



## Decision-Making for Extremely Preterm Infants: A Qualitative Systematic Review

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**Objective** To synthesize and describe important elements of decision-making during antenatal consultation for threatened preterm delivery at the margin of gestational viability.

**Study design** Data sources including PubMed, EMBASE, Web of Science, and CINAHL Plus were searched. We included all qualitative literature published on decision-making from 1990 to July 2021. Two authors independently screened and evaluated each study using the Critical Appraisal Skills Programme checklist; studies reaching moderate and high quality were included. We developed an extraction tool to collect and categorize data from each qualitative article, then used thematic analysis to analyze and describe the findings.

**Results** Twenty-five articles incorporating the views of 504 providers and 352 parents were included for final review. Thematic analysis revealed 4 main themes describing the experience of health care providers and parents participating in decision-making: factors that influence decision-making, information sharing, building a partnership, and making the decision. Parents and providers were not always in agreement upon which elements were most essential to the process of decision-making. Articles published in languages other than English were excluded.

**Conclusions** Qualitative literature highlighting key factors which are important during antenatal counseling can inform and guide providers through the process of shared decision-making. Communicating clear, honest, and balanced information; avoiding artificially dichotomized options; and focusing on partnership building with families will help providers use the antenatal consultation to reach personalized decisions for each infant. (*J Pediatr* 2022;251:6-16).

Parents and physicians must decide together between neonatal resuscitation and comfort measures for an anticipated extremely early birth at the margin of gestational viability. This shared decision-making (SDM) process is endorsed by obstetric and pediatric guidelines that describe bidirectional information exchange and discernment to help make decisions congruent with parents' values.<sup>1-6</sup> Although straightforward in theory, SDM can be challenging to execute in prenatal encounters.<sup>7</sup> Parents' responses are often emotional, influencing the processing of medical information and incorporating values into a plan.<sup>8-11</sup> Neonatal providers often struggle to communicate with parents in a way that is useful for decision-making.<sup>12,13</sup> Providers report difficulties engaging in SDM genuinely when their views differ from those of parents.<sup>14-17</sup> Providers reluctant to answer parents' requests for direct recommendations may leave parents feeling abandoned.<sup>18,19</sup>

Successful SDM in the prenatal encounter therefore necessitates a deep understanding of the perspectives of multiple stakeholders. This systematic review examines elements of SDM important to both parents and providers during antenatal counseling for extremely preterm deliveries.

### Methods

We performed a systematic review of the qualitative literature to assess parent and provider perspectives on decision-making during antenatal consultation for extremely preterm births. We utilized the methodology of thematic synthesis to develop a comprehensive understanding of the experiences of participants within the phenomenon of counseling for extremely preterm births.<sup>20</sup> This review followed the PRISMA statement.<sup>21</sup>

#### Data Collection

We conducted a literature search using these electronic databases: PubMed, EMBASE, Web of Science, and CINAHL Plus. Searches included indexed terms and free-text words for 'extremely premature infant,' 'antenatal/prenatal counseling,' 'shared decision making,' 'parent,' and 'periviability.' An additional search was conducted of reference lists and coauthors' personal files. Inclusion criteria were articles describing qualitative research published in English exam-

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NICU Neonatal intensive care unit  
SDM Shared decision-making

ining parent and/or provider perspectives on decisions in antenatal counseling for extremely preterm deliveries. We included articles published between January 1990 and July 2021, starting with the year of Harrison’s seminal work promoting family-centered neonatology care and greater parental involvement in neonatal decision-making in the early 1990s.<sup>22</sup> We excluded all articles exclusively addressing end-of-life care within the neonatal intensive care unit (NICU) following delivery, as well as editorials and commentaries.

Two reviewers first independently screened titles and abstracts to determine if they met inclusion criteria. Disagreements were kept for full independent article review. The same reviewers independently assessed full texts of the article for inclusion. Any disagreements were resolved through discussion. We then evaluated the included articles’ quality using the Critical Appraisal Skills Programme qualitative checklist, a validated quality assessment tool that examines various aspects of qualitative studies to ensure their rigor.<sup>23</sup> Only articles reaching the standard of moderate or high quality were analyzed (Figure).

### Data Extraction and Analyses

The researchers developed a data extraction tool utilizing Microsoft Excel (Microsoft) that collected the following information from each article: study aims, study design, population studied, sample size, data collection method, qualitative analysis technique, themes identified, and reviewer comments. We then performed thematic synthesis as described by Thomas and Harden, which extrapolates and integrates themes to analyze the results of individual studies to form a deeper understanding of the study concept.<sup>24</sup> Researchers met on 3 occasions after the initial line-by-line coding to discuss descriptive themes and to

develop analytical themes. After a period of revision and refinement, final consensus was achieved.

## Results

We analyzed 25 articles depicting provider and/or parent perspectives regarding decision-making for extremely premature infants (Table I). During thematic analysis, 4 main themes were discovered: factors that influence decision-making, information sharing, building a partnership, and making the decision. Parents and providers had some shared and some divergent views across each of these themes (Table II).

### Factors That Influence Decision-Making

Parents and providers shared similar perspectives regarding how parents make critical decisions for delivery. Many agreed that parents should generally make decisions for their children, especially as they will live with the long-term outcomes of those decisions as caregivers for their children.<sup>7,25,28,31,33,35,39</sup> Three studies diverging from this theme were all conducted outside the US. Providers in one Canadian study felt there are some instances when parental decision-making authority should be limited, especially when those decisions act against the infant’s best interest (as defined by the providers themselves).<sup>25</sup> Two Norwegian studies reported that parents should be involved in the decision-making process but that parents were not in a position to make a balanced decision given their emotional state and lack of experience with premature infants.<sup>46,47</sup>

Although the presentation of facts related to outcomes of premature infants and their survival was a large component of the prenatal consultation, some parents felt that it had little impact on their decision-making.<sup>11,33,37,40,41,44</sup> Instead, parents often relied upon other influences such as religion, spirituality, family, friends, and prior experiences.<sup>11,36,37,41,44</sup>

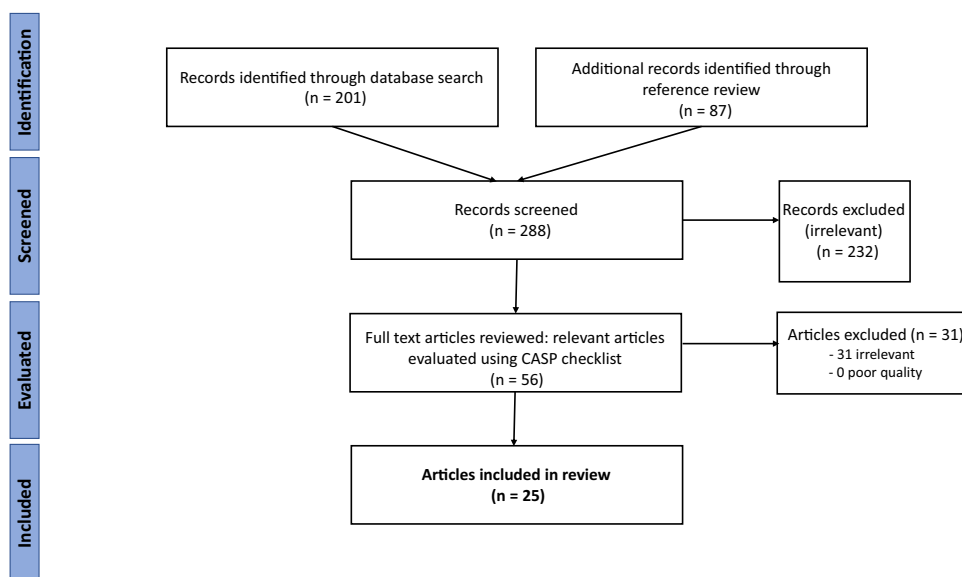


Figure. Article search process.

**Table I. Characteristics of articles included in analysis**

Author, year	Study design	Sample size	Participants studied	Analysis technique	Ethnicity/Race/Nationality of participants*
Albersheim SG, 2010 <sup>25</sup>	Semi-structured interviews	121 neonatologists	Canadian neonatologists	Interpretive description methodology	Canadian (88% fellowship training in Canada)
Barker C, 2019 <sup>7</sup>	Semi-structured interviews	25 physicians and nurses	Physicians and nurses working at Ottawa Hospital who cared for infants 22-25.6 weeks	Inductive content analysis with theoretical domains framework for higher analysis	No data
Boss RD, 2008 <sup>11</sup>	Semi-structured interviews	26 mothers	Mothers of infants who died from prematurity 22-25.6 weeks or a lethal congenital anomaly in the US (parents recruited >9 months from death of infant)	Thematic analysis	62% White, 38% Black/other
Daboval T, 2016 <sup>26</sup>	Ethnomethodological multiple case study, semi-structured interviews	5 mothers, 5 fathers 6 neonatologists/fellows	Parents admitted for preterm delivery from 20 to 26.6 weeks and consulting physicians in Ottawa, Canada (parents interviewed <4 hrs after consult, before baby's birth)	Content and theoretical analysis within an ethnomethodological model	No data
Drago MJ, 2018 <sup>27</sup>	Semi-structured interviews	22 parents (19 mothers, 3 fathers)	Latino parents of infants born before 26 weeks in the United States (parents recruited after hospital discharge)	Thematic analysis	All Latino; 52% Dominican, 14% Puerto Rican, 9% Guatemalan, 9% Mexican, 15% Other
Dupont-Thibodeau A, 2017 <sup>28</sup>	Structured interviews	80 clinicians	Pediatric residents and neonatal nurses in Ottawa, Canada	Thematic analysis	No data
Geurtzen R, 2017 <sup>29,30</sup>	Semi-structured focus group interviews	35 clinicians	Obstetricians and neonatologists in the Netherlands	Thematic analysis	Dutch
Geurtzen R, 2019 <sup>6,31</sup>	Semi-structured interviews	13 mothers, 7 fathers	Parents of infants born between 24.0 and 24.6 weeks in the Netherlands (parents interviewed 2-5 years after counseling sessions)	Thematic analysis	Dutch
Guillen U, 2012 <sup>32</sup>	Semi-structured interviews and focus groups	31 clinicians 30 parents	Neonatologists, NICU fellows, NICU nurses, maternal-fetal medicine specialists Parents of infants born <26 weeks and clinicians in Philadelphia hospitals (parents recruited after hospital discharge; groups interviewed separately)	Thematic analysis	Clinicians: 68% White, 16% Black, 13% Other Parents: 40% White, 47% Black, 13% Other
Haward MF, 2017 <sup>33,34</sup>	Semi-structured interviews	18 neonatologists	Neonatologists who were experts in the field of decision-making at the limits of viability in the United States and Canada	Mixed methods with descriptive statistics and thematic analysis	No data
Kavanaugh K, 2015 <sup>35</sup>	Semi-structured interviews, secondary analysis	40 mothers 14 fathers	Parents of infants who had a prenatal consultation for threatened preterm delivery 22.0-25.6 in the United States (longitudinal interviews both before and after birth)	Directive content analysis	57% Black, 23% Hispanic, 20% Other

(continued)

Table I. Continued

Author, year	Study design	Sample size	Participants studied	Analysis technique	Ethnicity/Race/Nationality of participants*
Kavanaugh K, 2005 <sup>36</sup>	Qualitative collective case study method, using the Ottawa decision support framework	6 mothers, 2 fathers, 4 maternal-fetal medicine physicians, 2 neonatologists, 2 obstetric nurses	Mothers hospitalized for threatened preterm delivery 22-25.6 weeks after the prenatal consultation in the United States (longitudinal interviews both before and after birth)	Coding according to the Ottawa framework	Mothers- 83% Black/African American, 17% Hispanic; no provider data
Keenan HT, 2005 <sup>37</sup>	Semi-structured interview 6 weeks after delivery	33 providers 15 mothers	Mothers of infants delivered 22-27 weeks and the provider who counseled them in a Southeastern US hospital (mothers interviewed 6 weeks after delivery)	Thematic analysis	Mothers: 33% White, 40% Black, 13% Hispanic, 13% other; No data on providers
Moro TT, 2011 <sup>38</sup>	Collective case study	5 mothers, 4 physicians, 3 nurses, 1 nurse practitioner	Mothers of infants 22-25.6 weeks where a live infant was born and died and providers in the US (longitudinal interviews ranging from prenatal to several months after infant's death)	Thematic analysis	Mothers: 20% Black, 80% Hispanic/Latino; no data on providers
Payot A, 2007 <sup>39</sup>	Semi-structured interviews	8 parent couples 4 neonatologists	Parents in a Quebec tertiary care center and neonatologists who counseled (parents interviewed immediately after consult and 4-6 months after)	Constant comparative analysis	No data
Pepper D, 2012 <sup>40</sup>	Semi-structured interviews	5 families (2 fathers, 5 mothers)	Purposeful selection of parents of ELBW infants born 24-26 weeks and survived in a western Canadian tertiary NICU (interviewed ~6 months after discharge)	Interpretive description, inductive analysis	No data
Roscigno CI, 2012 <sup>41</sup>	Longitudinal multiple-case study with semi-structured interviews	40 mothers 14 partners 71 healthcare providers	Families of newborns born 22-25 weeks who had a prenatal consult to discuss a delivery room care decision; women hospitalized for threatened delivery <26 weeks and their providers at 3 Midwestern US NICUs (longitudinal interviews spanning from prenatal to 2 months of life; if stillborn, conducted >3 weeks after death)	Content analysis	Parents: 57% Black, 28% Hispanic, 5% other Nurses: 72% White, 14% Black, 14% other Physicians: 43% White, 36% Asian, 21% other
Stanak M, 2019 <sup>42</sup>	Semi-structured interviews	5 neonatologists 1 neonatal clinical ethicist	Neonatal division heads and ethicists in Austria	Fragmentation, open coding, and structured thematic analysis	Austrian
Tucker Edmonds B, 2012 <sup>43</sup>	Semi-structured interviews	21 clinicians	Obstetricians and maternal fetal medicine specialists at 5 academic medical facilities in Philadelphia	Grounded theory analysis	62% White, 10% Black, 19% Asian, 10% Biracial

(continued)

Table I. Continued

Author, year	Study design	Sample size	Participants studied	Analysis technique	Ethnicity/Race/Nationality of participants*
Tucker Edmonds B, 2016 <sup>18</sup>	Semi-structured debriefing interviews	15 neonatologists	Neonatologists doing simulated consults at 23 weeks in a large urban academic medical center in the US	Thematic analysis	80% White, 7% Black, 13% Asian
Tucker Edmonds B, 2019 <sup>44</sup>	Semi-structured interviews	40 pregnant women 14 partners	Parents who had been counseled about treatment decisions 22 to 25 weeks at 3 US centers (mothers interviewed after counseling and before birth)	Thematic analysis	57% Black, 28% Hispanic, 15% other
Tucker Edmonds B, 2021 <sup>45</sup>	Semi-structured interviews	21 women	Women who experienced deliveries between 22.0 and 24.6 weeks at 2 US centers (parents recruited after discharge)	Conventional content analysis	57% White, 24% Black, 14.% Hispanic, 5% Asian
Ursin, 2018 <sup>46</sup>	Focus-group interviews	22 healthcare personnel	Healthcare personnel (neonatal nurses, midwives, obstetricians, mother-fetal specialists, and neonatologists) dealing with life-and-death decisions throughout pregnancy and birth in Norway	Thematic analysis	Norwegian
Ursin, 2020 <sup>47</sup>	Semi-structured interviews	8 mothers, 4 fathers	Parents who experienced prenatal counseling at the limit of viability in Norway (parents interviewed after discharge)	Thematic analysis	Norwegian
Young E, 2012 <sup>48</sup>	Ethnographic study, semi-structured interviews	10 families	Families of NICU patients (purposive sampling) born <27 weeks in one Toronto unit (families interviewed after discharge)	Constant comparative analysis	Canadian

\*Totals do not add up to 100% in some studies due to rounding. Ethnicity/Race/Nationality listed as described in original studies.

**Table II. Extracted parent and provider themes**

<b>Factors that influence decision-making</b>	
Themes from providers	<p>Parents generally have decision-making authority, but parental autonomy may be limited to preserve best interest.</p> <p>Parents must cope with long-term outcomes as the primary caregivers.</p> <p>Framing and bias may influence decision-making, along with formal hospital policies (though formal policies regarded as uncommon).</p> <p>Decision-making in the delivery room is not rational/emotions drive decisions.</p> <p>Physicians have the proper skills and training to make decisions.</p>
Themes from parents	<p>Physicians' predictions of death and morbidity are not central to parental decision-making.</p> <p>While medical information is important, environment, religion, spirituality, quality of communication, and relationships are more central to decision-making.</p> <p>Parents mistrust physicians who communicate only negative (unbalanced) information or have clearly made a decision-parent feels the need to "fight back", wants "everything done."</p> <p>Parents consider the quality of life for baby and family, and worry about pain and suffering, though have varying views on disability.</p> <p>Personal experience and external resources are important.</p>
<b>Information sharing</b>	
Themes from providers	<p>Statistics are viewed as an important way to ensure uniformity among providers and help parents make informed decisions, though actual use of statistics varies. Excessive detail thought to be unhelpful; information should be personalized as much as possible.</p> <p>Necessary to discuss how short-term morbidities affect long-term quality of life.</p> <p>Training/personal experience affect the content of the consultation.</p> <p>Topics should ensure parental engagement; information should help families align choices with their stated goals.</p> <p>Physicians need to communicate when a baby is "suffering."</p> <p>Dichotomy between "do nothing" and "do everything" with a default to "do everything."</p>
Themes from parents	<p>Information about immediate and long-term complications is important to parents, but it is important for information to be individualized to their baby.</p> <p>Goal is engagement—present clear options that go along with parents' values.</p> <p>Parents need information that is balanced and honest (especially when there is uncertainty).</p> <p>Parents need to be acknowledged as capable and their infant as valued to instill trust and confidence.</p> <p>Prepare parents for the NICU experience including learning new routines, equipment, appearance of the baby, delivery room, tour of the NICU.</p>
<b>Building a partnership</b>	
Themes from providers	<p>Inform parents with a focus on the baby and baby's best interest—relating hope to the baby's outcome (not the family's outcome).</p> <p>Many barriers exist to good communication including time, difficulty communicating uncertainty, managing expectations, avoiding conflicting messages.</p> <p>Parents need hope, but providers need to find a balance between hope and false hope. Pessimism is better than false hope.</p> <p>Environment and timing of providing information are important.</p> <p>Goal is to build a trustworthy relationship by validating parents' thoughts and emotions.</p>
Themes from parents	<p>Trust and communication are paramount. Be clear, direct, and truthful even with devastating information.</p> <p>Parents don't always perceive options – these should be clearly stated by all providers.</p> <p>Listen to what is said (and not said) and avoid assumptions—advice without knowing parents' values is useless.</p> <p>Parents have difficulty understanding information due to feeling emotionally overwhelmed and physically vulnerable.</p> <p>Parents feel abandoned when the physician is without hope or compassion; need to counterbalance uncertainty and pessimism with hope.</p> <p>Do not be rushed for time, allow for questions, show empathy/compassion, do not make assumptions, be supportive.</p> <p>Multiple conversations are better. It is helpful to have the bedside RN, partner present. Avoid delays.</p> <p>Perception that physicians are detached compared to "emotional" parents.</p> <p>Ideally an interactive space where the neonatologist's expertise in medicine and parents' expertise in family meet.</p>
<b>Making the decision</b>	
Themes from providers	<p>Physicians and parents can have different roles in decision-making depending on the situation and family preference.</p> <p>Worry about being overaggressive though in alignment with the family's wishes. Belief that parents fear bad outcomes and will have regret, though most families are adaptable to a degree.</p> <p>Families should be more involved in decision-making as the degree of uncertainty rises.</p> <p>Providers should support to parents; no "wrong" decisions.</p> <p>Question of whether birth was the right time to make decisions (question of parental competence in a high-risk, unplanned situation).</p> <p>"Good" decision perceived as the parent feels informed and makes a decision congruent with information or recommendations given.</p> <p>Shared decision-making may be beneficial but challenging to use. Some providers feel it limits freedom and creates false hope.</p>
Themes from parents	<p>Physicians and parents can have different roles in decision-making depending on the situation and preferences.</p> <p>Parents feel abandoned when they feel their decision is incongruent with the medical team's wishes.</p> <p>No wrong decision; respect choices without guilt or pressure.</p>

RN, registered nurse.



Of the information shared during the consultation, parents identified concerns about their infant's quality of life, with fears about pain and suffering weighing heavily on their decision-making.<sup>31,37,38,44</sup> Some parents mistrusted providers who focused their communication on mostly negative or unbalanced information about their infant's prognosis. Parents valued communication with providers that allowed room for hope.<sup>7,11,26,27,31,35,36,40,41,45,48</sup>

Both parents and providers acknowledged that decision-making for the delivery room is not rational and that emotions often drive decisions, especially when time is limited.<sup>7,11,27,35,36,40,46,47</sup> Providers acknowledged that their framing of information may influence decision-making and they made attempts to institute a consistent approach that removed individual bias that affected how they conveyed information (eg, some providers felt that presenting statistics removed their interpretation and, thus, their bias).<sup>7,27,32,42,43</sup> Providers also felt that hospital policies influenced how they counsel and overall decision-making, citing set gestational age cutoffs as one concern.<sup>28,42,43</sup>

### Information Sharing

Parents and providers differed in what they found most important for the content of the consultation. Providers valued the communication of clear medical facts to parents to facilitate informed decisions. Although many providers focused on conveying medical information, they varied in how they prioritized medical facts. Some felt it was necessary to discuss both short-term morbidities and how they would affect long-term quality of life.<sup>26,27,31,33</sup> Others focused on topics that would achieve parental engagement, either helping parents make decisions that aligned with their stated goals or improving their understanding of NICU life.<sup>7,18,29,31,35,37,46</sup> Although parents in several studies voiced concerns about their infants' pain or suffering,<sup>31,37,38,44,47</sup> providers in only 2 studies acknowledged this as an important component of their consultation.<sup>33,46</sup>

In several studies, providers viewed statistics as helpful for ensuring uniformity in communicating information, and in others, providers were hesitant to use them.<sup>26,27,29</sup> Some providers reported that they preferred to share information personalized to the individual baby and family as much as possible by either avoiding statistics or explaining how they applied to the individual situation.<sup>31,32</sup> When analyzing parental view, some valued providers' use of statistics to communicate outcomes as a way of conveying information free of the provider's value judgments.<sup>31,32</sup> Others felt overwhelmed by the discussion of general statistical outcomes and preferred to focus on information specific to their child.<sup>26,31,36,39</sup> Overall, parents largely expressed a desire for information that was balanced (ie, did not focus solely on negative outcomes without mentioning positive experiences) and honest throughout the consultation process.

### Building a Partnership

Both groups discussed the importance of the environment for counseling. Providers emphasized having enough time

and how the pressures of other clinical work sometimes impeded their ability to engage.<sup>7,29,46</sup> Parents agreed that it was important to have adequate time for discussion and questions.<sup>26,31,35,45,48</sup> In several studies, parents preferred multiple conversations about decision-making if the clinical situation allowed, but there was not consensus on this.<sup>26,31,35</sup> Parents stressed the importance of having support personnel available, which could include spouses, family members, friends, or bedside nurses.<sup>27,36,38,45</sup> Some studies emphasized the role of bedside nurses in communication, as they often remained with families following the consultation and helped deepen parents' understanding of the information from providers.<sup>31,36</sup>

Just as parents valued honest and direct information in the content of the consultation, they also expressed appreciation for providers who took time to understand what was most important to them. Parents viewed providers who did not do this as less effective in guiding them through the decision-making process as any advice they gave was too generic to have meaning for them.<sup>26,31,35</sup> Some studies demonstrated that providers agreed with this but struggled with communicating uncertainty in a way that helped manage parents' expectations and avoided giving conflicting messages.<sup>29,39,43</sup> Although providers acknowledged that parents needed room for hope, they found it challenging to give hope without creating false hope. Some viewed pessimism and emphasis of possible poor outcomes as better than providing false hope.<sup>7,33,41,43</sup> Parents, on the other hand, often felt abandoned when the provider did not leave room for hope in their counseling, with hope counterbalancing uncertainty and pessimism.<sup>11,27,36,41,45,48</sup> Interestingly, no study identified the concept of false hope as a concern for parents.

Parents and providers recognized the impact of emotion on decision-making. Parents relied heavily on the expertise of the providers, as they could remain somewhat detached from these emotions.<sup>26,31,35,42</sup> Parents had difficulty understanding and retaining any information, as they felt both emotionally overwhelmed and physically vulnerable.<sup>11,27,35,36,47</sup> They needed providers to acknowledge their emotions, show empathy and compassion, and be supportive of their decision. Through this support, parents could start building trusting relationships with providers, which could carry through an entire hospitalization.<sup>26,31,32,38</sup>

### Making the Decision

Parents and providers were in relative agreement regarding how they ultimately make decisions regarding resuscitation. Many studies indicated that individual families have different preferences for who ought to make the ultimate decision regarding resuscitation and the degree of involvement providers should have in that process, a difference important to recognize in forming an effective partnership.<sup>7,18,29,31,36,38,39,47</sup> Both providers and parents felt parents should be made to feel that there were no "wrong decisions" and to be supported in whatever choices they made for their child.<sup>29,31,35</sup>

Many parents reflected that it was often unclear that there was a decision to make and what options were available for

**Table III. Recommendations for providers during counseling for extremely preterm deliveries**

Recommendations for providers
Define the required decision
Avoid artificially dichotomized options
Determine parents' desired role in decision-making
Focus on building a partnership
Provide balanced and individualized information
Support parents' decision-making

delivery room resuscitation.<sup>11,27,31,35,41,47,48</sup> In some instances, this impaired parents' ability to feel like part of the decision-making team, leading to frustration and distress. Some parents who recognized the decision felt abandoned when their decisions did not align with what they perceived as the medical team's wishes.<sup>31,35,39</sup> Parents desired to be seen as capable and valuable members of the team, with their own expert knowledge in the values important to their family.

Although providers tended to dichotomize resuscitation decisions (ie, "do everything" or "do nothing"), parents felt overwhelmed by the decision and preferred the provider elicit their values in order to help them form a decision.<sup>11,26,35,39,45</sup> In this setting, parents expressed a need for providers to help them feel capable of making such a decision, largely through partnership building. Parents felt most empowered in this partnership when providers acknowledged the value of their role in the process as the infant's parent.<sup>35,40</sup>

Some providers reported struggling with how best to engage parents in SDM, given the highly emotional and unplanned nature of an extremely preterm delivery. Some even questioned if such decisions should be delayed until after a short trial of intensive care to gain more information about both the infant's medical status and the family's values.<sup>33</sup> Although attempting to elicit values, providers sometimes felt overly aggressive in their counseling, potentially including their own biases while trying to provide recommendations aligned with parents' wishes.<sup>7,37,41</sup> Some feared that parents would have future regrets if they did not adequately address their concerns and values.<sup>7,32,33</sup> Providers preferred more parental engagement in the resuscitation decision as the degree of uncertainty regarding outcome increased, as they felt ill-equipped to make recommendations without being able to understand fully what was most important to parents.<sup>29,33,39</sup> Ultimately, providers tended to agree that SDM was ideal in such situations but often challenging in practice.

## Discussion

The findings of this qualitative review offer a deeper understanding of vital perspectives which we hope will enhance providers' abilities to partner with parents and facilitate decision-making. Across the various studies, both stakeholder groups agreed on several elements that are important for SDM but also noted some important differences which have informed our key points to consider (**Table III**).

### Define the Required Decision

Although well-intentioned providers strive to be clear in their counseling, parents frequently do not understand that they need to make a decision for their infant. It is important for providers to engage parents to ensure they understand that a decision must be made, as SDM cannot proceed without that awareness.

### Avoid Artificially Dichotomized Options

When presenting a clear decision is important, it is equally important to avoid oversimplistic presentation of options as "do everything" vs "do nothing," without leaving room for more nuanced choices, which include an active provision of comfort in contrast to a simple absence of resuscitation. Rather, providers must strive to integrate parental values into their calculus of the options for interventions. This allows for the opportunity to share the burden with parents and to present all appropriate interventions at delivery as caring, proactive choices. One example of a more refined approach includes the mention of a "trial of intensive therapy."<sup>49</sup> Although this option may not be appropriate for every family and may be more suited to certain circumstances or cultures, it allows for the collection of further information that may help prognosticate an infant's possible future while continuing a dialogue with families regarding their values and wishes and keeps appropriate options, including redirection of care, under consideration.

### Determine the Parents' Desired Role in Decision-Making

Although parents are generally best suited to make decisions for their children, this review reinforces that parents have diverse views of their role in the decision-making process and that providers cannot properly understand their view without engaging in discussion.<sup>39</sup> Instead of feeling empowered, parents may feel abandoned when left to make decisions without the guidance of the medical team. For parents who prefer the medical team take an active role in decision-making, one of the primary goals of SDM is to ensure that parents feel that they have both the agency and ability to care for their child in their own way. Providers must share the role of expert in the consultation, acknowledging the parents' special knowledge of their own family dynamics. By alternating expert roles, providers reinforce that all participants in SDM are morally equivalent and integral to the process and help parents feel like "good parents."<sup>33,34,50</sup>

### Focus on Building a Partnership

The focus of prenatal counseling should shift away from a mere sharing of information to building a partnership between the parents and the medical team. This review reiterates that prognostication of outcomes has a limited impact on how parents make decisions. Future efforts at developing teaching models and counseling tools for neonatal providers should strive to emphasize not only the sharing of medical information but, more importantly, how to elicit values and engage parents in a bidirectional exchange of information.<sup>51</sup>



Gaucher and Payot previously proposed another such model, focusing on a relational autonomy approach to supporting parents in their decision-making by building a trusting relationship with the medical team.<sup>52</sup> Lantos expanded upon this model, emphasizing the importance of the process rather than the results of SDM.<sup>53</sup> The model offers a phased approach, explaining how to prepare for the meeting, the logistics and etiquette of the discussion, and the circular process of working toward a shared decision. This model aligns with the themes uncovered in this review.

### **Provide Balanced and Individualized Information**

Providers should strive to provide balanced information individualized for the family. Balanced information should continue to be transparent about potential poor outcomes but ought to balance a poor medical prognosis with potential positive experiences that may still be possible (eg, time with the baby, acts of love toward the infant, a peaceful death, etc.). The Parents on the Other Side of Treatment (POST) group, a group of neonatal clinicians and ethicists who were also family members of infants admitted to the NICU, previously emphasized this point, reminding providers that parents have both positive and negative impacts from a NICU experience and that focusing on only negative outcomes can be harmful to families.<sup>54</sup> Despite best intentions, providers come into consultations with biases they should strive to understand and, to the extent possible, address when partnering with parents.<sup>55</sup>

This review emphasizes the importance of hope for parents, even when faced with possible poor outcomes. Even in infants facing an extremely poor prognosis, hope may be framed around potential positive experiences that may still occur.<sup>33</sup> Our findings also highlight the reality that many providers continue to be concerned about providing “false” hope to parents but fail to demonstrate this as a significant concern for parents. This may relate to providers’ concerns that parents will experience regret if they leave room for this hope, but studies have shown that regret is not common among such parents.<sup>30,33,56</sup> Parents continue to desire a truthful discussion with providers about the range of possible outcomes for their children, but they lose faith and trust when information is presented in an overly pessimistic way with no allowance for hope, especially when their infant defies initial predictions. Such an unbalanced presentation of outcomes can lead parents to see themselves as the sole and entrenched protector of their infant, with a distrust of the medical team, hindering future engagement in SDM.

### **Support the Parents’ Decision-Making**

The medical team must ensure that parents feel supported in every step of the decision-making process. This review reiterates the value parents place on the relationships they form with the team and their desire for approval in making decisions for their infant. Although parents of children of all ages want to be viewed as “good parents,” parents of extremely preterm infants are especially vulnerable to the

judgment of others as they are still grappling to understand their roles as parent and grieving the loss of a “normal” parenting journey.<sup>10,57-59</sup> Haward et al have previously recommended ways to help parents feel supported throughout their time in the NICU.<sup>60</sup> This review reinforces the importance of unambiguous support for families throughout the consultation and SDM process.

These recommendations, though based on methodologic analysis of the current qualitative literature, are subject to limitations. We utilized the methodology of thematic synthesis, in which the findings of individual qualitative studies were extracted and pooled together for incorporation into a larger analysis. By removing findings from their original context, it is possible that the larger synthesis missed some nuances that have implications for our conclusions. This potential gap emphasizes the importance of an individualized approach to SDM for each family based on their needs. As with any qualitative study, the results of this review are likely not reflective of every person’s viewpoint but rather expose some common experiences. The recruitment strategies for each individual study may have affected which viewpoints were gathered, further influencing our compiled results. This review was limited to English-language studies, indicating that some parental and provider voices of different cultures were not included in the synthesis. Furthermore, our studies are based on data from various racial and ethnic groups in the US as well as international data. Further study is warranted to explore whether these factors have any impact on counseling sessions. Lastly, the review focused on articles published after 1990 to reflect current perspective, but we acknowledge that SDM practices change and evolve over time and in different geographic and cultural milieus.

It is worth noting that this review seeks to synthesize the perspectives on providers and parents engaging in SDM for extremely preterm births. Although we make recommendations to providers based upon these findings, we do not comment on the ethical justification for or against any of these recommendations. It is possible, for example, that the democratic assumption that acting based upon the perspectives of a majority of stakeholders may provide a suboptimal approach in some situations. This warrants further ethical analysis and underscores the importance of thoughtful, individualized consultations. ■

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