise have been associated with a parents' preference to delegate decisions.<sup>52</sup> Similarly, in oncology, parents have reported wanting the physician to assume decision-making when a child can probably be cured or when 1 best medical choice exists.<sup>53</sup> In contrast, parents prefer to maintain control of decisions when there is (1) high perceived risk, (2) experience with the decision, (3) involvement of foreign bodily fluids, and (4) a decision thought to be part of the normal parental role.<sup>50,52</sup> Families' style and expectations for decisional involvement and/or control may change over the course of the illness. Clinicians need to be aware and open to those changes.<sup>54</sup> The reality of decision-making is highly complex and evolves over time even within a family or a decision. Clinicians need to employ the skills described above to establish a human connection and an understanding by a series of invitations to explore how to approach and support a family for each decision; here is another

example in which synchrony may be deployed. We recommend avoiding the common mistake of asking the parents directly, "How do you prefer to make decisions for your child?" The ensuing blank stares will redirect the clinician to recognize that this approach may be misguided. Instead, the clinician should listen to cues (ie, verbalizations such as "This is too hard; I just cannot make a decision," "My husband is not able to make a decision, but I am," or "What would you do if this was your child?"). Such comments often result from achieving synchrony and a human connection and can help the clinician understand how the family wishes to make the decision in question.

### SUPPORTING THE CHILD'S VOICE IN DECISION-MAKING

How to support children in decisions about their own health adds an additional piece of complexity and challenge in pediatric decision-making. Coyne et al<sup>55</sup> defined child and adolescent SDM as "the ways in which children can contribute to the decision-making process, independent of who makes the final decision." This definition reveals the flexibility needed when engaging children in decisions about their illness and care.

The extent to which children and adolescents may want to be involved in decision-making depends on the clinical context, namely how acutely ill the child is currently and the child's experience with the illness.<sup>56,57</sup> In serious and chronic illness, the child may initially be too sick to participate in discussions but over time may want and need to have greater involvement in decision-making. When invited, children and adolescents of certain ages and experiences can report their preferences for how much information they want and how they want to be involved in treatment discussions.<sup>56-60</sup> Likewise, parents

may initially shield their children from distressing information but with gentle guidance and time to absorb the information, will engage their children in discussions.<sup>61</sup>

Parents report that it is helpful to initially hear distressing information without their child present so that they can fully attend to the discussion rather than also needing to worry about how their child is reacting to the information.<sup>62</sup> The context of the family is relevant when it comes to child and adolescent participation in decision-making. Some families do not include children in any major decisions, and similarly, in illness, the child may not be engaged in or informed of the seriousness. These situations, although typical for such families, create distress for the clinical team and concerns of violating the principle of autonomy. And yet, to betray the parents' preferences for involving their children would create confusion in the family. In the context of children with terminal cancer, Bluebond-Langner et al<sup>63</sup> describe this as mutual pretense in which both child and parents do not acknowledge what they understand to be true to each other. Shuttle diplomacy is recommended in these circumstances to facilitate discussions between the child and parents.

More evidence is needed to guide best practices for how to engage children and adolescents in decision-making<sup>6,64</sup> and how to help parents

and families transition from primary surrogate decision-makers to partners or supporters of their child's decisions.

### EARLY INCLUSION OF PALLIATIVE CARE CONCEPTS: HUMAN CONNECTION IN PRACTICE

Whenever there is perceived choice, there is the possibility of guilt and suffering.<sup>13</sup> Relieving suffering, whether physical, spiritual, or existential, is an important tenant of palliative care and is fundamental to supporting a family through decision-making.<sup>65</sup> Opportunities exist to provide relief of suffering of the child, parents, and other family members. Early conversations allow for understanding before the pressure of decision-making in end-of-life care is pressing.<sup>66,67</sup>

Early integration of a palliative care approach with a focus on communication, symptom control, understanding the child's condition, maintaining relationships, and the pragmatic needs of patients and families holds promise of a structured and collaborative way to support children with serious, life-threatening illness and their families. At its core, palliative care is focused on family-centered communication to bring all to a shared understanding about how care will be given to support the child facing illness, the child's family, and the clinical team.

### CONCLUSIONS

The concept of SDM, introduced a few decades ago, has continued to revolutionize the relationships between clinicians and families and patients. We have presented an examination of how to support families and children in decision-making, particularly those with serious and life-threatening illness. We acknowledge how difficult this process can be, and we acknowledge the risk of how dissatisfying and humbling this process can be for all involved despite the best of intentions and efforts. We embrace the purpose of SDM and suggest concepts that may be used to further explore and illuminate some of its limitations. We suggest that building a human connection, seeking synchrony, and always giving value to the life of the child might be next steps in helping clinicians know how to guide the family in making difficult decisions.

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### ABBREVIATION

SDM: shared decision-making

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