Delivery Room Decision-Making for Extremely Preterm Infants in Sweden

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ABSTRACT

OBJECTIVE. To assess neonatologists’ attitudes and practices regarding treatment of extremely preterm infants in the delivery room, particularly in response to parental wishes.

STUDY DESIGN. Cross-sectional survey of all neonatologists in Sweden registered with the Swedish Pediatric Society.

RESULTS. The response rate was 71% (88 of 124 neonatologists). At 24[1/7] to 24[6/7] weeks of gestation, 68% of neonatologists considered treatment clearly beneficial; at 25[1/7] to 25[6/7] weeks of gestation, 93% considered it clearly beneficial. When respondents consider treatment clearly beneficial, 97% reported that they would resuscitate in the delivery room despite parental requests to withhold treatment. At or below 23[0/7] weeks of gestation, 94% of neonatologists considered treatment futile. Nineteen percent reported that they would provide what they consider futile treatment at parental request. When respondents consider treatment to be of uncertain benefit, 99% reported that they would resuscitate when parents request it, 99% reported that they would resuscitate when parents are unsure, and 25% reported that they would follow parental requests to withhold treatment.

CONCLUSION. Although neonatologists’ attitudes and practices varied, respondents to our survey in general envisioned little parental role in delivery room decision-making for extremely preterm infants.
DELIVERY ROOM RESUSCITATION decisions for extremely preterm infants (<26 weeks of gestation) continue to be controversial. Some view initial treatment for all viable preterm infants, with the option of withdrawing care later when it is deemed appropriate, as the management strategy that optimizes the infants’ best interests.1–3 Others think that the risks of morbidity and death associated with neonatal intensive care justify selective nontreatment based on gestational age thresholds or parental wishes.4,5 As the survival and long-term morbidity outcomes for these infants begin to plateau,6–9 empirical studies of physician attitudes and practices can help characterize the standard of care and define the issues that remain controversial.

A recent survey study of neonatologists’ attitudes and practices at the threshold of viability that was conducted in the northeastern United States found that almost 90% of respondents considered treatment to be of uncertain benefit in the 23rd week of gestation and more than one half also considered treatment to be of uncertain benefit in the 24th week.10 Three quarters of respondents indicated that they would follow parental requests to withhold delivery room resuscitation from their preterm infants when the benefit of treatment is uncertain. The survey, which was developed and fielded in the northeastern United States, was based on the conceptual framework outlined by a landmark President’s Commission studying the treatment of seriously ill newborns.11 Although the decision-making framework was not developed specifically for treatment dilemmas at the threshold of viability, the commission proposed ethically appropriate physician responses to parental requests for the provision or withholding of treatment in each of 3 treatment categories, namely, clearly beneficial, of uncertain benefit, or futile. These recommendations are summarized in Table 1.

Our study aimed to provide data from a different geographic and cultural setting regarding delivery room management at the threshold of viability. During the northeastern United States survey study, it became clear to the US investigators that Sweden was engaged in considerable national debate on these issues. By fielding the same survey among neonatologists in Sweden, we sought to provide both an empirical dimension to the debate in Sweden and a point of comparison with the northeastern United States study. Our specific objectives were to determine Swedish neonatologists’ attitudes and practices regarding treatment of extremely preterm infants by assessing (1) their beliefs about the gestational age bounds of 3 treatment categories (clearly beneficial, of uncertain benefit, and futile), (2) their responses to parental requests in each treatment category, (3) their gestational age thresholds for initiating and withholding resuscitation at parental request, (4) their perceived prognoses for survival at these thresholds, and (5) the factors important to them in decision-making when the benefit of treatment is uncertain.

METHODS

Study Design

Between January and April 2003, an anonymous, self-administered survey was mailed to all neonatologists in Sweden who were registered in the Swedish Pediatric Society. Nonrespondents, who were identified through a return postcard tracking system, received 2 additional mailings.

Survey Instrument

Survey development took place in the United States and has been described elsewhere.12 The survey began with the caveats that (1) gestational age is accurate, (2) the infant’s weight is appropriate for gestational age, and (3) there are no severe congenital anomalies. All questions were closed-ended. The first section of the survey elicited neonatologists’ beliefs regarding clearly beneficial and clearly futile treatment. “Clearly beneficial” was defined as treatment whose potential medical benefits clearly outweigh the risks, and “clearly futile” was defined as treatment that will not significantly extend life or postpone death. Neonatologists were also asked to indicate their gestational age thresholds for initiating and withholding treatment at parental request and, in their clinical experience, an infant’s prognosis for sur-

<table>
<thead>
<tr>
<th>Clinical Scenario</th>
<th>President’s Commission Recommendation</th>
<th>Neonatologists’ Response (From Survey)</th>
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<tbody>
<tr>
<td>Physician considers treatment clearly beneficial; parents prefer to forego treatment</td>
<td>Provide treatment during review process</td>
<td>Respondents who would provide treatment: 97%</td>
</tr>
<tr>
<td>Physician considers treatment to be of uncertain benefit; parents prefer to accept treatment</td>
<td>Provide treatment</td>
<td>Respondents who would provide treatment: 99%</td>
</tr>
<tr>
<td>Physician considers treatment to be of uncertain benefit; parents prefer to forego treatment</td>
<td>Forego treatment</td>
<td>Respondents who would forego treatment: 25%</td>
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<tr>
<td>Physician considers treatment futile; parents prefer to accept treatment</td>
<td>Provide treatment unless provider declines to do so</td>
<td>Respondents who would provide treatment: 19%</td>
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vival at those thresholds. Additional questions asked whether, in the prior 5 years, respondents had either initiated or withheld delivery room resuscitation against parental request.

The second section assessed neonatologists’ beliefs regarding treatment of uncertain benefit. It began with a clinical vignette in which the neonatologist has spoken to parents about the impending delivery of their preterm infant and believes (on the basis of accurately measured gestational age) that the benefit of treatment is uncertain, meaning neither clearly beneficial nor clearly futile. The neonatologist was asked about the resuscitation decisions she or he would make in this setting when (1) parents ask that resuscitation be withheld, (2) parents ask that “everything possible” be done, and (3) parents are unsure of their wishes. Subjects were given 3 options, chosen to mirror management strategies characterized by Rhoden, namely, (1) to withhold treatment, (2) to resuscitate the infant and to allow the evolving clinical condition to guide decisions regarding additional treatment versus withdrawal of care, or (3) to initiate full intensive care until treatment appears futile or the infant dies.

In the third section, neonatologists were asked to rate the importance of 7 factors in their decisions to initiate or to withhold resuscitation in the delivery room when treatment is of uncertain benefit, namely, (1) condition of the infant at delivery, (2) likelihood of death, (3) potential long-term suffering, (4) likelihood of mental retardation, (5) likelihood of severe cerebral palsy, (6) potential burden on parents, and (7) child protection regulations. Response options for each factor were “very important,” “important,” “somewhat important,” or “not important.” The final section of the survey collected demographic information. Copies of the survey are available from the authors on request. The research ethics committee of Umeå University (Umeå, Sweden) approved the study.

Data Analysis
Frequency distributions for each response were generated. Logistic regression analysis was used to predict physician willingness to withhold delivery room resuscitation at parental request when the benefit of treatment is uncertain. Candidate predictor variables included respondent demographic characteristics (region, years of clinical experience, age, and NICU level, ie, I, II, or III), other characteristics (status as parent), and the factors considered important by the respondent in decision-making when the benefit of treatment is uncertain (listed above). Because of concerns about collinearity among the decision-making factors, principal component analysis was used to determine whether a subset of the factors seemed to measure the same dimension or attitude, such that they could be combined into 1 variable.

The results of this analysis were almost identical to those obtained with the northeastern United States data. Four of the decision-making variables strongly appeared to measure the same dimension, namely, (1) potential suffering of the infant, (2) likelihood of severe cerebral palsy, (3) likelihood of mental retardation, and (4) potential parental burden of caring for the child in the future. We judged these to represent components of quality of life, and so we combined ratings of their importance to create a quality-of-life score (range: 0–12). This score is a summary variable that reflects the degree to which potential quality of life is considered important by respondents in decision-making in the context of uncertainty. A higher score represents the belief that quality of life is relatively more important.

The logistic regression model was developed with a backward elimination process, starting with all of the candidate predictor variables. Variables that were not significant at a P value of <.05 in the model were removed in stepwise succession, after it was determined that their removal did not result in a >10% change in the risk estimate for any other variable. To assess whether respondents who were willing to withhold treatment at a perceived survival prognosis of >50% rated quality-of-life concerns greater in importance than did those who were willing to withhold treatment only at a perceived survival prognosis of <50%, quality-of-life scores for the groups were compared with Student’s t test.

RESULTS
Response Rate and Demographic Data
Surveys were mailed to 128 neonatologists. Four were ineligible to participate because of relocation or change in profession. Of the remaining 124 neonatologists, 88 returned completed surveys (71% response rate). Demographic and personal characteristics of the respondents are presented in Table 2. Fifty-two percent of respondents reported >15 years of clinical experience in neonatology, and 50% indicated that they work primarily in a level III NICU.

Thresholds for Clearly Beneficial and Clearly Futile Treatment
To indicate the gestational age at and below which they consider treatment clearly futile, respondents were given the response options of “≤22[0/7] weeks,” “22[1/7] to 22[6/7] weeks,” “23[0/7] weeks,” “23[1/7] to 23[6/7] weeks,” “24[0/7] weeks,” “24[1/7] to 24[6/7] weeks,” “25[0/7] weeks” and “>25[0/7] weeks.” To indicate the age at and above which they consider treatment clearly beneficial, response options were similar, beginning with ≤23[0/7] weeks and ending with >26[0/7] weeks. The proportions of neonatologists who considered treatment clearly beneficial or futile at each of these gestational ages
are shown in Fig 1. At 25[1/7] to 25[6/7] weeks of gestation, 93% of respondents considered treatment clearly beneficial. At or below 23[0/7] weeks of gestation, 94% of respondents considered treatment futile.

Responses to Parental Wishes in Each Treatment Category
Table 1 displays neonatologists’ responses to parental wishes in each of 3 treatment categories. When respondents consider the benefit of treatment to be uncertain, 99% reported that they would resuscitate in the delivery room at parental request and 99% reported that they would resuscitate when parents are unsure (data not shown). When parents prefer to forego treatment in this setting, 25% of neonatologists said that they would follow those wishes, allowing the infant to die, whereas 75% said that they would resuscitate the infant. Of the 75% who would resuscitate, 86% said that they would allow the infant’s evolving clinical condition to guide decisions regarding additional treatment versus withdrawal of care and 14% said that they would initiate full intensive care until it appeared futile or the infant died.

Initiating and Withholding Treatment at Parental Request
To indicate their gestational age thresholds for initiating and withholding treatment at parental request, respondents were given the same response options listed above. The oldest gestational age at which neonatologists would be willing to withhold delivery room resuscitation at parental request varied, although within a fairly narrow range (Fig 2). Only 5% were willing to withhold resuscitation above 25 completed weeks (25[0/7] weeks). Six percent of respondents reported having initiated delivery room resuscitation against the expressed wishes of parents in the past 5 years, not including fellowship training.

The youngest gestational age at which neonatologists would be willing to initiate treatment at parental request is also shown in Fig 2. Twenty-one percent of respondents reported willingness to initiate delivery room treatment at 22[1/7] to 22[6/7] weeks of gestation. Seven percent reported having withheld resuscitation in the past 5 years in a situation where parents requested it.

Prognosis for Survival at Gestational Age Thresholds for Withholding and Initiating Treatment
At the oldest gestational age at which they were willing to withhold treatment at parental request, 31% of respondents perceived the prognosis for survival to be <10% and 23% of respondents perceived the prognosis for survival to be 10% to 30%. A large majority reported

![Figure 1](image1.png)

**FIGURE 1**
Proportions of neonatologists who considered treatment clearly beneficial or futile at each gestational age. *Futile was defined as treatment that will not significantly extend life or postpone death. Clearly beneficial was defined as treatment whose potential medical benefits clearly outweigh the risks.*

![Figure 2](image2.png)

**FIGURE 2**
Neonatologists’ gestational age thresholds for initiating and withholding delivery room resuscitation at parental request.
perceived prognoses for survival that approximated published outcome statistics. For example, of the neonatologists who chose 23[0/7] to 23[6/7] weeks of gestation as the oldest gestational age at which they were willing to withhold treatment, 73% (36 of 49 respondents) considered the prognosis for survival at that age to fall in the range of <10% to 30%. Of respondents who chose 24[0/7] to 24[6/7] weeks of gestation, 75% (18 of 24 respondents) considered the survival prognosis to be 31% to 70%.

Overall, respondents who were willing to withhold treatment at a perceived survival prognosis of >50% rated quality-of-life concerns greater in importance than did those who were willing to withhold treatment only at a perceived survival prognosis of <50% (quality-of-life score: 9.1 vs 6.9; P = .003). At the youngest gestational age at which respondents were willing to resuscitate at parental request, 37% considered an infant’s probability of survival to be <10%.

Factors Important in Decision-Making in the Context of Uncertainty
Table 3 summarizes neonatologists’ ratings of the importance of 7 factors in delivery room decision-making when the benefit of treatment is uncertain. The factors considered very important by the largest proportions of respondents were the medical condition of the infant at delivery (49%) and the potential long-term suffering of the infant (41%).

Following Parental Wishes in the Context of Uncertainty
In the univariate and multivariate analyses, willingness to follow a parental request to forego treatment of uncertain benefit was associated significantly with beliefs about the importance of child protection regulations and quality-of-life considerations in delivery room decision-making. Respondents who considered child protection regulations either a very important or important factor in delivery room decision-making were less willing to withhold delivery room resuscitation at parental request when the benefit of treatment is uncertain (adjusted odds ratio: 0.2; 95% confidence interval: 0.05–0.8). Respondents with higher quality-of-life scores (i.e., those who considered quality-of-life considerations to be relatively more important in delivery room decision-making) were more willing to withhold resuscitation (adjusted odds ratio: 1.4 per unit of score; 95% confidence interval: 1.1–1.8) (Table 4).

DISCUSSION
An important finding of this study was that the majority of survey respondents (75%) indicated that, when the benefit of treatment is uncertain, they would resuscitate an extremely preterm infant in the delivery room despite a parental request to withhold treatment. At 23[1/7] to 23[6/7] weeks of gestation, 61% of respondents considered treatment to be of uncertain benefit; one third also included the 24th week of gestation in this category. At the oldest gestational age at which respondents were willing to withhold treatment at parental request, more than one half perceived the prognosis for survival to be <30%. In a widely quoted analysis of 3 management strategies for preterm infants that was published in 1986, Swedish neonatologists were thought to illustrate, in general, a “statistical prognostic” strategy whereby infants born at gestational ages with poorer prognoses are selectively nontreated in the delivery room. In our study, however, Swedish neonatologists overall reported fairly proactive management of extremely preterm infants, perhaps indicating a general change in approach over the past few decades. The Swedish National Board of Health and Welfare issued guidelines in 2004 that also reflect a more proactive approach. Departing from former guidelines that recommended selective nontreatment at <25 weeks of gestation, the new guidelines encourage centralized perinatal management and an individualized approach for infants between 23 and 25 weeks, with the goal of obtaining parental consent.

The same survey fielded to neonatologists in the northeastern United States yielded contrasting results; only 24% of US respondents said they would resuscitate...
a preterm infant in the delivery room against parental wishes when the benefit of treatment is uncertain. Thirty-three percent of US respondents (compared with 19% from Sweden) were willing to provide what they consider futile treatment at parental request. Although almost 90% of neonatologists from each study population considered treatment clearly beneficial at 25[6/7] weeks of gestation, Swedish respondents were significantly more likely to consider treatment clearly beneficial at 24th and 23rd weeks of gestation as well (data not shown). In both study populations, willingness to withhold treatment of uncertain benefit was associated significantly with beliefs about the importance of quality-of-life considerations in delivery room decision-making.

The findings of this study are consistent with those reported by the EURONIC group. In their 2000 study, 95% of neonatologists from Sweden indicated that they would resuscitate the 24-week gestation infant described in a vignette. Moreover, only 15% of the same neonatologists reported that they would reverse their decision if parents opposed resuscitation. However, parental wishes in delivery room decision-making did not seem to influence most neonatologists from the 11 European countries surveyed; only in Great Britain and the Netherlands did substantial proportions of physicians say they would change their resuscitation decisions on the basis of parental wishes. Overall, the literature reveals international variation in management of extremely premature infants,14–20 for example, a recent commentary on management at the limits of viability in Denmark described their “minimally invasive approach,” whereby mechanical ventilation is generally withheld from infants at 23 and 24 weeks of gestation and sometimes at older ages at parental request.21 Studies show that parents’ preferred decision-making roles also vary.22–25 Nonetheless, areas of consensus are emerging. Decisions to limit delivery room resuscitation involve primarily infants born before 25 weeks of gestation. Also, a recent study in 6 Pacific Rim countries found that, just as in Sweden and the northeastern United States, neonatologists generally consider a preterm infant’s potential quality of life and likelihood of death more important reasons to limit resuscitation than potential burden on the infant’s family.26

Whether treatment is beneficial for extremely preterm infants depends largely on their prognosis for survival and major morbidity. However, there is substantial heterogeneity among the numerous published studies of outcomes statistics for these infants, in part because of variation in study design and perinatal practices. Physicians’ attitudes toward viability may influence perinatal management, thereby also affecting outcomes.33,34 In a population-based comparison of proactive versus selective delivery room treatment strategies in Sweden, proactive management more than doubled the chance of survival for infants of gestational age 22 to 25 weeks, without increasing morbidity at 1 year of age.35 The heterogeneity in outcomes renders ethical decision-making and communication with parents particularly difficult. Still, it is reasonable to inform parents about the range of outcomes for preterm infants and to explain the factors that may contribute to this variation.

Although the ethics of intensive care for extremely preterm infants have long been debated, a recent court case in the United States6 prompted additional commentaries regarding the role of parental wishes in delivery room decision-making.5,35–37 At issue is whether the general prognosis for these infants, the surrounding uncertainty, or the information gleaned from a treatment trial justifies initiation of treatment against parental wishes. Although an infant’s response to treatment can provide prognostic information not available in the delivery room, initiating treatment also introduces the dilemma of winnowing out and withdrawing support from infants who face impairments that would pose an unbearable burden to them. Ethicists propose that treatment decisions be made according to an infant’s best interests.39 Parents and physicians sometimes disagree, however, regarding the best course of action.

Legal, economic, and social factors probably Influence decision-making, although their roles are difficult to assess. In our study, Swedish neonatologists who considered child protection regulations important were less willing to follow parental requests to withhold treatment in the delivery room. The legislative and judicial history of explicit child protection regulations seems more extensive in the United States than in Sweden, where viable newborns’ rights are derived from general regulations establishing the rights and value of Swedish citizens.41 However, in the northeastern United States study, neonatologists’ attitudes toward regulations were not associated with responses to parental wishes to withhold treatment. In the court system Swedish physicians are less likely to face litigation from parents and the
corresponding influence that threat of litigation may have on treatment decisions.42 Regarding economic and social factors, all Swedish citizens have taxpayer-supported, guaranteed, medical care at no additional cost. With minimal loss of income, parents are generally allowed 13 months of leave to care for a newborn, and even longer for a hospitalized infant. It is possible that, with this economic and social support, Swedish parents of extremely preterm infants are willing to accept a smaller role in delivery room decision-making. Such policies cannot explain the whole picture, however, because countries with similar social systems, such as Denmark and the Netherlands, provide delivery room treatment more selectively and with greater parental input than in Sweden.

Our study has several limitations. First, the survey caveat that gestational age is accurately known, although necessary to achieve the survey objectives, is unrealistic in many clinical situations. Second, survey responses may not reflect actual attitudes and practices. The survey was fielded anonymously, however, in an effort to elicit sensitive information from respondents. Third, with a response rate of 71%, our data may reflect a respondent bias. If all nonrespondents had participated and reported willingness to withhold treatment in the delivery room, just less than one half of neonatologists from Sweden would have been willing to withhold treatment. This would still be significantly smaller than the proportion willing to do so in the northeastern United States. Finally, the sample size did not allow examination of regional policy differences in Sweden.

Although Swedish neonatologists’ attitudes and practices varied, in general respondents to our survey envisioned little parental involvement in delivery room decision-making at the threshold of viability. Their preference for resuscitation in the context of uncertainly, even when parents oppose treatment, seems to reflect both a more proactive attitude toward treatment of extremely preterm infants and a belief that parents’ decision-making role in this setting should be limited. However, management decisions for these infants in Sweden and elsewhere are likely to have multiple influences, which may include varying cultural expectations of physicians, the medical-legal environment, the structure and funding of health care, and assessments of the benefits and burdens of neonatal intensive care.

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