Accuracy of the Diagnosis of Bronchopulmonary Dysplasia in a Referral-Based Health Care System

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Objective To evaluate the accuracy of the diagnosis of bronchopulmonary dysplasia (BPD) in a national database of a referral-based health care system, where preterm infants are often transferred back to regional hospitals before 36 weeks postmenstrual age (PMA).

Study design We evaluated preterm infants <32 weeks, born between 2004 and 2008 in the Academic Medical Center in Amsterdam with a high-risk profile for BPD. In addition to patient characteristics and outcomes, we collected data on respiratory support at 36 weeks PMA. True incidence of BPD, defined as needing supplemental oxygen and/or positive pressure support at 36 weeks PMA, was compared with the diagnosis registered in the National Perinatal Registry. Two imputation algorithms for patients transferred before 36 weeks PMA were validated.

Results We identified 243 preterm infants with a high-risk BPD profile. Sixty-seven percent of these infants had a correct BPD diagnosis recorded in the National Perinatal Registry, 2% had a false positive, and 31% a false negative diagnosis. Infants with a false negative diagnosis of BPD were twice as often transferred to a regional hospital before 36 weeks PMA compared with a true positive diagnosis. Imputation algorithms did not improve the accuracy of BPD registration.

Conclusions Registration of the diagnosis BPD in a national database in countries with a referral-based health care system may not be accurate. Optimizing data collection and monitoring data entry is necessary to improve BPD registration before data can be used for national and international benchmarking. *(J Pediatr 2015;167:540-4)*.

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Complications of preterm birth are often registered in national and international databases.[1-3] These databases are increasingly used for benchmarking in an attempt to identify variations in clinical practice and outcome, and to improve neonatal care.[1,3-7] In The Netherlands, data on preterm births and complications are registered in the National Perinatal Registry (PRN).

Bronchopulmonary dysplasia (BPD) is the most common complication of preterm birth.[8-11] BPD is characterized by the need for prolonged respiratory support, recurrent pulmonary infections during the first years of life, and compromised lung function lasting into adolescence.[12-15] In addition, BPD is associated with adverse neurodevelopmental outcomes.[12,13,16,17]

According to the National Institutes of Health Workshop criteria, a preterm infant born <32 weeks gestation is diagnosed with BPD when the infant received supplemental oxygen for a cumulative duration of at least 28 days.[8] If this criterion is fulfilled, the severity of BPD is determined at 36 weeks postmenstrual age (PMA) by assessing the oxygen need and the level of respiratory support.[8] Because the cumulative number of days on oxygen is difficult to extract from patient records, some national and international databases have simplified this criterion by assessing the need for supplemental oxygen at 28 days postnatal age.[18] Others have dichotomized the diagnoses of BPD and assess the presence or absence of respiratory support at 36 weeks PMA and use this outcome for classifying the patients as having, respectively, BPD or no BPD.[19]

Many countries, including The Netherlands, have a referral-based health care system, where preterm infants are transferred back to regional hospitals before 36 weeks PMA if the clinical condition of the infant is stable. The accuracy of diagnosing BPD is, therefore, highly dependent on the clinical information from both admission sites. Failing to combine data on respiratory support from both admission sites can result in over- or underestimation of the true incidence of BPD. Specific data on the reliability and accuracy of the diagnosis BPD in databases using a referral-based health system are lacking. Other national and international databases dealing with this same problem have attempted to

BPD	Bronchopulmonary dysplasia
NICHD	*Eunice Kennedy Shriver* National Institute of Child Health and Human Development
NICU	Neonatal intensive care unit
PMA	Postmenstrual age
PRN	National Perinatal Registry
VON	Vermont Oxford Network

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resolve the issue of missing data at 36 weeks PMA by applying an imputation algorithm using the amount of respiratory support at discharge from the tertiary hospital.[5,7]

The objective was to investigate the accuracy of recording the diagnosis of BPD in a referral-based health care system by comparing the incidence of BPD in the PRN to the (true) incidence of BPD based on chart reviews. Furthermore, the previously reported imputation algorithms used by large neonatal networks were validated in our study cohort.[5,7]

Methods

This is a single-center retrospective cohort study including all patients <32 weeks gestation with a high-risk profile for BPD admitted to the level 3 neonatal intensive care unit (NICU) of the Emma Children's Hospital, Academic Medical Center in Amsterdam between January 2004 and December 2008. A high-risk profile for BPD was defined as needing nasal continuous positive airway pressure or invasive/noninvasive positive pressure ventilation and/or supplemental oxygen between 25 and 32 days postnatal age. None of the infants were treated with high-flow nasal cannula. The study was approved by the institutional review board.

The PRN uses a dichotomized diagnosis of BPD (yes/no) assessed only on the amount of respiratory support at 36 weeks PMA. Data entering was a joined responsibility of the pediatricians in the tertiary and the regional hospitals. In case the patient was transferred back to the regional hospital before 36 weeks PMA, the pediatrician in the tertiary center assessed the need for respiratory support at the time of transfer. If the patient was without respiratory support or on nasal cannula without supplemental oxygen, he or she was classified as having no BPD. Otherwise he or she was diagnosed as having BPD. The pediatrician in the local hospital assessed the actual respiratory status at 36 weeks PMA and, if necessary, adjusted the classification of BPD in the PRN.

The following perinatal and clinical data were collected from the patient records at the tertiary center and (if applicable) at the regional hospital: gestational age, birth weight, small for gestational age (birth weight <10th percentile), Apgar scores, the use of surfactant, the use of mechanical ventilation, total days of ventilation, patent ductus arteriosus requiring pharmacologic and/or surgical treatment, any stage of necrotizing enterocolitis, severe intraventricular hemorrhage (Papile stage III or IV), periventricular leukomalacia >stage I, use of postnatal steroids, mortality before 36 weeks PMA, respiratory status of the patients at 36 weeks PMA, transfer to regional hospital before 36 weeks, total days of stay in the NICU, and total days of hospitalization. The individual BPD diagnosis at 36 weeks PMA was also extracted from the PRN.

Data Analyses

Based on the chart reviews from our center and (if applicable) the regional hospitals, we determined the true diagnosis of BPD for each individual infant alive at 36 weeks PMA. The diagnosis and severity of BPD was assessed according to the National Institutes of Health Workshop criteria.[8] The infant was diagnosed as no BPD if less than 28 days supplemental oxygen was administered before the date of 36 weeks PMA. In case of cumulative more than 28 days supplemental oxygen, the diagnosis was BPD and severity was assessed at 36 weeks PMA. Mild BPD was diagnosed if the infant had no respiratory support or was on low flow without oxygen at 36 weeks PMA. Severe BPD was diagnosed if the infant was on continuous positive airway pressure or positive pressure ventilation or on low flow with supplemental oxygen >30%. All the other infants had moderate BPD. Oxygen reduction tests were not performed.[20,21]

Using a 2 by 2 table, we compared this with the BPD diagnosis in the PRN and calculated the number of true positive and false negative BPD diagnoses. In addition, we compared the patient characteristics of these 2 subgroups.

To explore the impact of 2 previously published algorithms on the accuracy of the BPD diagnosis registered in our national database, we applied these algorithms to all patients that were transferred before 36 weeks PMA to regional hospitals and compared this registered incidence of BPD with the true incidence based on the chart reviews. The Vermont Oxford Network (VON) imputed missing outcomes of BPD at 36 weeks PMA using the following algorithm: patients discharged between 34 and 36 weeks on oxygen, were classified as being on oxygen at 36 weeks PMA. Infants not on oxygen at discharge were classified as not being on oxygen at 36 weeks PMA. Patients, who were discharged before 34 weeks on oxygen, were classified as "unknown" for the diagnosis BPD at 36 weeks PMA. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Neonatal Research Network (NICHD) classified missing BPD diagnosis according to respiratory support at hospital discharge, in case a room air challenge was not possible at discharge and the receiving institution could not give information about respiratory support at 36 weeks PMA. Both algorithms did not classify the severity of BPD diagnosis, considering mild BPD as no BPD. Therefore, these analyses were performed classifying mild BPD in our cohort as no BPD.

Statistical analyses were done with SPSS v 20.0 (SPSS Inc, Chicago, Illinois). The χ^2 test was used to compare dichotomous data and the independent samples *t* test for continuous data. Differences were considered statistically significant when the 2-tailed *P* value was <.05.

Results

A total of 915 preterm infants were born in the study period, with a mean gestational age of 29.2 (±1.9) days and a mean birth weight of 1246 (±365) g (**Figure**; available at www.jpeds.com). Of these infants, 261 were classified as having a high-risk profile for BPD based on the oxygen need around 28 days postnatal age. Of these 261 infants, 14 infants died between day 28 after birth and 36 weeks PMA, and in 4