



Moving toward meaningful shared decision-making in neonatal care: clinical practice and policy implications in Korea

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Shared decision-making (SDM), which has become a core principle of patient-clinician communication, emphasizes respect for autonomy, partnership, and transparency. In neonatal practice—where decisions often carry profound ethical and emotional weight—SDM helps align medical recommendations with the family's values, fosters trust, and may reduce moral distress for both parents and clinicians. However, in Korea, the systematic recognition and formalization of SDM remains limited, underscoring the need for practical guidance and institutional support in neonatal and pediatric care. This review discusses key principles of SDM and illustrates their application in real clinical communication through hypothetical neonatal case vignettes. SDM is best understood not as a single model but as a continuum shaped by the balance between medical judgment and parental values. Drawing on Opel's stepwise framework, SDM is most appropriate when more than one medically reasonable option exists and value considerations meaningfully influence the choice. Physicians must also remain aware of personal biases that can shape how options are framed and discussed. Building on this conceptual foundation, this paper describes how meaningful SDM can be practiced using the 4 conversational phases outlined by Madrigal and Kelly: (1) acknowledging the need for a decision and inviting participation; (2) sharing information while listening; (3) uncovering values, hopes, and fears; and (4) reaching a balanced and ethically grounded decision. Through clinical examples, these phases demonstrate how empathy, pacing, and reflective dialogue can transform information exchange into shared moral reasoning. Finally, structural and cultural barriers continue to hinder the implementation of SDM in Korea, including time constraints, limited training, and restrictive legal frameworks. Policy reform, education, and team-based strategies

are essential to support its broader adoption. SDM ultimately offers an ethically robust and relational framework for navigating complex, value-laden decisions in neonatal and pediatric care that is grounded in communication that recognizes bias and engages families as true partners.

Key words: Shared decision-making, Clinical decision-making, Communication, Neonatology

Key message

Shared decision-making (SDM) offers an ethically grounded, relational approach to making difficult decisions in neonatal care. Its effective use depends on recognizing when its use is appropriate and enacted in clinical conversations. In Korea, while parents are often involved in decision-making, SDM is not yet consistently articulated or evaluated as a structured practice. Culturally grounded research, education, and institutional support are needed to strengthen family-centered neonatal care.

Introduction

The birth of a child is universally anticipated as a joyful and peaceful moment, yet this is not always the case. Approximately 10%–20% of newborns require admission to the neonatal intensive care unit (NICU).¹ While most are discharged in good health, some undergo multiple interventions and remain hospitalized for several weeks or longer. Sadly, a small number of admitted newborns die. The NICU is a setting where complex and often time-sensitive decisions must be made, such as whether to initiate neonatal resuscitation for an anticipated periviable

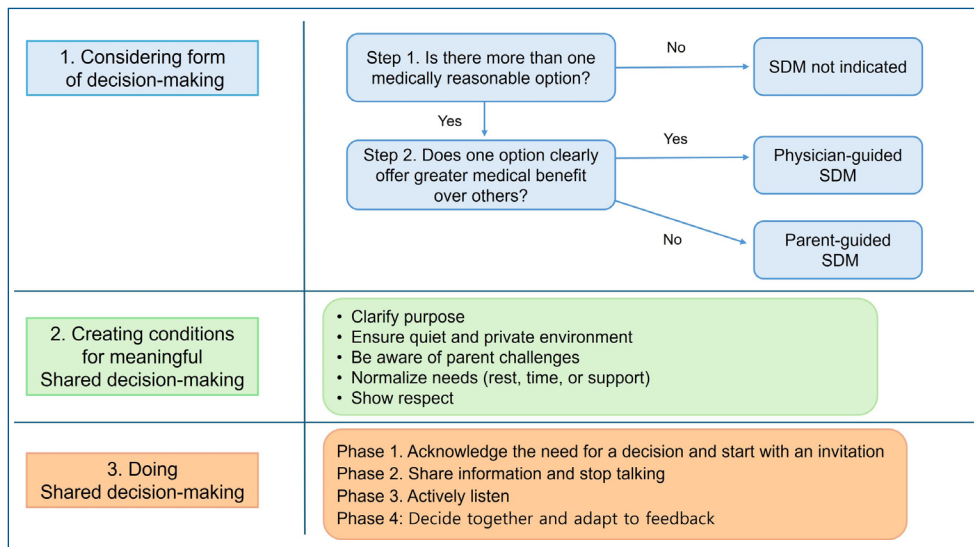
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Graphic abstract. Shared decision-making (SDM) in neonatal care requires integrating medical judgment with parental values to guide ethically sound choices. Clinicians first determine whether multiple medically reasonable options exist and assess their benefit-burden balance to decide between physician-guided and parent-guided approaches. Meaningful SDM depends on preparing supportive conditions and using structured communication that invites participation, shares information with synchrony, uncovers hopes and fears, and reaches decisions through reciprocity. This integrated framework highlights SDM as a relational process that strengthens trust, reduces moral distress, and supports family-centered care in the neonatal intensive care unit.

birth, when to proceed with surgery or an invasive procedure, or whether to continue life-sustaining treatment.

Rapid advances in perinatal medicine, including non-invasive prenatal testing and high-resolution ultrasound, have enabled the earlier diagnosis of congenital conditions. These developments have increased the frequency and complexity of decision-making surrounding their management. Furthermore, improved survival rates among peri-viable preterm infants have broadened the scope of neonatal care, introducing new dilemmas about how to manage the complications that accompany survival.²⁾

Because NICU care often involves high-stakes and emotionally charged choices, the medical community has long emphasized the importance of providing parents with adequate information and obtaining their consent before initiating treatment.²⁻⁴⁾ However, information transfer alone does not guarantee meaningful participation. One-way communication remains susceptible to the physician’s own values and assumptions.²⁾ Moreover, parents in these circumstances often understandably experience intense emotions—such as anxiety, fear, and guilt—that can hinder their ability to process complex information and clearly express their perspectives.^{2,5)}

This review aimed to describe how shared decision-making (SDM) can assist with addressing these challenges and propose a practical framework for its use in the neonatal context based on a nuanced conceptual understanding of when and how it is the appropriate approach. A clinical vignette is used to illustrate the framework.

The proposed framework is intended as a conceptual and normative guide rather than an empirically validated model; thus, this review does not aim to present comprehensive empirical data on SDM practice or outcomes. Rather, it is founded on an expert-informed narrative review of the ethical literature on SDM.

What is SDM?

Physicians are increasingly encouraged to move beyond the mere transfer of information and instead build relationships with parents that help them clarify their goals, values, and preferences. This collaborative approach, known as SDM, seeks to integrate parental values with relevant medical knowledge to arrive at a joint decision.^{2,6-10)} SDM emerged in the early 2000s; in 2016, the American Academy of Pediatrics (AAP) identified it as “a central tenet of the family-centered medical home.”^{2,11)} In 2018, the AAP published a dedicated supplemental issue on SDM in its official journal, *Pediatrics*, focusing on SDM and its application in clinical care.⁶⁾

Value of SDM in neonatal care

Ideally, through SDM parents gain the opportunity to understand complex medical information at their own pace, ask questions freely, and express their values and

concerns. This process aims to foster a sense of partnership and help parents feel genuinely respected as integral members of the care team. When parents sense that their perspectives are acknowledged and taken seriously, they are more likely to trust clinicians and remain engaged in their child's care, even amid uncertainty or distressing outcomes.²⁾

For physicians, intentional use of SDM cultivates a more collaborative and transparent communication environment. By sharing the decision-making responsibility, clinicians may feel less isolated when facing morally complex situations, thereby mitigating moral distress and burnout. The ongoing dialogue between parents and clinicians also strengthens mutual understanding and supports continuity of care.^{2,12)}

From a broader perspective, SDM can enhance families' long-term emotional well-being. When parents are given adequate space to explore their options, clarify their hopes, and make decisions that align with their values, they are less likely to experience anger, guilt, or regret in the future. Families who participate in open and meaningful discussions about their baby's care often adapt better over time and retain more positive memories of their child's early medical journey.⁷⁾

Critiques of SDM and responses to such critiques

Some may argue that there is often insufficient time to engage in SDM. For example, if a periviable infant is delivered unexpectedly and no prior decision has been made regarding neonatal resuscitation, clinicians may initiate resuscitation immediately and hold discussions with the parents once more information about the infant's condition becomes available. However, in most situations in which SDM is infeasible due to true emergency circumstances, there is usually only one medically reasonable option. These situations represent exceptions in which SDM is not required, as will be discussed further below.

Another frequent critique is that physicians are too busy to practice SDM. However, clinicians already have regular opportunities to communicate with parents and discuss aspects of their child's care. The emphasis, therefore, is not necessarily on spending additional time but rather on reframing existing communication within the SDM framework. In many cases, the barrier lies not in time constraints but in clinicians' willingness to engage in SDM and understand what it truly entails.

Reports indicate that some pediatricians avoid SDM in an attempt to spare parents from the perceived emotional burden of decision-making, including guilt and regret.^{13,14)} However, this approach is ethically problematic and may

not represent the full range of parental experiences of being involved in the decision-making process. Excluding parents from the decision-making process can constitute a form of paternalism that is often grounded in physicians' perceptions that parents are too emotionally overwhelmed to make decisions or the belief that clinicians are better positioned to make an objective judgment for the child. Such an approach risks undermining trust between clinicians and families and should be adopted only with great caution.¹³⁾ Moreover, empirical evidence does not support the assumption that involving parents necessarily harms them. For example, McHaffie et al.¹⁵⁾ found that 60 of 108 participating parents (56%) who decided to forgo or withdraw life-sustaining treatment viewed the decision as their responsibility, with only one father describing it as a burden.

Rather than experiencing harm, many of the parents interpreted participation in these decisions as a meaningful expression of their role as a "good parent," especially focusing on advocating for the child and making informed medical decisions on their behalf.¹⁶⁾ Similarly, other qualitative studies show that parents often see decision-making as a central expression of advocating for their child's best interests as a way of affirming their parental identity during an otherwise disempowering time.^{17,18)} When parents are adequately supported, participating in these difficult decisions can be experienced not as an added burden but as a meaningful and deeply valued aspect of parenting at the end of their child's life.^{15,17)}

Another potential issue with SDM is that it may be harder to implement among parents who have low health literacy or communication barriers. This may lead to inequity if these parents miss out on the benefits of SDM.^{19,20)} This is a valid concern and represents a key challenge for the equitable enactment of SDM; however, it constitutes a limitation of implementation rather than an objection to the concept itself.

Taken together, these critiques and ethical responses to them support the importance of SDM as an ethically meaningful and relational approach rather than argue against it. However, this does not imply that SDM is free from practical or ethical challenges. Evidence from behavioral science research indicates that preference formation and decision-making are shaped by cognitive biases, emotional distress, and difficulty predicting future values, particularly in high-stakes clinical contexts.²¹⁾ Research on affective forecasting further shows that individuals often mispredict their future preferences and emotional experiences, typically overestimating future suffering and underestimating their capacity for adaptation.²²⁾ Because SDM relies heavily on eliciting parental preferences at the time of decision-making, these limitations challenge the

assumption that stated preferences necessarily reflect long-term values or experienced well-being, a concern that may be amplified in neonatal care.

Recognizing these constraints highlights the need to approach SDM not as a fixed procedure but as a relational and adaptive process that requires practical guidance, iterative communication, and contextual sensitivity. Questions have also been raised regarding how SDM quality should be evaluated in clinical practice. Several instruments, such as the Observing Patient Involvement scale and the Shared Decision-Making Questionnaire, have been developed to assess SDM elements that primarily focus on observable clinician behaviors or self-reported perceptions of involvement.^{23,24} While these tools have contributed to advancing SDM research, their applicability to neonatal care is limited by the complexity, longitudinal nature, and relational depth of decision-making in this context. In the NICU, SDM often unfolds over multiple conversations under evolving clinical uncertainty, making it difficult to capture its ethical quality using cross-sectional or checklist-based measures alone. This is an important consideration when evaluating and improving practice, but this review focuses on a conceptual and practical understanding of SDM rather than an evaluation of its practice.

While the ethical and practical challenges of SDM remain under discussion, interest in its application within clinical practice is growing. In Korea, research on SDM has only recently begun that mainly focuses on adult patient care, whereas practices in pediatrics and neonatology have rarely been explicitly articulated or examined through an SDM framework. This article aims to contribute to the scholarly exploration of SDM in neonatology.

Clinical vignette

The following case vignettes are hypothetical scenarios that were developed to illustrate key elements of SDM in neonatal care and do not represent an actual case or clinical outcome.

1. Case 1

A female infant born at 26 weeks and 4 days of gestation with a birth weight of 970 g is now 31 weeks postmenstrual age and remains on invasive mechanical ventilation. A hemodynamically significant patent ductus arteriosus (PDA) continues to compromise her respiratory status. She has already received 2 courses of ibuprofen, neither of which successfully closed the PDA, although she experienced no adverse effects. We now must discuss with her parents whether to proceed with surgical ligation or

consider another course of medical therapy. How can SDM be applied in this situation?

2. Case 2

A female infant born at 26 weeks and 4 days of gestation weighing 970 g at birth is now 5 months of corrected age. She has remained on invasive mechanical ventilation since birth due to progressive severe bronchopulmonary dysplasia (BPD). Despite multiple extubation attempts, weaning has been unsuccessful and the ventilator settings remain high. The team is now preparing to discuss with the baby's parents whether to proceed with a tracheostomy or continue with prolonged invasive respiratory support. How can SDM be applied in this situation?

PART 1: Laying the SDM foundation

SDM is not a single uniform process; rather, it exists along a continuum that varies according to the nature of the medical options as well as the parents' values. To better understand how clinicians can navigate this continuum in practice, Part 1 of this article reviews the model proposed by Opel, which outlines a structured, stepwise approach to SDM in pediatrics (Fig. 1).³ As Opel emphasized, the essence of SDM lies in selecting the most context-appropriate approach rather than rigidly adhering to a single model. This continuum ranges from physician- to parent-guided approaches, each of which has both strong and weak forms. In strong physician-guided SDM, the clinician takes a more directive role when one option offers clear medical superiority, while the parental values

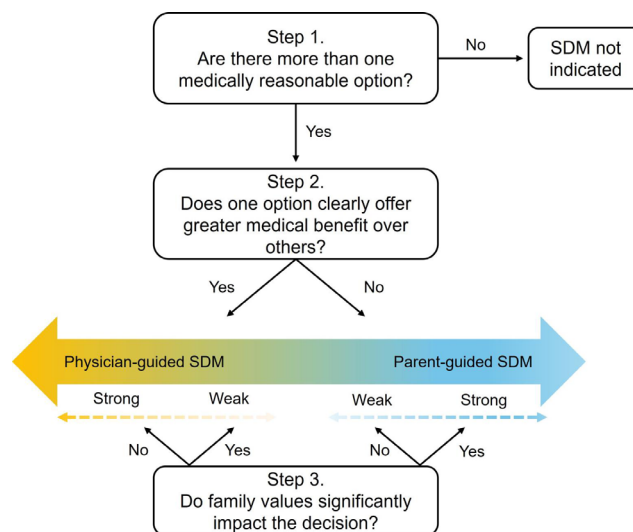


Fig. 1. Determining when shared decision-making (SDM) is appropriate in neonatal care, adapted from Opel.³ This figure illustrates the stepwise assessment of medically reasonable options and their benefit-burden balance that guides whether a physician- or parent-guided SDM approach is indicated.

play a lesser role. Conversely, strong parent-guided SDM is appropriate when no option demonstrates an evident medical advantage and the choice primarily depends on parental goals and beliefs. The weak forms of each approach represent a more balanced and mutual process characterized by shared deliberation and negotiation. Beyond parental preferences, several contextual factors—such as the urgency of the decision, whether the intervention is ongoing or a single event, and who will implement it—can further influence which SDM approach is most suitable. Determining how to weigh these overlapping factors remains an important area for future research and clinical reflection.

1. Step 1. Assessing the existence of multiple medically reasonable options

In Opel's framework, the first step is to assess whether more than one medically reasonable option exists. SDM applies only when 2 or more viable treatment choices are available; if only one option exists, a physician-directed approach with simple informed consent is appropriate. An option is considered medically reasonable if it aligns with the standard of care (SOC), which defines a minimum threshold for competent practice that is typically guided by evidence-based medicine. However, defining "medically reasonable" can be challenging due to variability in SOC and the fact that it is not always based on high-quality evidence. In some cases, limited evidence may become accepted as the SOC through professional guidelines, and while ideally grounded in robust, reproducible data, the SOC may temporarily rely on lower-quality evidence when stronger data are lacking. Options based on anecdote, opinion, or ideology are excluded since they fail to meet the minimum standard for competent care.

In case 1, the patient has a hemodynamically significant PDA and already underwent 2 courses of medical treatment. Because multiple management options exist—including pharmacologic therapy with nonsteroidal anti-inflammatory drugs or acetaminophen, interventional approaches such as surgical or device closure, and conservative observation—this situation is well suited to the application of SDM. In case 2, the discussion concerns whether to perform a tracheostomy in an infant with chronic lung disease who requires long-term ventilator support. If the clinician believes that close observation without immediate tracheostomy is also a medically reasonable option under the current circumstances, then this decision also qualifies as an appropriate setting for SDM.

2. Step 2. Determining whether one option has a more favorable medical benefit-burden ratio

If 2 or more medically reasonable options are available,

the next step involves weighing each option's potential benefits against its burdens to determine which best promotes the child's interests. When one option clearly offers a more favorable benefit-burden profile, a physician-guided SDM approach is appropriate, enabling the physician to take a more directive role. If no single option stands out, a parent-guided SDM approach empowers parents to take the decision-making lead. This judgment relies on evidence-based estimates of the likelihood, magnitude, and certainty of each option's benefits and burdens.

In case 1, the physician favored surgical closure since the 2 previous courses of medical therapy had been ineffective. However, given the infant's current hemodynamic stability, the physician considered that one additional course of medical treatment would not pose undue harm. Because neither option demonstrated a clearly favorable benefit-burden profile, the parent-guided SDM approach was deemed most appropriate. In case 2, the physician determined that a tracheostomy would be the more favorable option. The infant, now 5 months of corrected age, was entering a stage of developmental progress involving head control and oral exploration, which a tracheostomy would permit. A tracheostomy was also likely to reduce the infant's discomfort. Prolonging the endotracheal intubation posed increasing risks and burdens, such as subglottic stenosis and infection. Therefore, the physician planned to proceed with the physician-guided SDM approach by taking a more directive role in discussing the tracheostomy option with the parents.

3. Step 3. Assessing the preference sensitivity of each option

After assessing the medical favorability of each option, step 3 centers on understanding and integrating the parents' values and preferences into the decision. Parents bring unique insights into their child's needs, the family's priorities, and the values they hold and wish to impart to their children. The physician's role is to identify parental wishes and help parents clarify, explore, and refine their values so that the decision reflects the parents' considered thinking in a situation that is mostly like outside their previous experience. In this context, preference sensitivity refers not simply to the presence of parental preferences but rather the extent to which parental values meaningfully influence what constitutes a preferred choice among the medically acceptable options. When decisions are highly preference-sensitive, understanding and integrating parental values becomes central to ethical decision-making. Clinicians assess preference sensitivity by considering whether different choices would be reasonable depending on what parents value. This assessment is refined through dialogue with the parents.

At each step of the framework, physician bias can influence how options are defined and weighed. The framework does not seek to eliminate bias but rather to recognize and manage it. Defining “medically reasonable” care in step 1 by aligning it with the SOC and explicitly evaluating benefits and burdens in step 2 are measures that can reduce subjectivity. Still, physicians’ personal values and experiences may shape these judgments, and they have an ethical obligation to reflect on—and, when appropriate, disclose—their own values, particularly when parents seek personal recommendations. By acknowledging and openly addressing such biases, clinicians can minimize their personal (rather than professional) influence and lay the groundwork for more balanced deliberation. This aims to achieve an appropriate integration of parental autonomy and the physician’s professional responsibility to safeguard the child’s health and well-being.

PART 2: Conducting SDM discussions

This section focuses on the actual SDM conversation. It aligns with the general steps of the SDM framework while integrating principles of empathy, active listening, and value clarification. The communication process described below was adapted from the four-step model proposed by Madrigal and Kelly,²⁵⁾ which is presented here as 4 phases for clarity (Fig. 2).

Before the conversation: creating the conditions for meaningful SDM

As John Lantos points out, meaningful SDM begins long before the conversation itself.²⁾ Before engaging with parents, clinicians should prepare themselves and the environment to facilitate an open and trusting dialogue. This preparation includes clarifying the purpose of the conversation—not to persuade parents toward a predetermined choice, but rather to listen actively, build trust, and develop a plan that integrates medical evidence with the family’s values. Attention to practical details is also essential: discussions should occur in a quiet, private setting with only essential participants present and ideally include the primary nurse who knows the family well.

Equally important is recognizing and normalizing the factors that may make participation difficult for parents—such as exhaustion, maternal pain or illness, or feeling overwhelmed by the medical environment. Clinicians should be attentive to these challenges, help parents feel at ease with the participants in the room, and explicitly acknowledge that needing time, rest, or emotional support is natural. Such attention alleviates parental stress and conveys respect for parents as genuine partners in the decision-making process. Once these conditions are in place, clinicians can begin the SDM conversation itself with guidance from the 4 key phases outlined below. A continuation of each of the 2 clinical vignettes introduced earlier (infant with unclosed PDA and infant with BPD unable to wean from ventilation) illustrates how these

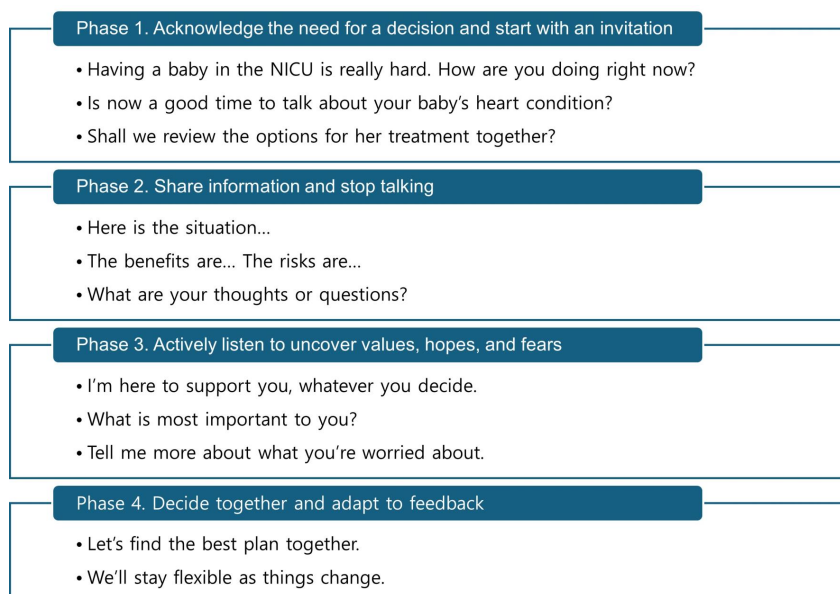


Fig. 2. Key communication phases of meaningful shared decision-making. The 4 phases—inviting participation, sharing information, uncovering values, and deciding together—illustrate how clinicians and parents coconstruct decisions through synchrony and reciprocity. NICU, neonatal intensive care unit.

phases can be implemented.

1. Phase 1: Acknowledge the need for a decision and start with an invitation

The neonatologist begins by first establishing rapport—specifically by acknowledging the parents’ emotional burden and inviting them into the conversation. Here are some examples:

- “Having a baby in the NICU is really hard. How are you doing right now?”
- “Is now a good time to talk about your baby’s heart condition?”
- “I know this has been an incredibly difficult journey. We’ve reached a point where we need to think together about the next steps for your daughter’s breathing support. Would now be a good time to talk through the options?”

In both cases, the clinician gently signals that a decision is approaching—whether about PDA treatment or the next step in long-term breathing support—without rushing into details about either choice. By doing so, the conversation begins with empathy and establishes readiness, setting the tone for open dialogue in the next phase.

2. Phase 2: Share information and stop talking

Once a sense of connection and readiness has been established, the clinician begins to share medical information in a clear and compassionate manner. This phase aims to build mutual understanding, pacing the conversation according to the family’s emotional and cognitive readiness—a principle that Madrigal and Kelly describe as synchrony. The clinician alternates between providing information and pausing to listen, checking for understanding, and acknowledging the family’s emotional responses.

In the first case, the neonatologist begins by exploring what the parents already understand, as follows:

- “What have other doctors or nurses told you about your baby’s PDA?” This not only clarifies their baseline knowledge but also communicates respect for their perspective.

Next, information is shared in plain, balanced language, as follows:

- “We face some decisions here. Your baby’s PDA has remained open despite 2 courses of ibuprofen, so we now need to decide whether to move ahead with surgery or try another medication. Surgery is definitive—once the PDA is clipped, it usually stays closed. The operation is brief but does require anesthesia and a small chest incision.”

When the parents express concern about the risks of surgery, the physician validates their feelings before elaborating as follows:

- “I understand how worrying this sounds—surgery feels like a big step. Let me explain why we consider it. If the PDA stays open, it can keep sending too much blood to the lungs, making it harder for her to come off the ventilator and grow. That’s why we usually discuss closing it after 2 rounds of medication haven’t worked.”

The physician then pauses, allowing the parents time to absorb the information, and continues, “That said, we can talk together about what matters most to you right now—whether to focus on avoiding surgery for now, or to take a more definitive step.”

Similarly, in the second case, after inviting the parents into the discussion, the physician gently explains the current medical situation, as follows:

- “At this stage, keeping the breathing tube in place for a long time can cause problems with her airway and make it harder for her to grow and feed. A tracheostomy would provide a more stable and comfortable way for her to breathe.”

The parents’ immediate reaction—fear, sadness, or hesitation—is met with empathic listening rather than persuasion.

- “I can see how painful this feels. Can you tell me more about what worries you most?”

In this phase, information is not merely delivered but coconstructed. The physician checks the parents’ understanding, reflects back their language, and adjusts the depth and pace of the conversation in response to their cues. This rhythm of telling, listening, and recalibrating helps establish synchrony and lays the groundwork for shared meaning in the next phase.

3. Phase 3: Actively listen to uncover the parents’ values, hopes, and fears

At this point, the clinician’s role shifts from explaining to listening. According to Madrigal and Kelly, active listening is more than remaining silent; it is an intentional effort to understand—through eye contact, empathic acknowledgment of emotions, and reflection of what has been heard. Through this process, the clinician begins to grasp what truly matters to the parents and how their values shape their sense of what is acceptable or unbearable.

In both cases, the dialogue moves from facts to meaning.

In the PDA case, after explaining treatment options, the physician pauses and listens as the parents share their apprehension about surgery. The mother says, “She’s

so small... I'm scared surgery will be too much for her." The father adds, "We don't want to put her through pain unless we have to." The physician reflects: "So what I'm hearing is that avoiding surgery right now feels most important to you—is that right?" Having understood their priorities, the physician then introduces an alternative, framing the information around the parents' values: "Since you would prefer to avoid surgery, there is another option—paracetamol. The success rate is much lower given medications have not worked so far, and there is a small theoretical risk of liver toxicity, but major complications haven't been reported in infants. This could give us another chance with medication while keeping surgery available if needed." This step—linking medical reasoning to parental values—illustrates how active listening not only reveals what matters to families but also guides how information is tailored and communicated in response.

In the tracheostomy case, the mother voices distress about her daughter "having a hole in her neck," and the father fears she will "always be seen as disabled." Rather than immediately correcting these misconceptions, the physician listens and explores further:

"It sounds like you're worried about her future—both her health and how others might see her. Can you tell me more about that?"

Through this listening, deeper layers of meaning emerge: the parents' longing for normalcy, their protective instincts, and their hope for the future. Active listening in this phase mirrors step 3 of the framework described earlier—assessing how preference-sensitive the options are. By uncovering what the parents value most, the clinician identifies areas of flexibility as well as moral or emotional boundaries. This understanding guides how far the decision can—and should—be shaped by parental preference versus medical necessity.

In practice, this phase transforms the conversation from a presentation of options into a process of shared moral reasoning. The physician's empathy and curiosity support the parents in clarifying their priorities and prepare both parties to move toward a balanced and ethically grounded decision in the next phase.

4. Phase 4: Decide together, find common ground, and exercise reciprocity

In this final phase, the clinician and the parents integrate medical reasoning with personal meaning to move toward a decision that feels both right and bearable. Madrigal and Kelly describe this as an "exercise in reciprocity"—a process of emotional and intellectual alignment that restores balance between the clinician's responsibility and the parents' hopes and fears. Through this synchrony, the family not only understands what decision is made but

why it makes sense for their child.

In the parent-guided PDA case, the parents' wish to avoid surgery guided the plan.

After active listening, the physician summarizes: "We both want her to grow stronger and stay safe. Since avoiding surgery now is most important to you, trying another medication first makes sense. We'll watch her closely and keep surgery as a backup if things do not improve."

This formulation reassures the parents that their priorities were heard and respected while maintaining medical safety. The clinician's reassurance—"We'll stay close and re-evaluate together"—helps alleviate their lingering anxiety and preserves trust for future discussions.

In the physician-guided tracheostomy case, the medical urgency was greater and required a more directive stance. The mother worried about the scar and her daughter's comfort; the father feared she will "always be seen as disabled." The physician acknowledges these feelings and reframes them with empathy and hope: "I can understand how painful this feels to imagine. A tracheostomy is not about giving up—it's about helping her breathe safely and comfortably. The scar is small, and as she grows, most people won't notice it. More importantly, it may help her spend more time out of bed and even learn to feed by mouth." These responses provide both emotional reassurance and a sense of continued possibility.

Importantly, SDM is rarely a single event; rather, it unfolds over multiple encounters, evolving as the child's condition, treatment response, and family's understanding change. A decision reached today may require revisiting tomorrow. By maintaining openness and continuity, the clinician conveys that revising a decision is not a failure but a natural part of good care.

A physician's response to "What would you do, doctor?" should reflect the appropriate balance between medical guidance and respect for family values. In parent-guided situations, the clinician might answer: "I can share what the options mean medically, but I want to understand what feels right for your family. What matters most to you as you think about this choice?"

In physician-guided situations, where one option is clearly safer or medically indicated, the physician may respond more directly but still relationally: "If this were my family member, I would recommend the tracheostomy because it's the safest way to help her breathe and grow. But I also know this decision is emotionally very hard, and I'll be here to support you every step of the way."

In both cases, the clinician's response centers on empathy, transparency, and ongoing partnership—affirming that decisions are shared but the family never carries them alone.

Through this reciprocity, SDM becomes not a single choi

ce but an ongoing moral conversation guided by evolving understanding, trust, and mutual care. For completeness, the full dialogue examples for the 2 illustrative cases are available in Supplementary File 1. Moreover, the key elements discussed in parts 1 and 2 can be combined into an integrated framework that summarizes how clinicians can determine the appropriate form of SDM, prepare the conditions for a meaningful discussion, and conduct the dialogue in practice (Fig. 3).

How to encourage SDM in practice in Korea

This article reviewed the principles of SDM and used illustrative cases to explore their application in real clinical communication. SDM has become a central principle of patient-clinician communication across multiple fields of medicine, and its relevance is equally evident in neonatal care. In Korea, while parents are frequently involved in neonatal decision-making, the systematic articulation of these practices as SDM remains limited.

In Korea, structural and cultural barriers hinder the adoption of SDM.²⁶⁾ Chief among these is the lack of time: many physicians cite insufficient consultation time as a major obstacle, underscoring the need for policy reform and adjustments in reimbursement structures.²⁶⁾ Yet, as discussed earlier, while additional time may help, transforming the nature of clinical conversations—from information delivery to genuine dialogue—is even more critical for achieving meaningful SDM. Another pressing challenge is the lack of systematic education and training.²⁶⁾ SDM should be incorporated into undergraduate and postgraduate medical curricula that emphasize

communication skills such as open-ended questioning and active listening as well as helping physicians recognize and manage their own biases.^{12,26)}

Legal and institutional barriers also limit opportunities for SDM. The Life-Sustaining Treatment Decision Act emphasizes respect for patient autonomy but restricts treatment withdrawal to cases of imminent death, thereby directing decisions toward the timing of death rather than the child's suffering or best interests.²⁷⁾ This limitation reduces opportunities for meaningful SDM in end-of-life care and highlights the need for legislative reform.

Korea is currently transitioning toward a specialist-based care system. Experience from Western healthcare systems suggests that frequent physician rotation may undermine continuity of care²⁸⁾; similar risks may emerge in Korea. Active SDM could mitigate these risks by ensuring that treatment goals and plans are clearly articulated, documented, and consistently followed. However, further institutional measures are needed to define leadership roles in SDM discussions and promote alignment across multidisciplinary teams.

Finally, there is growing recognition of the need for decision aids to support SDM.²⁶⁾ Such tools can help organize information and clarify options, yet their reach is limited. Most decision aids focus on the cognitive aspect of decision-making—providing facts, probabilities, and values clarification—while the essence of SDM lies in the interpersonal process: building trust, responding to emotion, and achieving mutual understanding.⁶⁾ Decision aids do not replace this human exchange, nor can they perform the entire SDM task. They can complement, but never substitute for, the relational dialogue between clinicians and families that gives meaning to decisions. Moreover, the

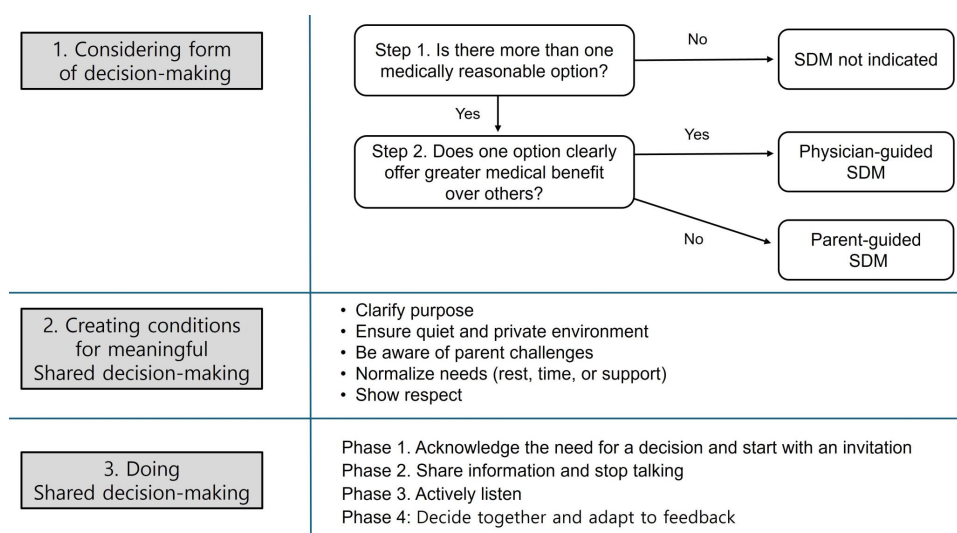


Fig. 3. Integrated framework for meaningful shared decision-making (SDM) in neonatal care. This summary figure combines: 1. determining the appropriate form of decision-making; 2. preparing conditions for meaningful SDM; and 3. conducting the SDM conversation linking structural, relational, and communicative components into a coherent model.

absence of a formal decision aid should never be viewed as a justification for not engaging in SDM.⁷⁾

Conclusion

SDM is not a single fixed model but rather exists along a continuum—from physician-guided to parent-guided—depending on the relative emphasis placed on medical judgment versus family preferences.⁹⁾ In implementing SDM, it is crucial to recognize the situations where SDM is most appropriate; that is, when more than one medically reasonable option exists and when the decision depends on medical facts as well as family values and preferences.^{7,8)} When one option poses clear harm to the child, forgoing SDM or adopting a more physician-directed approach may be ethically justified.¹³⁾ Conversely, in situations in which harm is not at stake, parental preferences should be respected.¹³⁾

SDM requires careful exploration and integration of parental needs and values. In some cases, parents' choices may diverge from what clinicians believe to be in the child's best interests while still falling within the zone of parental discretion and thus being ethically legitimate.²⁹⁾ Nevertheless, implementing such decisions can create significant moral distress for healthcare providers. Recognizing, addressing, and managing this moral distress remains a complex challenge that requires ongoing ethical reflection and further research.

SDM ultimately offers an ethically robust and relational framework for navigating the complex, value-laden decisions that characterize neonatal and pediatric care. Its success depends less on decision aids or formal tools—which can inform but never replace the interpersonal process—than on the quality of communication, mutual trust, and shared understanding between clinicians and families. The development of evaluation tools that consider the interpersonal nature of SDM and the particular features of the neonatal context is an important area for future research.

In Korea, however, the systematic adoption of SDM remains limited. One contributing factor is the lack of empirical evidence of how Korean parents perceive and wish to participate in medical decision-making; most existing studies have examined Western families, making it difficult to translate SDM practices directly into the Korean cultural and clinical context. Addressing this research gap is essential for developing forms of SDM that are both culturally grounded and responsive to the expectations of Korean families. Strengthening SDM in Korea will require coordinated efforts, including policy reform, structured education, relevant research, institutional support, and

a broader cultural shift that recognizes families as equal care partners. Through such measures, SDM can become a sustainable and integral component of clinical practice that enhances both decision quality and the therapeutic alliance between families and healthcare professionals.

Footnotes

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