

# Estimation of Outcome and Restriction of Interventions in Neonates

James L. Haywood, MD\*; Steven B. Morse, MD\*; Robert L. Goldenberg, MD‡; Janet Bronstein, PhD§; Kathleen G. Nelson, MD\*; and Waldemar A. Carlo, MD\*

**ABSTRACT.** *Objective.* To learn whether pediatricians accurately estimate rates of survival and freedom from handicap in preterm infants and to learn whether their knowledge and attitude influence their choice of interventions that may enhance survival of extremely preterm infants.

*Methods.* Pediatricians practicing in Alabama were surveyed using a pretested questionnaire designed to identify pediatricians' knowledge regarding survival and handicap-free rates of infants born at gestational ages between 21 and 36 weeks. For infants born at each week of gestation, they were asked if they would provide specific therapeutic interventions. Survival and handicap-free rates were compared with published national rates. Pediatricians were divided into an optimist group and a pessimist group based on how their estimates of survival compared with national published data. The rates at which each group used therapeutic interventions were compared.

*Results.* The 159 (57%) responding pediatricians underestimated survival rates from 23 through 34 weeks' gestation and freedom from serious handicap from 23 through 36 weeks. Responses of the optimists approximated actual data whereas the pessimists underestimated neonatal outcome. Those pediatricians who underestimated neonatal outcome would intervene less often with invasive therapies, including mechanical ventilation, cardiopulmonary resuscitation, inotropes, and intravenous fluids, compared with those who accurately predicted outcome from 23 through 27 weeks' gestation.

*Conclusion.* Pediatricians often underestimate neonatal outcome of preterm infants. Appropriate neonatal practice may be affected by this underestimation of the survival potential of preterm infants. *Pediatrics* 1998; 102(2). URL: <http://www.pediatrics.org/cgi/content/full/102/2/e20>; prematurity, survival, knowledge, attitudes, practice.

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ABBREVIATION. NICHD, National Institute of Child Health and Human Development.

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Variations in the use of therapeutic interventions depend in part on the perceived overall or long-term effectiveness of the intervention by health care providers. The reported misperceptions about the effectiveness of neonatal care in rela-

tion to neonatal survival and eventual quality of life for preterm infants may result in less than appropriate care for pregnant women and their infants.<sup>1,2</sup> This is especially important because advances in medical care for the very preterm infant have improved survival without increases in rates of serious handicap.<sup>3-5</sup> We have observed that physicians who perform deliveries currently underestimate rates of survival and freedom from handicap in preterm infants. Through analysis of hypothetical treatment by surveyed physicians it was demonstrated that physicians with inaccurate knowledge were less aggressive in attempting to salvage potentially viable fetuses.<sup>6</sup>

Because the pediatrician is often called to the delivery room to attend the birth of an extremely preterm infant, it is important to determine pediatricians' knowledge and attitudes regarding survival and handicap rates particularly of infants born at the shortest gestational ages consistent with viability. It is important to determine whether pediatricians' knowledge and attitudes about survival and handicap-free rates of preterm infants affect their treatment practices. This study was therefore done to determine whether pediatricians underestimate survival and freedom from handicap of preterm infants and to further understand the relationship between knowledge and attitudes regarding outcome and the pediatrician's propensity to intervene therapeutically for the preterm infant.

## METHODS

A questionnaire that asked pediatricians to estimate survival and the percentage of survivors who would be expected to be free of major handicap for preterm infants born under optimal conditions at a perinatal center at 23 through 36 weeks' gestation was developed and pretested. The pediatricians were asked for the earliest gestational age they would intervene with thermal support, oxygen by hood for cyanosis, intravenous fluids for hydration and/or nutrition, inotropic agents for treatment of hypotension, mechanical ventilation for respiratory distress, and cardiopulmonary resuscitation. In addition, demographic information, including age, gender, year of graduation from medical school, and residency training was requested. The questionnaire was a modification of one used to survey obstetricians' knowledge and attitudes.<sup>1,6</sup>

In 1993, cover letters and questionnaires were mailed to 278 physicians listed as fellows of the American Academy of Pediatrics in Alabama who were not practicing a pediatric subspecialty, according to the Academy's 1993 *Fellowship Directory*,<sup>7</sup> or known from our departmental address database to be board-eligible or board-certified in pediatrics but not listed in the 1993 *Fellowship Directory*. Questionnaires were serially coded to allow a second mailing to nonresponders. Study participants were told in the cover letter the reason for the serial number coding and ensured anonymity of their responses. Two weeks after the first mailing,

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nonrespondents were contacted by telephone and asked to complete the questionnaire. A second mailing was sent to all nonrespondents at this time. Participants who indicated subspecialty practice or faculty status in pediatric subspecialties at either of the two medical schools were eliminated from analysis.

Data obtained from the 1988 to 1989 National Institute of Child Health and Human Development (NICHD) Neonatal Network<sup>3</sup> and from the 1982 to 1986 March of Dimes Multicenter Prevention Trial<sup>8</sup> were used for survival rate comparisons. NICHD data were chosen for gestational ages 23 through 30 weeks, inclusive, because at the time of the questionnaire, they were the most recent multicenter survival data of extremely preterm infants published. However, because the NICHD Neonatal Network study reported outcomes of infants who were born at <1500-g birth weight, data of infants up to 30 weeks' gestation were used because infants of >30 weeks' gestation were more likely to have been small for gestational age. Survival rates for infants of 31 through 36 weeks' gestation were obtained from the earlier March of Dimes Trial that entered all infants born before 37 weeks' gestation regardless of birth weight.<sup>8</sup>

Handicap-free rates from a summary of outcome studies published between 1978 and 1984 were used.<sup>9</sup> This reference was chosen because handicap rates were reported by gestational age rather than birth weight. Handicap-free was defined as not having a major handicap, including cerebral palsy, mental retardation (development or intelligence quotient less than 70), blindness, deafness, or severe failure to thrive. More recent reports show even lower handicap rates, but the data could not be used in the current study because they were analyzed by birth weight and not by gestational age.

To determine whether the estimates of survival rates correlate with the willingness to use therapeutic interventions, participants were subdivided into optimists and pessimists based on their estimates of survivability at each gestational age. An optimist group was formed at each gestational age from those pediatricians who estimated survival greater than the median response. Similarly, a pessimist group for each week of gestation was composed of those who estimated survival below the median response. The groups were compared regarding their willingness to intervene with succeedingly aggressive therapeutic interventions.

The estimates of survival and freedom from handicap at each gestational age were compared with actual rates using unpaired *t* tests performed at each gestational age between 23 and 36 weeks' gestation, inclusive. To assess the relationship between survival estimates and willingness to use therapeutic interventions, differences in estimates of survival and freedom from handicap between the optimist and pessimist groups were tested for significance using  $\chi^2$  analysis.

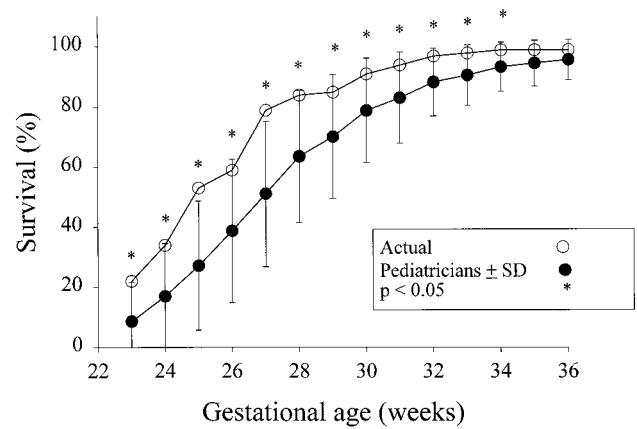
## RESULTS

One hundred fifty-nine physicians (57%) responded to the two mailings. Demographics between the responders and nonresponders were similar with regard to gender. Nonresponders were more likely to be board-certified earlier and to work in a location with a neonatologist (Table 1).

Pediatricians significantly underestimated survival rates at each week from 23 through 35 weeks (each  $P < .05$ ; Fig 1). At the extreme of prematurity (23 weeks), pediatricians estimated <10% survival as compared with the actual survival rate of 23%. At the more advanced gestational ages, pediatricians' estimates were progressively closer to the actual ones. However, underestimation of survival rates occurred until 35 weeks.

**TABLE 1.** Demographics of Responders Versus Nonresponders

	Responder	Nonresponder	<i>P</i>
Gender (male/female)	108/31	100/49	NS
Year board-certified	1974 ± 20	1969 ± 13	<.005
Location with neonatologists	57%	67%	<.05

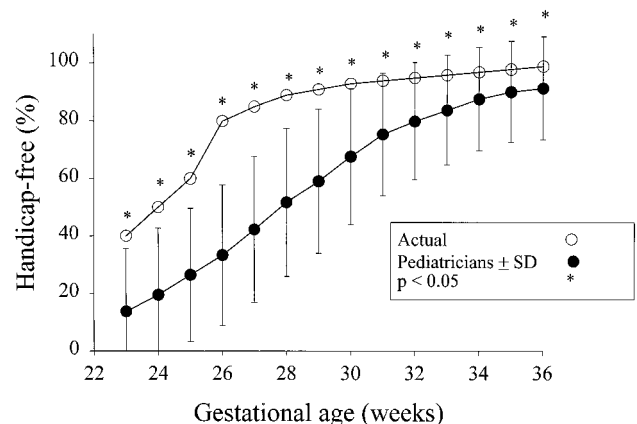


**Fig 1.** Comparison of pediatricians' estimates (●) of survival rates to actual survival rates (○) obtained from national data. Pediatricians' estimates were significantly lower than actual survival rates at each gestational age from weeks 23 to 34.

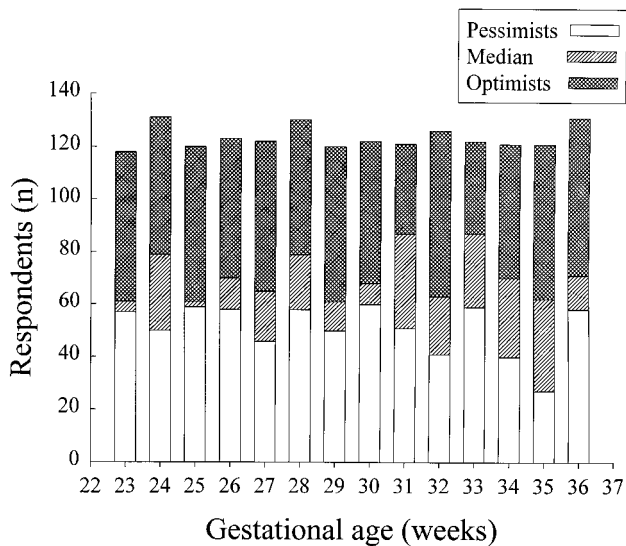
Also, pediatricians significantly underestimated handicap-free rates of infants born from 23 through 36 weeks' gestation (each  $P < .05$ ; Fig 2). At 23 weeks' gestation, pediatricians estimated 18% handicap-free versus the actual 40% rate. As noted for the estimates of survival, at the more advanced gestational ages, pediatricians' estimates were closer to the actual ones.

The optimists as well as the pessimists comprised approximately one-third to almost one-half of respondents at each gestational age (Fig 3). The optimists' estimates of survival were comparable to actual survival rates ( $P = NS$ ; Fig 4) and did not overestimate actual data at any gestational age. As expected, the pessimists' estimates of survival consistently underestimate actual survival rates at each gestational age (each  $P < .05$ ; Fig 4).

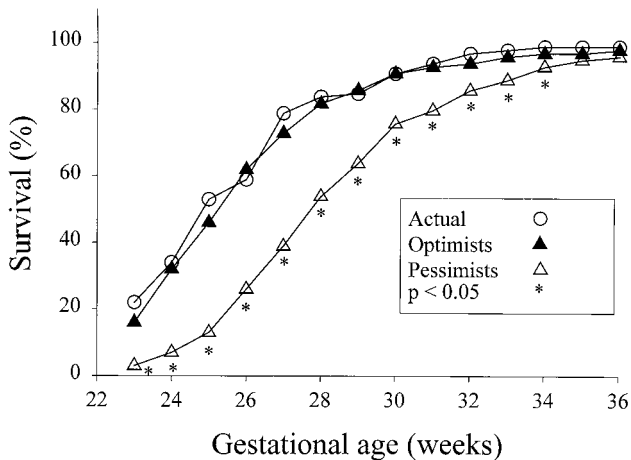
The optimist and pessimist groups differed in their stated willingness to use aggressive therapeutic interventions. The pessimist group advocated the use of cardiopulmonary resuscitation (Fig 5), mechanical ventilation, inotropic drugs, and intravenous fluids (not shown) consistently less often than the optimists at each week from 23 through 27 weeks' gestational



**Fig 2.** Comparison of pediatricians' estimates of freedom from handicap (●) to actual handicap-free rates (○) obtained from national data. Pediatricians' estimates were significantly lower than actual handicap-free rates at each gestational age from 23 to 36 weeks.



**Fig 3.** Optimistic and pessimistic group composition. There were both optimists (double-hatched area) and pessimists (white areas) at each gestational age.



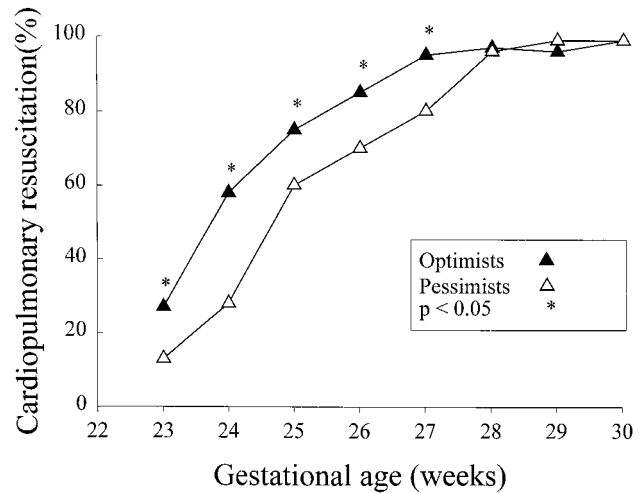
**Fig 4.** Comparison of optimists (▲) and pessimists (△) estimates of survival to actual survival rates (○). Optimists' estimates of survival approximated actual survival rates. Pessimists' mean estimates were significantly lower than the actual survival rate at each gestational age from 23 to 34 weeks.

age (all  $P < .05$ ). The optimists indicated a willingness to use each of these interventions ~1 week earlier than the pessimists. Groups did not differ in their use of thermal support and hood oxygen (Table 2).

### DISCUSSION

The purpose of this study was to determine whether pediatricians have an accurate knowledge of survival and outcome of preterm infants and whether this knowledge affects their willingness to use therapeutic interventions. Overall, we found that pediatricians consistently underestimate both survival and freedom from handicap of preterm infants. Additionally, pediatricians who think infants have a poor outcome potential couple their knowledge with less willingness to use therapeutic practices at the earliest gestational ages.

To reach as many physicians as possible a ques-



**Fig 5.** Earliest cardiopulmonary resuscitation use among pediatricians when divided into optimists (▲) and pessimists (△). Optimists were significantly more willing to intervene with cardiopulmonary resuscitation than pessimists from 23 to 27 weeks' gestation. Results from 23 through 30 weeks are shown.

**TABLE 2.** Gestational Age (in Weeks) of Earliest Use of Therapeutic Interventions

Intervention	Optimists	Pessimists	<i>P</i>
Thermal support	22 ± 0.4	22 ± 0.0	NS
Oxygen by hood	23 ± 0.3	23 ± 0.3	NS
Intravenous fluids	23 ± 0.4	24 ± 0.3	<.001
Inotropes	24 ± 0.0	25 ± 0.6	<.001
Cardiopulmonary resuscitation	24 ± 0.4	25 ± 0.5	<.001
Mechanical ventilation	24 ± 0.4	25 ± 0.6	<.005

tionnaire was used. However, the accuracy of a questionnaire to assess knowledge, attitudes, and practice, is limited by several factors, including the ability to reach the appropriate target audience and the ability of the individual respondent to interpret the question as it is asked and answer appropriately.<sup>10</sup> This questionnaire was completed by 57% of its targeted audience. Although a higher response rate would have been preferred, this rate is comparable to that of similar studies using a survey format.<sup>11,12</sup> Because the nonrespondents were more likely to work in areas with neonatologists, they may have had less direct involvement with the most preterm infants. Also, nonrespondents were board-certified earlier and therefore they may be less aware of current outcome data. Both of these characteristics would likely make nonrespondents more likely to underestimate outcome more than respondents. Published data indicate that pediatricians in Alabama take care of a large number of preterm infants. We have published that 28% of very low birth weight infants born in Alabama initially receive care from general pediatricians.<sup>13</sup> The pediatricians were only surveyed regarding interventions that they may have to initiate.

Survey-based data collection is also subject to other potential biases. Study participants may say what they believe is correct although it may not agree with what they do in practice. A respondent's

answer to one question may be dependent on his or her answer to another. However, the survey technique used in this study is very similar to the one used in 1982 and again in modified form in 1992. It was therefore substantially pretested, and results of all three studies are similar.<sup>1,6</sup>

Another limitation in this study design, includes the use of survival data to approximate the true survival rate. Survival data for this study was taken from two large multicenter databases that were the most recent sources available at the time of the survey.<sup>3,8</sup> Since then, more recent outcome results have been published by the NICHD Neonatal Research Network.<sup>14</sup> These results evaluate a cohort born between May 1991 and December 1992. In all birth weight categories between 501 g and 1500 g, survival and handicap-free rates increased significantly. Most, but not all, recent studies report that survival of preterm infants continues to improve.<sup>15</sup> If more current data with improved survival had been used for comparison, the underestimation by the pediatricians would have even been more marked. In contrast, handicap-free rates reported in recent years continue to be comparable to the reference actual rates used in this study despite the increase in survival.<sup>16–21</sup>

Uniform standards for the prediction and description of long-term impairment in children are elusive. Handicap rates for surviving preterm infants are measured and reported according to variable criteria, including type of impairment (ie, sensory, motor, intellectual), age at follow-up, and testing protocol. Although most investigators agree on what generally constitutes severe handicap, it is possible that the pediatricians' interpretation differs, accounting for part of the underestimation of handicap-free rates. Pediatricians' responses may have been influenced by their experience with preterm infants with normal early physical and neurologic exams who manifested difficulties later, such as on school entry.<sup>22,23</sup>

Surveys of physicians' beliefs regarding the prognosis of preterm infants have been published using various formats. Wilson et al<sup>11</sup> found that among obstetricians, family practitioners, and pediatricians, the pediatricians were most accurate in their assessment of prognosis and that all physicians were more accurate in their prediction of mortality than morbidity. Among neonatologists surveyed in 1995, most counseled parents that at 22 weeks' gestation mortality was 100% and at 23 weeks, it was 75%.<sup>12</sup>

In summary, these data show that pediatricians underestimate the survival and handicap-free rates of preterm infants. In this study, pediatricians' estimates of survival rates were compared with nationally published rates for infants born just before the surfactant era. The underestimation of survival rates at shorter gestations would have been even more pronounced if compared with survival data for infants treated with more recent technologies, including surfactant therapy.<sup>24</sup> In addition, physicians' knowledge may lag behind current statistics and this may explain the underestimation of outcome reported here.

Reduction in infant mortality continues to occur

with advances in neonatal care.<sup>15,25</sup> However, many question the aggressive treatment of extremely immature neonates who might have significant morbidity if they do survive.<sup>14</sup> Survival has been shown to improve dramatically with access to advanced perinatal services.<sup>6,26–28</sup> Despite increased rates of maternal and fetal referral to a perinatal center, there are many preterm infants born in hospitals without advanced perinatal services<sup>29</sup> underscoring the importance of the pediatricians' attitudes regarding resuscitation and lifesaving therapeutic practices for potentially viable infants. Improving pediatricians' knowledge regarding outcome of preterm infants may result in more appropriate use of therapeutic practices that may be lifesaving.

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