www.jpeds.com • THE JOURNAL OF PEDIATRICS

Population-Based Outcomes Data for Counseling at the Margin of Gestational Viability

Patrick Myers, MD[1], Naomi Laventhal, MD[2], Bree Andrews, MD, MPH[3], Joanne Lagatta, MD[4], and William Meadow, MD, PhD[3]

Objective To survey neonatologists as to how many use population-based outcomes data to counsel families before and after the birth of 22- to 25-week preterm infants.

Study design An anonymous online survey was distributed to 1022 neonatologists in the US. Questions addressed the use of population-based outcome data in prenatal and postnatal counseling.

Results Ninety-one percent of neonatologists reported using population-based outcomes data for counseling. The National Institute of Child Health and Human Development Neonatal Research Network Outcomes Data is most commonly used (65%) with institutional databases (14.5%) the second choice. Most participants (89%) reported that these data influence their counseling, but it was less clear whether specific estimates of mortality and morbidity influenced families; 36% of neonatologist felt that these data have little or no impact on families. Seventy-one percent reported that outcomes data estimates confirmed their own predictions, but among those who reported having their assumptions challenged, most had previously been overly pessimistic. Participants place a high value on gestational age and family preference in counseling; however, among neonatologists in high-volume centers, the presence of fetal complications was also reported to be an important factor. A large portion of respondents reported using prenatal population-based outcomes data in the neonatal intensive care unit.

Conclusion Despite uncertainty about their value and impact, neonatologists use population-based outcomes data and provide specific estimates of survival and morbidity in consultation before and after extremely preterm birth. How best to integrate these data into comprehensive, family-centered counseling of infants at the margin of viability is an important area of further study. *(J Pediatr 2017;181:208-12).*

The incidence of mortality[1] and major neonatal morbidity[2] has improved for extremely preterm infants on a population level, but it remains difficult to predict the trajectory of each individual infant, particularly before birth. Uncertainty around individual postnatal trajectories of illness complicates counseling families about the risks and benefits of starting, continuing, withholding, or withdrawing life-sustaining interventions.

Historically, gestational age has been the focus of how the lower limits of viability have been described and discussed. Multicenter collaborative efforts such as the Vermont Oxford Network[2] and Pediatrix[3] have led to user-friendly short- and long-term outcomes databases that can be used in prenatal discussions with families. The National Institute of Child Health and Human Development (NICHD) Neonatal Research Network: Extremely Preterm Birth Outcome Data[4] (NICHD outcomes calculator) added neurodevelopmental follow up and a multifactorial approach to prognostication, highlighting the impact of other fetal attributes on outcomes for extremely preterm infants. Along with aggregations of institutional outcomes data, this body of work has created population-based outcomes data that provide data to neonatologists about possible neonatal outcomes.

It is not known how and when neonatologists use these population-based outcomes data or which factors most influence how neonatologists frame discussions with families. Regional surveys[5] have evaluated practice patterns and governing bodies have issued policy statements[6-10] to guide practitioners. Prenatal counseling is done frequently, but with a wide range of variation across different centers.[11] Less is known about how population-based outcomes data are used to frame conversations with families at risk of delivering at the margins of viability or in neonatal intensive care units (NICU). Against this background, we set out to survey neonatologists in the US to better understand the role of population-based outcome prediction data.

Methods

Surveys (**Appendix**; available at www.jpeds.com) were sent to all listed neonatologists and neonatology fellows in 2 organizations from whom e-mail addresses were accessible during October of 2014: the American Academy of Pediatrics Section on Perinatal Pediatrics and the Organization of Neonatal-Perinatal Medicine Training

NICHD	National Institute of Child Health and Human Development
NICU	Neonatal intensive care units

From the [1]Feinberg School of Medicine, Northwestern University, Chicago, IL; [2]C.S. Mott Children's Hospital, University of Michigan, Ann Arbor, MI; [3]The University of Chicago Comer Children's Hospital, Chicago, IL; and [4]Medical College of Wisconsin, Milwaukee, WI

The authors declare no conflicts of interest.

http://dx.doi.org10.1016/j.jpeds.2016.10.021

Program Directors. This wide-net approach yielded a large number of e-mail addresses that were no longer operational but, owing to concerns about anonymity, we were unable to exclude the nonfunctional e-mail addresses before sending the survey. Potential participants were sent an email, given a short study description, assurance of anonymity, and the opportunity to decline. Each participant was asked to confirm their professional role as a neonatologist and participants were excluded if they did meet this screening criterion. The study was submitted and exempted by institutional review boards.

In our survey, we defined population-based outcomes data as "aggregated sources of outcomes data (i.e. the NICHD Neonatal Research Network: Extremely Preterm Birth Outcomes Data (NICHD outcomes calculator), Pediatrix/Obstetrix Outcomes Data, Vermont Oxford Network, or institutional outcomes data)." This survey asked clinicians to focus their responses to infants at 22-25 completed weeks gestation.

Qualtrics (Provo, Utah) was used to send the survey, send 2 reminders, collect responses, and provide anonymity. Demographic information was gathered, namely, years in practice, frequency of prenatal counseling, hospital characteristics, and specialty. Before the deployment of the full survey, multiple pilot surveys were sent to optimize both survey questions and skip logic flow. Pilot respondents helped to improve survey flow and to clarify questions and answers choices. Questions were divided into prenatal and postnatal categories and focused on the use of population-based outcomes calculators, perception of families' response to empiric data, and the respondents' priorities in counseling. For rank order questions, participants were given the option of ranking only those choices that they felt applied.

Stata SE version 13 (StataCorp, College Station, Texas) was used to analyze the data. We used χ^2 tests or Fisher exact test (for cell size < 5) to compare the different characteristics among participants.

Table. Demographics

Questions	n	%
How many years have you been practicing since completing your training?		
Fellow	65	6
<3	88	9
3-5	122	12
6-10	157	15
11-20	167	16
>20	423	41
How often do you counsel families of infants born at or before 25 completed weeks in the NICU, who might consider withdrawal of life-prolonging interventions?		
Less than once a year	110	11
Few times a year	693	70
Few times a month	173	18
Few times a week	9	1
How many infants are born between 22 and 25 completed weeks at the hospital where you most often provide counseling?		
None	7	1
1-2 every couple of years	86	8
About once a month	231	23
About twice a month	253	25
More than twice per month	445	44
What best describes the primary NICU where you most often provide counseling?		
No planned high-risk deliveries; cannot provide mechanical ventilation	1	0
No planned high-risk deliveries; can provide mechanical ventilation	26	4
Planned high-risk deliveries; can provide mechanical ventilation	618	94
No deliveries; can provide mechanical ventilation	15	2

Results

Of 7100 functional and nonfunctional e-mail addresses, there were 1291 emails that were opened and 1225 people (95%) completed the survey. Of the participants, 1022 (83%) confirmed that they were neonatologists and are the focus of this paper. Among website visitors, we had a 95% response rate, but our overall response rate was only 18%. Respondent demographics (Table) showed that the average respondent had worked for >20 years, practiced in a hospital with planned high-risk deliveries, could provide mechanical ventilation, and had more than one 22- to 25-week infant born per month.

Use of Population-Based Outcomes Data

The vast majority (99%) of surveyed neonatologists provided counseling to parents at risk of delivery between 22 and 25 weeks. Of the participating neonatologists, 91% used data to counsel families prenatally, with 80% using data 50% of the time or more and 30% reporting using data all of the time.

The NICHD outcomes calculator[4] was the most frequently used population-based outcomes data source (Figure 1). Institutionally derived data compiled for the participant's own hospital system was second followed by almost equal numbers for Pediatrix/Obsterix[3] and Vermont Oxford[2] datasets. The majority (78%) of those who picked the "other" option and entered free text indicate that they used multiple sources to counsel prenatally.

Impact of Population-Based Outcomes Data on Prenatal Counseling

Of those neonatologists who consult data before counseling, 89% stated that population-based outcomes data had at least some impact on how they counseled. Despite consulting a data source before counseling, 11% of respondents felt population-based outcomes data had "little" or "no" impact on how they counseled.

Of the neonatologists who used population-based outcomes data, 80% said that they provide families "specific numerical estimates of adverse outcomes, such as survival or survival without neurologic impairment." When asked how much impact data had on parent's decisions about initiating or withholding resuscitative efforts in the delivery room, 36% stated that these estimates had "little" or "no" impact on parents. The majority felt that numerical estimates had at least some effect and 10% responded that data estimates had a major impact on families.

Neonatologists who use population-based outcomes data were asked, "When you use a population-based outcomes data,