



# Parental Decision-Making Preferences in Neonatal Intensive Care

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**Objective** To explore how characteristics of medical decisions influence parents' preferences for control over decisions for their seriously ill infants.

**Study design** In qualitative interviews, parents of infants in the neonatal intensive care unit (NICU) were asked to consider all medical decisions they could recall, and were prompted with decisions commonly encountered in the NICU. For each decision, parents were asked detailed questions about who made each decision, whom they would have preferred to make the decision, and why. Using standard qualitative methods, responses were coded and organized such that decision-level characteristics could be analyzed according to preferred decision-making role.

**Results** Parents identified 2 factors that were associated with a preference to delegate decisions to the medical team (high degree of urgency, high level of required medical expertise) and 4 factors associated with a preference to retain parental control (high perceived risk, high personal experience with the decision, involvement of foreign bodily fluids, and similarity to decisions that they perceived as part of the normal parental role).

**Conclusions** Characteristics of decisions influence preferences for control over medical decisions among parents of patients in the NICU. These insights may guide improvements in physician-parent communication and consent. (*J Pediatr* 2016;179:36-41).

For most of the history of medicine, physicians assumed responsibility for making decisions for patients. With the ascendance of respect for autonomy as a bioethical principle, the locus of decision-making control shifted from physicians to patients. Studies over the past 3 decades demonstrate that patients differ in their desires for decision-making control<sup>1</sup> and that many prefer to delegate control to their physicians.<sup>2-4</sup> They also reveal differences between the desire for information, which is usually strong, and the desire to assume responsibility for medical treatment decisions, which may be weaker.<sup>5</sup> More recently, commentators have noted the perils of forcing undesired decision-making responsibility onto patients.<sup>6</sup>

Discordance between desired and actual decision-making control has important consequences for care. Such a discrepancy correlates with poor communication and low satisfaction among both parents<sup>7</sup> and adult decision makers.<sup>8</sup> Although physicians and surrogates generally endorse shared decision-making, they may bring different values and assumptions to the process.<sup>9</sup> Parents identify quality of life, prognosis, and pain and suffering as the most important factors related to end-of-life decisions for their child.<sup>10,11</sup> Personal values<sup>12</sup> and a connection with their physician<sup>13,14</sup> may be more important than medical facts. Parents within the complex arena of the neonatal intensive care unit (NICU)<sup>15-17</sup> identify action taking,<sup>18</sup> trust in modern medicine, and religious faith as central to their choices.<sup>19</sup> These preferences often differ from what physicians identify as most important.<sup>20,21</sup>

Parental decision-makers often receive less information than they desire,<sup>22</sup> potentially decreasing their decision-making capacity and emotional well-being.<sup>23</sup> Decisional burden surrounding momentous decisions made rapidly with incomplete information may be significant,<sup>24,25</sup> and is an underexplored and underappreciated phenomenon among parental decision-makers.<sup>13,26</sup>

Several classes of factors might influence a person's preferred degree of control over a medical decision, including those related to the decision maker, the disease, and the specific decision.

The local environment as well as broad societal factors may also influence preferences. Most prior work has focused on agent-related (eg, sex, socioeconomic status, profession)<sup>5,27-32</sup> and disease-related (eg, prognosis, comorbidities, illness severity)<sup>21,33</sup> factors influencing preferences for decision-making responsibility and control. Less attention has been paid to how characteristics of the specific decision, such as its urgency or the degree to which it requires technical expertise, may influence patients' or parents' preferred decision-making roles. In response, Joffe and Truog proposed a decision-making model that focuses on the nature of the particular

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NICU Neonatal intensive care unit

decision at hand.<sup>34</sup> Building on this model, we sought to identify decision-level factors that influence a NICU parent's preferred decision-making role.

## Methods

This study was conducted in NICUs at 2 urban academic medical centers, the Hospital of the University of Pennsylvania and Pennsylvania Hospital. Each NICU has an average daily census of approximately 34 neonates. The University of Pennsylvania institutional review board approved the study, and all participants provided written informed consent.

We conducted semistructured open-ended interviews with 30 parents of 35 very premature infants (5 sets of twins) born at less than 32 weeks estimated gestational age between February and May 2015. Parents qualified for inclusion on their infant's third day of life.

Purposive sampling was used so that equal numbers of parents of extremely premature (22 0/7-27 6/7 weeks) and very premature (28 0/7-31 6/7 weeks) infants were included. Parents were excluded from participation if they did not speak English, were under 18 years of age, or were judged not capable of consent by the infant's treating physician. Parents of multiples were eligible for inclusion; in those cases parents could discuss decisions made for each particular child, as well as any issues unique to multiples. Participants were offered a gift card at the end of their interview session. Accrual continued until thematic saturation was reached.

After a detailed review of the relevant literature on decision-making, we developed a semistructured interview guide aimed at eliciting parents' preferences for decision-making related to their infant's medical care ([Appendix](#); available at [www.jpeds.com](http://www.jpeds.com)). The content of the guide was derived from our primary research question: how do decision-related factors influence preferences for decision-making responsibility? Face validity for the types of decisions included in the interview was derived from a review of the most common decisions made in the participating NICUs. The domains that were covered by the interview instrument were derived from the existing literature on decision-making.<sup>7,33-36</sup> Parents were asked to consider all medical decisions they could recall and were also prompted with decisions commonly encountered in the NICU that they did not spontaneously raise. For each decision, parents were asked detailed questions about who made each decision, whom they would have preferred to make the decision, and why. All interviews were performed by a single interviewer (E.W.) who was trained by a study team member with extensive experience in qualitative methodology (F.B.). The interview guide was reassessed, updated, and finalized after broad-codes were created from the pilot set of interviews using a team-based approach. We collected demographic data on participants and conducted a brief medical record review for each infant to capture clinical characteristics through the date of the interview.<sup>37</sup> Interviews were recorded digitally, transcribed, checked for accuracy, deidentified, and entered into NVivo 10.0 (QSR International, Melbourne, Australia), a qualitative software analysis package, for coding and analysis by the research team.

## Data Analyses

We used an integrated approach to the process of data analysis.<sup>38</sup> We started with an a priori list of codes derived from our research question. This included the categories of decisions that parents faced, the preferred decision maker (parent, physician, shared), and reasons why they preferred that decision maker. Next, 6 research team members with experience in qualitative methods conducted independent line-by-line readings of the first 3 interviews to identify ideas present in the text. We compared and combined ideas to represent a parsimonious list of the main ideas present in the transcript. Each discrete idea became a code. Using the codebook function in NVivo, we defined each code and created decision rules for the use of each code that were entered into the codebook. Three research team members, none of whom was involved in data collection, then applied the codes to a new set of 3 transcripts. We edited the interview guide after coding the 6 initial pilot interviews to improve consistency across subjects and enhance elicitation of decision-making preferences. Using the interrater reliability function in NVivo, we assessed agreement in coding across the 3 coders, resolving all disagreements by consensus. By using an iterative process, we regularly reviewed codes, identified emerging themes, and resolved any discrepancies in coding through consensus. After completion of broad-coding, the 6 team members identified and standardized subcodes across nodes so they could be aggregated and evaluated together. For example, the "high level of urgency" subcode was identified as a recurrent salient feature within several separate broad-coded decisions.

Aggregation enabled similar subcodes to be evaluated together. Additional measures to ensure trustworthiness of the data included peer debriefing and maintaining an audit trail. Each transcript was linked to participant demographic and clinical data using NVivo. Representative verbatim comments were selected for presentation.

## Results

Of 42 eligible parents screened, 30 were enrolled. Infants of nonparticipants were similar to those of participants by estimated gestational age and birth weight. Most of the 12 nonparticipants were unable to be reached at bedside before discharge of their infant. Participant demographics and data extracted from infants' medical charts are presented in [Table I](#).

### Decisional Features

Four representative decisions were most commonly raised and discussed by participants: feeding choice (n = 26), blood transfusions (n = 16), intubation (n = 10), and research participation (n = 22). Parents' preferences for delegating decision-making control to the medical team were associated with their perceptions of a high degree of urgency and high level of required medical knowledge or expertise. In contrast, preferences for greater parental control were associated with high perceived risk, high parental knowledge about or personal experience with the decision, involvement of foreign bodily fluids such as blood, and similarity to decisions that parents perceived

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