Ensuring Accurate Knowledge of Prematurity Outcomes for Prenatal Counseling

Fermin Blanco, MD*; Gautham Suresh, MD‡; Diantha Howard, MS§; and Roger F. Soll, MD*

ABSTRACT. Objectives. To determine the accuracy of knowledge of different health care providers regarding survival and long-term morbidity rates for very premature infants and to examine whether a focused educational intervention improves the accuracy of this knowledge and influences health care decisions.

Methods. Using hypothetical case scenarios with infants at ≤28 weeks of gestation, we surveyed a variety of caregivers involved in perinatal communication and decision-making processes at a tertiary center that provides intensive care for neonates. We asked physicians from the pediatrics and obstetrics services and nurses and nurse practitioners from the NICU and obstetrics ward for their best estimates of survival and major long-term disability rates and for their opinions regarding the appropriateness of resuscitation and life support at each week of gestation of <29 weeks. After the survey, we educated all providers about current data on survival and long-term disability rates for preterm infants and gave them pocket-sized cards summarizing this information for reference during prenatal counseling. One month after the educational intervention and complete dissemination of the cards, a questionnaire with questions identical to those in the first survey was mailed to the same individuals.

Results. Fifty-one health care providers were involved in the baseline survey. The response rates for the postintervention survey were 100% for physicians (20 of 20 subjects) and nurses (20 of 20 subjects) and 91% (10 of 11 subjects) for the nurse practitioners. In the baseline survey, statistically significant underestimates of survival rates were seen for physicians and nurses at 23 to 28 weeks of gestation and for nurse practitioners at 23 to 27 weeks of gestation. Statistically significant overestimates of disability rates were seen for physicians and nurse practitioners at ≤26 weeks of gestation and for nurses at ≤28 weeks of gestation. After the intervention, respondents demonstrated significant improvements in the accuracy of survival and disability estimates at many, but not all, gestational ages. Although underestimation of survival rates and overestimation of disability rates decreased after the intervention, it persisted to some degree. After the intervention, a larger proportion of physicians (53% vs 21%) and a smaller proportion of nurses (10% vs 37%) were likely to recommend resuscitation for infants born at 23 weeks of gestation.


Prenatal counseling is an important component of medical management before a preterm delivery is counseling the parents about the probabilities of survival and of neurodevelopment and neurosensory impairment among preterm infants.1,2 Ideally, health care providers from different disciplines who care for pregnant patients at risk of preterm delivery should counsel expectant parents by using current statistics on perinatal survival rates and long-term outcomes of preterm infants. It was shown that the great majority of mothers who experienced prenatal consultation found it helpful and comforting.3

In the past decade, with the rapid evolution of obstetric imaging studies, gestational age estimates have become more reliable, especially when early ultrasonographic examinations are combined with menstrual history and laboratory data. Gestational age estimates have been shown to predict survival rates better than estimated fetal weights, and, because they are available before delivery, are extremely useful in prenatal parental counseling. At the borderline of current perinatal viability, such information about outcomes can help the family make well-informed choices about withholding or withdrawal of life support for the infant.

We observed that, in our institution, there were often differences among health care providers in their estimates of survival and morbidity rates for preterm infants born at various gestational ages, especially at the margin of viability. Therefore, we conducted this study to determine the accuracy of knowledge of different health care providers about survival and long-term morbidity rates for very preterm infants and to determine whether a focused educational intervention could improve the accuracy of these decisions.
of this knowledge and influence health care decisions.

METHODS

Study Participants

Study participants included a variety of caregivers who communicate information to expectant parents frequently or otherwise might be involved in decision-making regarding the pregnancy. They consisted of (1) a physicians group that included attending physicians in general pediatrics, obstetrics, and maternal-fetal medicine and residents in general pediatrics and obstetrics, (2) a nurses group that included registered nurses from the NICU, the labor and delivery floor, and the maternity ward, and (3) a nurse practitioners group that included neonatal nurse practitioners, obstetric nurse practitioners, and certified nurse midwives. Attending physicians and fellows from the neonatal division were excluded. For groups that had a total membership of ≤20 (nurse practitioners), we included all members of the group. For each group that had ≥25 members (physicians and nurses), we randomly selected 20 individuals from each group.

Questionnaire Design and Baseline Survey

We developed a survey that described the following hypothetical case scenario. “A healthy primigravida is admitted in preterm labor with intact membranes, an uncomplicated prenatal course, and a singleton pregnancy. Her gestational age is based on a sure last menstrual period and confirmed by an early ultrasound examination at 10 weeks’ gestation. There are no obvious anomalies on ultrasound, amniotic fluid is adequate, and there are no signs of infection. The infant is born under optimal conditions at a perinatal center.”

We asked participants to provide their best estimates of odds of survival with full treatment and long-term disability among survivors for the type of infant described in the case scenario, at each week of gestation from 23 to 28 weeks and also at ≤23 weeks of gestation. Survival was defined as the infant being alive at discharge from the hospital. Major disability was defined as the presence of ≥1 of the following conditions among survivors: mental retardation/developmental delay, cerebral palsy, blindness, or deafness. We asked participants to indicate a specific disability, including mental retardation/neurodevelopmental delay, cerebral palsy, blindness, and deafness (Table 1).

We randomly selected 20 individuals from each group. For groups that had a total membership of ≤20 (nurse practitioners), we included all members of the group. For each group that had ≥25 members (physicians and nurses), we randomly selected 20 individuals from each group.

Intervention

We prepared laminated, pocket-sized cards (Fig 1) that summarized bar graphs the survival rates and major disability rates for infants born at ≤23 weeks’ gestational age and at each week of gestation between 23 and 28 weeks. Data regarding survival odds were obtained from the Vermont Oxford Network Quality Management Report for the most recent available year (2000).5 Rates of major disability (Table 1) were derived from a comprehensive review of the published literature6–14 that included cohorts from single referral centers6–10 and from geographically defined regions.6,7,9,10,13,15,17,18 We included only long-term outcome studies that reported data based on gestational age (information that is more useful in the context of prenatal counseling); reported follow-up data ≥18 months after the estimated date of delivery, with significant proportions of survivors assessed (11 studies had rates of 83-100% and 2 studies had rates of 54% and 73%); used validated tools for assessment; and had similar definitions for major disabilities, including mental retardation/neurodevelopmental delay, cerebral palsy, blindness, and deafness (Table 1).

The principal investigator (F.B.) conducted educational sessions for participants to discuss the survival and major disability data mentioned above. These were either small-group sessions or person-to-person sessions scheduled at the convenience of the participants and held immediately after participants completed the baseline survey. When all of the baseline surveys were completed, we provided each participant with a copy of the laminated pocket card. We recommended that participants refer to the card during prenatal parental counseling before a preterm delivery.

Postintervention Survey

One month after the last discussion session, we mailed a survey identical to the baseline survey to all participants. Respondents could refer to the pocket card when answering this survey and returned the surveys by mail. All surveys were anonymous and noted only the professional designation of the respondents.

Informed Consent

The institutional review board of the University of Vermont at Burlington approved this study. We obtained informed consent from each participant before the baseline survey.

Sample Size Calculation and Statistical Analyses

We compared (1) baseline survey results with actual rates, (2) postintervention survey results with actual rates, and (3) baseline results with postintervention survey results at each week of gestation. In the baseline survey, we compared each provider group’s mean survival and major disability estimates with the actual rates (from the Vermont Oxford Network data and the literature, respectively), with t tests. For this analysis, using estimates and variability reported by Morse et al,19 we calculated that 20 subjects per provider group would give 80% power to detect, at the 5% significance level, a difference of 15% from the actual survival and disability rates. A difference of 25% could be detected with 10 subjects per group. We anticipated that differences between group means would be <15% and therefore we would not have adequate power for comparisons between groups but would have adequate power for within-group comparisons.

To evaluate the effect of the educational intervention, we com-

![Fig 1. Front and back views of the laminated, pocket-sized card summarizing the survival rates and major disability rates for infants at ≤23 weeks of gestation and at every week of gestation between 23 and 28 weeks.](image-url)
<table>
<thead>
<tr>
<th>Source</th>
<th>Time Period</th>
<th>Follow-up</th>
<th>% Follow-up</th>
<th>Major Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;23 wk*</td>
</tr>
<tr>
<td>Cooke⁷ 1994</td>
<td>1980–1989</td>
<td>3 y</td>
<td>54</td>
<td>—</td>
</tr>
<tr>
<td>Asztalos et al⁸ 1994</td>
<td>1988–1991</td>
<td>2 y</td>
<td>83</td>
<td>—</td>
</tr>
<tr>
<td>Synnes et al⁹ 1994</td>
<td>1986–1989</td>
<td>18 mo</td>
<td>93</td>
<td>—</td>
</tr>
<tr>
<td>Asztalos et al⁹ 1994</td>
<td>1991–1993</td>
<td>18 mo</td>
<td>73</td>
<td>1/1 (n = 21)</td>
</tr>
<tr>
<td>LeBlanc et al¹⁶ 1997</td>
<td>1983–1986</td>
<td>1–2 y</td>
<td>100</td>
<td>0/1 (n = 39)</td>
</tr>
<tr>
<td>Battin et al¹⁵ 1998</td>
<td>1987–1990</td>
<td>1–2 y</td>
<td>100</td>
<td>—</td>
</tr>
<tr>
<td>Wood et al¹⁷ 2000</td>
<td>1995</td>
<td>30 mo</td>
<td>95</td>
<td>7/18 (n = 37)</td>
</tr>
<tr>
<td>Doyle¹⁸ 2001</td>
<td>1991–1992</td>
<td>2–5 y</td>
<td>98</td>
<td>1/2 (n = 138)</td>
</tr>
<tr>
<td>Total survivors</td>
<td></td>
<td></td>
<td>154</td>
<td>67 (0.14–1.20)</td>
</tr>
</tbody>
</table>

Major disabilities/major neurodevelopmental impairments include moderate to severe mental retardation/developmental delay and/or cerebral palsy or other major neurologic impairment and/or blindness and/or deafness. Cerebral palsy was defined as a group of nonprogressive but often changing motor impairment syndromes (abnormal muscle tone in at least 1 extremity) with impairment of control of movement and posture, secondary to lesions or anomalies of the brain arising in the early stages of development. Moderate to severe mental retardation/developmental delay was defined as Mental Developmental Index <70, <68 revised Bayley Scales, or developmental quotients <70. Blind/visual impairment was defined as lack of normal vision, requiring corrective lenses, blindness with no ability to fixate, or no useful vision. Deaf/hearing impairment was defined as any restriction or lack of ability to perform within the normal range including sensory neural, conductive, or mixed loss and cases requiring hearing aids. Lefebvre et al¹¹ considered developmental quotients <80 (Griffiths Mental Development Scales). CI indicates confidence interval; n, live births; —, data not available.

* Gestational age.
pared the baseline and postintervention mean group survival and major disability estimates by using analysis of variance, with provider group and time as the 2 factors. Individual comparisons were then used to compare baseline and postintervention estimates within each provider group. We estimated that 20 subjects per group would provide 80% power, at the 5% significance level, to detect a before/after difference of 12%. To evaluate the effect of the intervention on the participants’ views on the appropriateness of resuscitation, we compared, with \( \chi^2 \) tests, the percentages of respondents choosing “definitely resuscitate,” at each week of gestation, before and after the intervention.

Finally, we compared each group’s mean survival and disability estimates from the postintervention survey with the actual rates by using \( t \) tests. For all comparisons listed above, we used a \( P \) value of .05 to define statistical significance. The data were entered into an Excel spreadsheet. Statistical testing was performed with SAS software (SAS Institute, Cary, NC).

**RESULTS**

**Response Rates**

All 51 health care providers selected for participation (20 physicians, 11 nurse practitioners, and 20 nurses) completed the baseline survey. The response rates for the postintervention survey were 100% for physicians (20 of 20 subjects) and nurses (20 of 20 subjects) and 91% (10 of 11 subjects) for the nurse practitioners.

**Survival Estimates**

Figures 2 to 4 illustrate the mean survival estimates at baseline and after intervention for each provider group, as well as the actual survival rates. In the baseline survey, the mean survival estimates of all 3 groups were lower than the actual survival rates, with statistically significant differences from actual rates seen for the physicians group at 23 to 27 weeks of gestation \((P < .01)\), 24 to 26 weeks of gestation \((P < .01)\), and 27 weeks of gestation \((P < .05)\). In no group was the mean survival estimate higher than the actual survival rate.

Compared with the baseline survey estimates, the mean group survival estimates in the postintervention survey were higher, with these before/after differences being statistically significant for the physicians group at 25 weeks of gestation, for the nurses group at 25 to 28 weeks of gestation, and for the nurse practitioners group at <23 to 27 weeks of gestation. The \( P \) values for these before/after comparisons are depicted in Figs 2 to 4.

In the postintervention survey, the mean survival estimates of all 3 groups were closer to the actual rates than they were at baseline. However, compared with the actual rates, estimates in the physicians group were still statistically lower at 23 to 24 weeks of gestation \((P < .01)\) and 25 to 28 weeks of gestation \((P < .05)\) and in the nurses group at 23 to 28 weeks of gestation \((P < .01)\). The mean postintervention survival estimates for the nurse practitioners group were higher than the actual survival rates in some cases but with no statistically significant difference at any gestational age.

**Major Disability Estimates**

Figures 5 to 7 illustrate the mean major disability estimates before and after intervention for each provider group, as well as the actual rates. In the baseline survey, the mean major disability estimates of each group were higher than the actual rates, particularly at the youngest gestational ages, with statistically significant differences from the actual rates be-

ing noted for the physicians and nurse practitioners groups for <23 weeks and 23 to 26 weeks of gestation ($P < .01$) and the nurses group for <23 weeks and 23 to 28 weeks of gestation ($P < .01$). In no group was the mean major disability estimate lower than the actual major disability rate.

Compared with the baseline survey, the mean group major disability estimates in the postintervention survey tended to be lower, with statistically significant differences from the baseline survey being noted for the physicians group for <23 weeks and 23 to 24 weeks of gestation, for the nurses group for all gestational ages, and for the nurse practitioner group for <23 weeks through 27 weeks of gestation. The $P$ values for these before/after comparisons are depicted in Figs 5 to 7.

In the postintervention survey, the mean major disability estimates were closer to the actual rates.
than they were at baseline. However, compared with the actual rates, estimates were still statistically higher for the physicians group at <23 weeks through 25 weeks of gestation ($P < .01$) and 26 weeks of gestation ($P < .05$) and for the nurses group at 24 to 26 weeks of gestation ($P < .01$). The postintervention estimates in the nurse practitioners group did not differ significantly from the actual rates.

**Appropriateness of Resuscitation**

After exposure to the educational material, differences were noted in the responses of health care...
providers regarding whether they thought it was appropriate to resuscitate and provide life support for infants at <23 weeks of gestation. Compared with the baseline survey, the proportion of respondents in the postintervention survey who thought that it was appropriate to resuscitate an infant of 23 weeks' gestational age was higher in the physicians group (21% vs 53%, P < .05) but lower in the nurses group (37% vs 10%, P < .05). There were no other statistically significant differences between the baseline and postintervention surveys in the responses to appropriateness of resuscitation.

**DISCUSSION**

When a preterm delivery is expected, parental counseling should be based on accurate data regarding survival rates and the likelihood of major disability among survivors at the given gestational age. This is crucial at the borderline of viability, when management options being discussed with the parents often include withholding or withdrawal of life support. However, health care professionals often differ in their estimates of survival and morbidity rates for preterm infants born at various gestational ages, especially at the extremes of viability.

We found that health care providers who are involved routinely in the counseling and support of parents at risk of preterm delivery, including physicians, nurses, and nurse practitioners, underestimated survival rates and overestimated long-term disability rates. Morse et al reported similar findings. However, their survey was restricted to physicians, whereas ours included physicians and other health care providers who participate in preterm deliveries. Our findings indicate that health care providers may approach prenatal counseling with a gloomier prognosis than is justified. Our results emphasize the need to provide accurate knowledge of outcomes, especially at gestational ages bordering on viability, for which inaccurate estimates of outcomes can lead to mistaken decisions to provide or withhold intensive care. Providers' estimates of outcomes may vary from actual data because of reliance on outdated data, difficulty in recalling outcome statistics (especially if not used regularly), and the lack of a readily available reference source.

Other studies evaluated health care providers' knowledge of prematurity outcomes as a component of assessment of their attitudes toward resuscitation, without separating the inaccurate knowledge of outcomes from the process of decision-making about resuscitation. Any assessment of attitudes toward resuscitation is flawed if it does not ensure that the providers have accurate knowledge regarding outcomes. Furthermore, none of those studies included an assessment of knowledge after an educational intervention. Ours is the first study to address solely the accuracy of health care providers' knowledge regarding outcomes and to study the effect of an educational intervention.

After education, the accuracy of estimates of survival and disabilities consistently improved for the 3 groups. However, providers still underestimated survival rates and overestimated disability rates, which leads us to speculate that education alone may not be sufficient to correct deficiencies in counseling knowledge and that techniques such as computerized decision support may be required to optimize knowledge for counseling. Our data indicated that, when physicians improved the accuracy of their
knowledge of outcomes, they became more inclined to resuscitate aggressively infants at the edge of viability. This finding is in accordance with previously reported studies by Haywood et al.21,22 It is unclear why nurses were less likely to intervene for these extremely premature infants. Perhaps this tendency is related to nurses’ greater pessimism, compared with physicians, regarding the chances of survival and morbidity of prematurity.20

The strengths of our study are the high survey response rate and the wide variety of health care providers studied. Its limitations are that it was conducted in a single academic center and therefore the results should be generalized cautiously to other centers; we surveyed participants only 1 month after the education ended and therefore are uncertain about the long-term duration of effect of the educational intervention. The small number of nurse practitioners in our study makes a type II statistical error the likely cause of statistically insignificant results for that group.

We used survival statistics from the Vermont Oxford Network database because the data are derived from nearly 30 000 very low birth weight infants from a wide spectrum of NICUs. Also, because our hospital participates in the Network, ideally providers in our hospital should be aware of the Network data. These data are similar to the data from another large neonatal database.23 Although the Network data represent one of the best sources available, providers who use these data for prenatal parental counseling should be aware of their limitations for outcome prediction. These data are not epidemiologic data, because they are derived from a heterogeneous collection of live-born infants of 401 to 1500 g, with a wide range of risk factors for death, who were born at or transferred to participating hospitals. The collection includes infants who are resuscitated with the intention of providing full life support and infants from whom life support is withheld or withdrawn.

Our literature review for statistics on major disabilities among survivors was restricted to articles in which outcomes were reported according to gestational age and excluded those in which outcomes were reported according to birth weight. Studies varied in the proportions of survivors monitored and in the duration of follow-up monitoring, introducing some heterogeneity into the aggregate data. A special limitation of the outcome data at <23 and 23 weeks of gestation is the lack of precision because of small sample sizes, with consequent wide confidence intervals (Table 1).

During prenatal counseling, the caveats mentioned above should be discussed with the parents. In addition, the prognosis for a given infant should be individualized on the basis of the presence of variables that influence outcomes, such as congenital anomalies, chorioamnionitis, placental abruption, oligohydramnios, and prenatal steroid use. During prenatal counseling, especially at the borderline of viability, providers should remember that there is a distinction between the probability of survival of a fetus and that of a newborn infant. Therefore, after delivery and admission of the infant for ongoing intensive care, it is more suitable to present survival data based exclusively on live births.24,25

Outcome statistics are generally well received by prospective mothers of preterm infants during prenatal consultation.3 According to published data, the chances of survival increase by 2% to 4% with each additional intrauterine day for gestations of 23 to 26 weeks,5,15,26 and the majority of infants who survive are free of major disabilities.27 There seems to be sufficient evidence now to establish the limit of viability in the United States at 23 weeks of gestation.28–30 What appears to hold true across published studies is that survival for infants born at <23 weeks of gestation is more an exception than the rule.31–36 Survival rates for extremely low birth weight infants have increased substantially in the past decades,37–41 but major neurologic impairments have remained practically unchanged.42–47 However, compared with normal birth weight infants, extremely low birth weight survivors without major impairments are still at greater risk of learning disabilities during the school years,48–51 which persist into early adulthood.52 Health care providers must realize that at least one half of extremely low birth weight infants will require special education services in the future49–51,53,54 and that they are less likely than normal birth weight control subjects to graduate from high school. In addition, when monitored through young adulthood, they were found to have lower mean IQ scores and lower academic achievement scores.52 During prenatal counseling, the full spectrum of possible outcomes, including the milder impairments, should be discussed with the family. We did not address the risks of such minor disabilities in our study.

In our hospital, the laminated pocket cards with the survival and disability data are now carried routinely by many physicians, nurses, and nurse practitioners who are involved in the delivery of preterm infants. These providers report anecdotally that they use the data on the card during parental counseling and find it a useful aid to counseling. We aim to keep the outcome data updated as new information becomes available, so that consistent accurate information is provided to parents during prenatal counseling. Although the outcome percentages provided on the card may not reflect “true values,” these are the most current data available and can be used as a starting point in discussions with prospective parents of very premature infants.

CONCLUSIONS

We found that physicians, nurses, and nurse practitioners underestimated survival rates and overestimated major disability rates for infants at <23 to 28 weeks of gestation. After education and provision of a pocket card containing the data, providers improved the accuracy of their estimates of outcomes. Improvement in knowledge about outcomes was associated with increased willingness by physicians and decreased willingness by nurses to provide resuscitation to infants at the threshold of viability. A national sample of health care providers from different disciplines should be surveyed to determine the
extent of inaccuracy of outcome estimates. If this problem is widespread, then large-scale efforts are required to correct it, so that expectant parents of preterm infants receive counseling based on accurate data.

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