

Pulmonary Important Outcomes After Extremely Preterm Birth: Parental Perspectives

Thivierge E, Luu TM, Pearce R, Barrington K, Bourque CJ, Jaworski M, Janvier A
Pediatrics Department, CHU Sainte-Justine, Montréal, Québec

Context

- Extreme prematurity is associated with significant pulmonary morbidities.
- Doctors and researchers have been deciding which pulmonary outcomes are important.
- The diagnosis of bronchopulmonary dysplasia or the need for oxygen at 36 weeks CA have been used as the most frequent pulmonary outcomes in many randomized studies looking to improve pulmonary health.

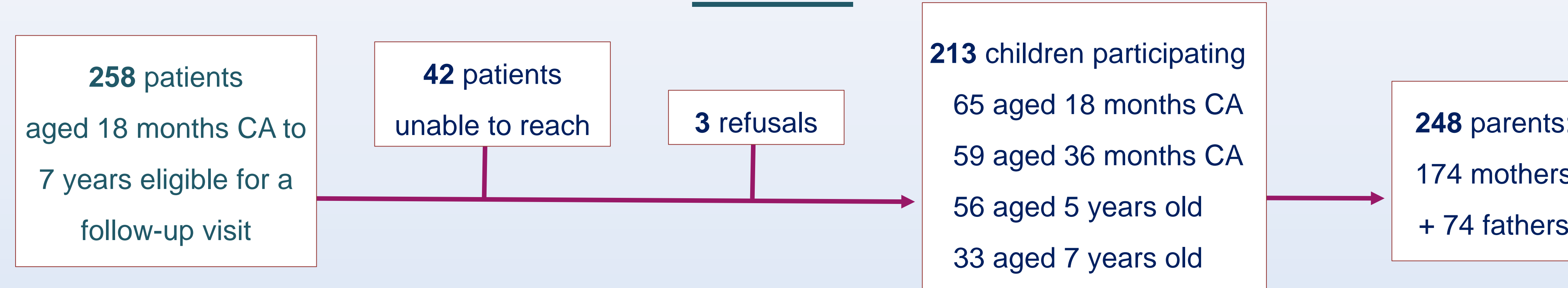
Aim

To describe pulmonary important outcomes (PIO) reported by parents of children born extremely preterm.

Methods

- **Design** : cross-sectional survey
- **Population** : All parents of infants born below 29 weeks' GA and seen at CHU Sainte-Justine NICU follow-up clinic at age 18 months to 7 years from July 2018-July 2019
- **Measure**: Parental questionnaire including open-ended items
- **Analysis** : Descriptive content analysis and independent coding by three reviewers (medical professionals and parent).
- Mixed methods to assess the frequency of each theme in relation to clinical factors.

Results



- 44% of parents mentioned PIO with 24 different themes invoked.
- No parent mentioned the absence or presence of BPD or the need for oxygen at 36 weeks.
- The proportion of parents who had concerns about pulmonary outcomes was not related to birth weight, gestational age or diagnosis of BPD.
- Parents of boys, of children who had been re-hospitalized within the first 18 months after discharge and those with mild or moderate neurological impairment were more likely to have mention PIO.

NICU Outcomes	Long Term Outcomes
Intubation and length Spasms on tube	Home oxygen - Length - Harder with other children or animals - Limitations in movement of child / family
Reintubations/Accidental extubations - Parental fear, highs and lows	Difficulty breathing / cough / wheezing - Parental fear & impact on sleep of child / family
Respiratory insufficiency - Fear of death - Capacity to hold their child - Steroids to prevent death	Family isolation to prevent infections
Time on respiratory support - HFNC better than CPAP	Readmissions and hospital visits Frequent Infections Recommendations to avoid daycare
Work of breathing	Tracheostomy
ENT problems: stridor, tests, surgeries	ENT problems & surgeries
Nasal or face injuries 2 nd to ventilation or intubation	Medications - Difficulty giving it, follow up, efficiency
Length of post-term oxygen need	Nutritional impact - Oral aversion, gastrostomy
Tracheostomy	Limitation of exercise or school activities

Discussion

- High response rate (98%) which leads us to believe that these views are a true reflection of parental perspectives in our centre.
- Possible underestimation of % of parents for whom PIO are important.
- Relative value of the different themes invoked needs to be explored in future studies.
- Future studies should also focus of finding predictors of optimal function according to the families.

Conclusion

- The medical community tries to evaluate and decrease the impacts of prematurity of the pulmonary health of children.
- However, most studies do not measure what parents describe as important outcomes such as their child's functioning and daily impacts of their respiratory health.
- Future studies should align main medical outcomes with family-important outcomes.

A big THANKS to all the families who participated in this study!