



Provider Perspectives Regarding Resuscitation Decisions for Neonates and Other Vulnerable Patients

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Objectives To use structured surveys to assess the perspectives of pediatric residents and neonatal nurses on resuscitation decisions for vulnerable patients, including neonates.

Study design Pediatric providers were surveyed using scenarios for 6 critically ill patients of different ages with outcomes explicitly described. Providers were asked (1) whether resuscitation was in each patient's best interest; (2) whether they would accept families' wishes for comfort care (no resuscitation); and (3) to rank patients in order of priority for resuscitation. In a structured interview, each participant explained how they evaluated patient interests and when applicable, why their answers differed for neonates. Interviews were audiotaped; transcripts were analyzed using thematic analysis and mixed methods.

Results Eighty pediatric residents and neonatal nurses participated (response rate 74%). When making life and death decisions, participants considered (1) patient characteristics (96%), (2) personal experience/biases (85%), (3) family's wishes and desires (81%), (4) disease characteristics (74%), and (5) societal perspectives (36%). These factors were not in favor of sick neonates: of the participants, 85% reported having negative biases toward neonates and 60% did not read, misinterpreted, and/or distrusted neonatal outcome statistics. Additional factors used to justify comfort care for neonates included limited personhood and lack of relationships/attachment (73%); prioritization of family's best interest, and social acceptability of death (36%). When these preconceptions were discussed, 70% of respondents reported they would change their answers in favor of neonates.

Conclusions Resuscitation decisions for neonates are based on many factors, such as considerations of personhood and family's interests (that are not traditional indicators of benefit), which may explain why decision making is different for the neonatal population. (*J Pediatr* 2017;188:142-7).

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The majority of pediatric deaths occur in intensive care units,^{1,2} most often after a decision to limit life-support.³⁻⁷ These decisions, made by parents and providers, are among the hardest decisions in pediatrics. Evaluating the interest of children is complex.^{8,9} Some authors invoke their best interests,¹⁰ others "good enough" or "not unreasonable" interests,¹¹ and for others, avoiding harm is the main goal.¹² When an intervention is in the interest of a child and nonintervention places a child at significant harm, the intervention is generally considered as being legally and ethically preferable.

Empirical investigations have demonstrated that neonates are treated differently when life and death decisions are made.¹³⁻²⁵ In questionnaire studies, scenarios of critically ill incompetent patients of different ages were presented with outcomes explicitly described. Although many respondents evaluated that resuscitation was in the interest of neonates, a larger proportion estimated that resuscitation was in the interest of older patients with similar or worse outcomes.¹⁴⁻²² For older patients, a family's request for comfort care was rarely accepted when respondents evaluated resuscitation to be in a patient's interest. On the other hand, comfort care was generally accepted for neonates, despite estimating that resuscitation was in their interest.¹⁴⁻²² This differential treatment seems to transcend culture and has been demonstrated in 7 culturally different countries,¹⁸ in a large non-medical population,¹⁴ among pediatricians who do not work in neonatology¹⁶ and among physicians who do not work in pediatrics.²⁰ In none of these studies were participants asked to explain their answers. The goal of this study was to investigate how providers evaluate the interests of vulnerable patients and why their decision making differs for neonates.

Methods

A mixed methods sequential explanatory design was used. First, participants answered a questionnaire that has been validated, widely used, and systematically

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NICU Neonatal intensive care unit

replicated.¹⁴⁻²⁰ This questionnaire was not the primary goal of the study, but rather a tool to address the main goal of the study. The questionnaire and the interview were in French.

Two target groups of healthcare providers were approached in a tertiary university-affiliated academic center: pediatric residents and full-time neonatal nurses. Sainte-Justine hospital has a 67-bed neonatal intensive care unit. The project was approved by the Sainte-Justine Internal Review Board.

A questionnaire comprising 6 scenarios of critically ill patients of different ages were presented.¹⁴⁻²² Four patients had a survival of 50%. If they survived, 50% would be unimpaired, 25% mildly disabled, and 25% severely disabled: (1) a 24-week premature infant, (2) a term infant with a congenital anomaly, (3) a 2-month-old with meningitis/shock, and (4) a 50-year-old trauma patient. The fifth scenario was a severely disabled 7-year-old with a new head trauma, with 50% survival and 50% risk of further impairments. The last scenario was a 35-year-old with brain cancer, with 5% survival and 100% risk of disability with interventions (**Appendix**; available at www.jpeds.com). Participants were also asked for a preferred order of resuscitation if all the patients required intervention at the same time.

Differential treatment of neonates was considered as present when participants (1) evaluated that resuscitation was not in the interest of the neonate but was in the interest of other patients and/or (2) evaluated that resuscitation was in the interest of the neonate but accepted a family decision for comfort care (no resuscitation).

All participants were asked the following questions: (1) How did you evaluate the best interest of these patients? (2) How did you decide the order of resuscitation?

Participants were asked additional questions as applicable: (1) Why do you think resuscitation is in the best interest of (patient) but not in the best interest of the (neonatal scenario[s])? (2) Why did you rank the premature/term neonate(s) after (other patient[s])? You evaluated resuscitation as in the interest of the (neonate[s]), but you accepted to give comfort care, why? (4) The 7-year-old in the scenario was designed to be a “bad outcome” preemie. If I told you that less than 5% of 24-week preemies are as disabled as the child in the scenario, would you change some of your answers?

Statistical Analyses

For quantitative data, proportions of respondents were compared using the χ^2 with Yates correction, *P* values of $<.05$ were considered significant.

All answers to the open-ended questions were audiotaped and transcribed. Answers were analyzed using NVivo 9 software (QSR International).²⁶⁻²⁸ After reading all the transcripts, 3 investigators developed themes and subthemes independently. Together, they finalized the main themes and subthemes that would be used for coding.²⁸ Each code was rigorously defined. Coding of all interviews was then performed independently by 2 investigators. To ensure reliability, we aimed for an 85% percentage agreement between coders. For each questionnaire answer and open-ended question, discrepancies in coding were resolved by consensus. Quantitative

descriptions of participants' answers/coding were also analyzed.

For each questionnaire question, each interview theme, and subthemes invoked, we examined if there was a statistical association between demographic data (residents vs nurses; junior vs senior residents; nurse working more or less than 5 years in the neonatal intensive care unit [NICU]; having children or not) and participants' answers. To avoid repetitions and optimize style, we only report the statistically significant associations between respondents' answers and their demographic characteristics.

Results

Eighty respondents agreed to participate, for a response rate of 74%. Of the residents, 88% were women, 54% were junior residents, 68% were less than 30 years old, and 30% had children. Of the nurses, 96% were female, 64% were less than 30 years old, and 28% had children.

As anticipated, the answers to the questionnaire were similar to those previously reported in other studies.¹⁴⁻²⁰ The 2-month-old and the 7-year-old had the largest proportion of respondents stating that resuscitation was in their best interest ($P < .05$; **Figure**). A higher number accepted comfort care for the neonates and the 35-year-old relative to other patients ($P < .05$). For neonates, 86% of respondents who reported resuscitation to be in their interest accepted comfort care (no resuscitation), which was significantly greater than for other scenarios ($P < .05$; **Figure**).

The median ranking for order of resuscitation was 2-month-old > term neonate > 7-year-old > preterm infant > 50-year-old > 35-year-old. There were no statistical association between participants' answers and their demographic data.

Structured Interview Findings

When explaining how they determined the best interest and ranking of the patients, respondents stated reasons pertaining to 5 themes: (1) patient characteristics (96%), (2) personal experience/biases (85%), (3) family's wishes/desires (81%), (4) disease characteristics (74%), and (5) societal perspectives (36%; **Table**). All participants satisfied our definition of differential treatment of neonates in their questionnaire answers and, therefore, were asked to explain their answers.

Patient Characteristics. Survival (70%) and quality of life (65%) were frequently mentioned as influencing decision making. Prior level of functioning was also important for 78% of the respondents:

“Yes he has handicaps, learning difficulties and a corrected deafness, but I didn't find that his multiple handicaps impacted his quality of life.”

Age was also important for 54% of participants, generally favoring children over adult scenarios:

“Children have not lived as long as adults; they have a right to live to be adults.”

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