



Parent Preferences Regarding Home Oxygen Use for Infants with Bronchopulmonary Dysplasia

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Objectives To determine parent preferences for discharge with home oxygen in infants with bronchopulmonary dysplasia.

Study design This was a prospective study of parents of infants born at <32 weeks' gestation with established bronchopulmonary dysplasia and approaching neonatal intensive care unit (NICU) discharge. Parents were presented a hypothetical scenario of an infant who failed weaning to room air and 2 options: discharge with home oxygen or try longer to wean oxygen. The initial scenario risks reflected a 1.5-week difference in NICU length of stay and no differences in other outcomes. Length of stay and readmission outcomes were increased or decreased until the parent switched preference. Three months after discharge, parents were asked to reconsider their preference. Differences were analyzed by χ^2 or Kruskal-Wallis tests.

Results Of 125 parents, 50% preferred home oxygen. For parents preferring home oxygen, the most important reason was comfort at home (79%). Forty percent switched preference when the length of stay difference decreased by 1 week; 35% switched when readmission increased by 5%. For parents preferring to stay in NICU, the most important reason was fear of taking care of the child at home (73%). Thirty-two percent switched preference when the length of stay difference increased by 1 week; 31% switched when readmission decreased by 5%. One hundred ten parents completed the 3-month follow-up; 80 were discharged with home oxygen. Seventy-eight percent would prefer home oxygen (97% who initially preferred home oxygen and 60% who initially preferred to stay in the NICU).

Conclusions Parents weigh differences in NICU length of stay and readmission risk similarly. After discharge, most prefer earlier discharge with home oxygen. Earlier education to increase comfort with home technology may facilitate NICU discharge planning. (*J Pediatr* 2019;213:30-7).

Bronchopulmonary dysplasia (BPD) is one of the most common complications of preterm birth, with an estimated 15 000 new cases annually.^{1,2} BPD prolongs length of stay in the neonatal intensive care unit (NICU), and increases the risk of hospital readmissions and developmental delay.^{3,4} Home oxygen is a common therapy for infants with BPD at NICU discharge.⁵⁻⁹ Home oxygen use varies across US NICUs, from 10% to 95% of infants with BPD.¹⁰ NICUs with higher rates of home oxygen use have a shorter length of stay, adjusted for gestational age and illness severity.¹⁰ So far, outcome studies of infants with BPD discharged with vs without home oxygen have not found major differences in readmissions, ICU admissions, or developmental delay.¹¹⁻¹³

Given the wide variation in home oxygen use and few observed differences in patient outcomes, parent preferences are a factor in deciding whether it should be initiated.¹⁴⁻¹⁷ For parents of preterm infants, home oxygen use is a major stressor.^{18,19} At the same time, inpatient admissions are associated with lower quality of life for parents of infants with BPD.²⁰ It is unknown how parents view the balance between longer NICU stay vs earlier discharge with home oxygen.

Our objectives for this study were to determine how parents of infants with BPD in the NICU view the balance between longer NICU stay and earlier discharge with home oxygen and to understand how parents' theoretical preferences change after NICU discharge.

Methods

We conducted a prospective study of parents of infants born at <32 weeks' gestational age with BPD, defined as requiring supplemental oxygen for ≥ 28 continuous days of life,^{1,4} admitted to our level IV NICU from April 2015 to September 2018, who had not previously been discharged. We excluded parents who did not speak English or who could not provide consent. We excluded infants with major

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BPD Bronchopulmonary dysplasia
NICU Neonatal intensive care unit

congenital anomalies, a tracheostomy, or surgical comorbidities such as ventriculoperitoneal shunts or surgical necrotizing enterocolitis that would impact length of stay separate from BPD.³ Infants were screened weekly, and parents were approached when the infant was receiving noninvasive respiratory support (either high flow or regular nasal cannula) and had improving clinical status. After consent, interviews were conducted in the NICU by trained research assistants who followed a standardized script that included surveys and visual aids. The interview script used a third-grade reading level and was tested for understanding by nurses and parent volunteers. During the interview, parent responses were recorded electronically into REDCap (<https://www.project-redcap.org/>), a secure research database.²¹ At NICU discharge, the infant’s clinical chart was reviewed. Three months after discharge, repeat interviews were completed in person or by phone. Parents received a stipend for participation.

We used the threshold technique to elicit how strongly parents preferred being discharged with home oxygen or staying in the NICU. In general, the threshold technique presents respondents with a standardized scenario and 2 alternatives that are associated with respective outcomes.²² The respondent is initially asked to state a preference between the 2 options. Depending on the preference, 1 outcome is systematically

increased or decreased, and the respondent is again asked which option they prefer. The process of increasing or decreasing the outcome and asking for a stated preference continues until the respondent switches their preference to the alternative option. These switch points are used to measure strength of preference. Unlike other preference elicitation techniques, it does not establish a utility value; however, it has been thought by participants in previous studies to effectively simulate real-world decision making.^{16,23,24}

For this study, we presented a hypothetical scenario of a premature infant requiring supplemental oxygen at 36 weeks corrected age who can eat 75% of feeds orally, has had caffeine discontinued, but who recently failed weaning to room air. Two options were presented: (1) discharge with home oxygen after reaching full oral feeds (home oxygen preference) and (2) reattempt to wean oxygen in another week, with a possible discharge on home oxygen (stay in NICU preference). Outcomes in the scenario were chosen based on available literature, and included a 1.5-week difference in NICU length of stay between the options, with no differences in readmission, reintubation, or developmental delay.^{10-12,25} The 2 options and their respective risks were provided to the parents as a visual aid, with outcomes presented both numerically and pictorially in factors of 20 rather than percentages (Figure 1).

Imagine that your baby is still on oxygen at 36 weeks corrected age, which is one month before your due date. Your baby is stable on low flow oxygen, off caffeine, and eats 3/4 of feedings by mouth. When the nurse tried to take off the oxygen 3 days ago, your baby’s oxygen saturations on the monitor were 88-92%. Your baby has looked comfortable since then but has been breathing faster and has not gained any weight in those 3 days.

	Choice A: Re-start oxygen, let your baby finish learning to eat and plan to go home with oxygen.	Choice B: Re-start oxygen, try again to stop oxygen in about a week.
Time to going home from the NICU	1 week	2 1/2 Weeks
Chance of home oxygen	 20 out of 20 babies	 10 out of 20 babies
Risk of hospital admission in the next year	 10 out of 20 babies	 10 out of 20 babies
Risk baby will need breathing tube again in the next year	 2 out of 20 babies	 2 out of 20 babies
Risk of developmental delay at 2 years	 4 out of 20 babies	 4 out of 20 babies

Figure 1. Initial theoretical scenario with starting risks.

Table I. Relevant risks of outcomes between treatment options for BPD

Risks	Option A: Restart oxygen, let the baby eat on his or her own schedule, and send you home with oxygen.	Option B: Restart oxygen, wait until the baby is eating 100% on his or her own schedule, and try again to take off the oxygen in a week.
Chance of home oxygen	20 in 20	10 in 20
Time to going home from the NICU	1 week Option A scale: 1.5 weeks 2 weeks 2.5 weeks No switch	2.5 weeks Option B scale: 3.0 weeks >3 weeks No switch
Chance of hospital admission in the next year	10 in 20 Option A scale: 11 in 20 12 in 20 13 in 20 14 in 20 >14 in 20 No switch	10 in 20 Option B scale: 9 in 20 8 in 20 7 in 20 6 in 20 <6 in 20 No switch
Chance of intubation in the next year	2 in 20 Option A scale: 3 in 20 4 in 20 5 in 20 >5 in 20 No switch	2 in 20 Option B scale: 1 in 20 No switch
Chance of developmental delay at 2 years	4 in 20 Option A scale: 5 in 20 6 in 20 >6 in 20 No switch	4 in 20 Option B scale: 3 in 20 2 in 20 1 in 20 No switch

Ranges of outcome attributes used in the threshold technique interview. The starting attributes are listed in bold. Below the starting attributes are the entire scale choices that a parent could choose after selecting their initial preference.

After stating their preferred scenario, parents rated their strength of preference on a 11-point Likert scale (5 [strongly prefer home oxygen]; 0 [neutral]; -5 [strongly prefer staying in the NICU]). Parents were asked to rank factors that potentially influenced their preference. Factors were chosen based on literature and clinical experience²⁶ and included fear of taking care of child at home, comfort with surroundings at home, comfort with surroundings in the hospital, needs of other family members, travel difficulty, ability to take time off from work, child does not like oxygen in the nose, and cost issues. Parents were asked to rank factors from 1 (most important) to 8 (least important), assigning each value only once. A visual aid was used to show the 2 options and associated outcomes of length of stay, readmission, reintubation, and developmental delay. The visual aid was created as a slider that allowed the interviewer to alter a single outcome within the table sequentially (Figure 2; available at www.jpeds.com). Each outcome was tested individually. Based on the parent's initial preference, the risk of a specific outcome would

increase or decrease until the parent either chose to switch their preference to the other option or stated they would not change their preference based on this outcome alone (Table I).

Three months after discharge, parents were reminded of their initial preference from the NICU interview and asked if they would keep their initial preference or switch based on their postdischarge experience, and why. Responses were documented and grouped into categories.

Parent demographic factors, based on parent report at enrollment, included caregiver type (mother or father), parent age, race and ethnic group, education, number of other children, number of adults in the home, minutes from home to the hospital, staying at Ronald McDonald house, plans for childcare, and access to a car. Chart review was completed to record infant clinical characteristics. Variables included insurance type, sex, gestational age at birth based on obstetric estimate, birth weight, inborn (discharged from the NICU associated with the colocated birth hospital), antenatal steroids, birth mode, multiple vs singleton, maximum grade of intraventricular hemorrhage,²⁷ stage 2+ or surgical necrotizing enterocolitis,²⁸ patent ductus arteriosus management, surfactant use, systemic steroid use for chronic lung disease, respiratory support at 28 days of life, pulmonary hypertension per echocardiogram report, days of mechanical ventilation, days of supplemental oxygen, and BPD severity per National Institutes of Health consensus statement including a physiologic challenge.^{1,4,29}

Statistical Analyses

We compared infant clinical characteristics, parent demographic characteristics, and parents' self-rated strength of preference between those who initially stated preferring going home with oxygen to those preferring staying in the NICU. We then compared parents' ranked factors influencing their preference, grouping the 8 options into most important (ranks 1-3), moderate importance (ranks 4-5), and lower importance (ranks 6-8) for easier visualization. For the threshold questions in which outcomes were systematically varied, we recorded the cumulative proportion of parents in each preference group who switched preference at each incremental outcome change. At 3 months after discharge, for the parents whose infants were discharged with home oxygen, we compared the proportion who would change their preference from their initial theoretical preference. All differences between groups were calculated by χ^2 or Fisher exact tests.

The study was approved by the Institutional Review Board at the Children's Hospital of Wisconsin. Written consent was obtained for both infant and parent.

Results

Of the 130 parents who completed the NICU interview, 5 were subsequently ineligible for follow-up owing to the infant

receiving a tracheostomy (n = 2) or parent loss of custody (n = 3). Of the 125 eligible for 3-month follow-up, 110 (88%) completed the interview. When presented with the hypothetical scenario of an infant nearing discharge who failed weaning to room air, 62 (50%) initially preferred home oxygen and 63 (50%) preferred to stay in the NICU. Most parents strongly preferred their stated option, with 48 parents (77%) who preferred home oxygen and 41 parents (65%) who preferred to stay in the NICU ranking their preference 4 or 5 in the appropriate direction on the 11-point Likert scale; there was no significant difference in strength of preference ranking between preference groups ($\chi^2 P = .16$). Infant and parent characteristics based on initial preference are shown in **Table II** (available at www.jpeds.com). Parents of later gestational age infants were more likely to prefer home oxygen; otherwise, there were no parent or infant characteristics associated with preference for home oxygen vs staying in the NICU. Similarly, parent preferences were not associated with the infant's corrected gestational age or feeding or respiratory status on the date of interview.

The ranked importance of factors influencing parent preference are depicted in **Figure 3**. For parents who preferred

home oxygen, the needs of other family members and comfort with surroundings at home were ranked as most important (65% and 60%, respectively), whereas these were only ranked as important by 31% and 5% of parents preferring to stay in the NICU. For parents who preferred to stay in the NICU, comfort with surroundings in the hospital and fear of taking care of their child at home were ranked as the most important factors (60% and 54%, respectively); these factors were only ranked as important by 25% and 6% of parents preferring home oxygen. Cost, travel difficulty, ability to take time off from work, or the child not liking the nasal cannula were ranked as less important, with no significant difference between groups.

Figure 4 shows the cumulative proportion of parents who switched preference as each outcome was manipulated. For the outcome of NICU length of stay (**Figure 4, A**), the original scenario reflected infants discharged with home oxygen having a 1.5-week shorter length of stay than infants staying in the NICU to attempt to wean to room air.¹⁰ For parents who initially preferred home oxygen, 25 (40%) would switch if the difference were decreased by 1 week, for a 0.5-week difference in length of stay between groups. Seventeen (27%) would not switch preference for

REASON FOR PREFERENCE

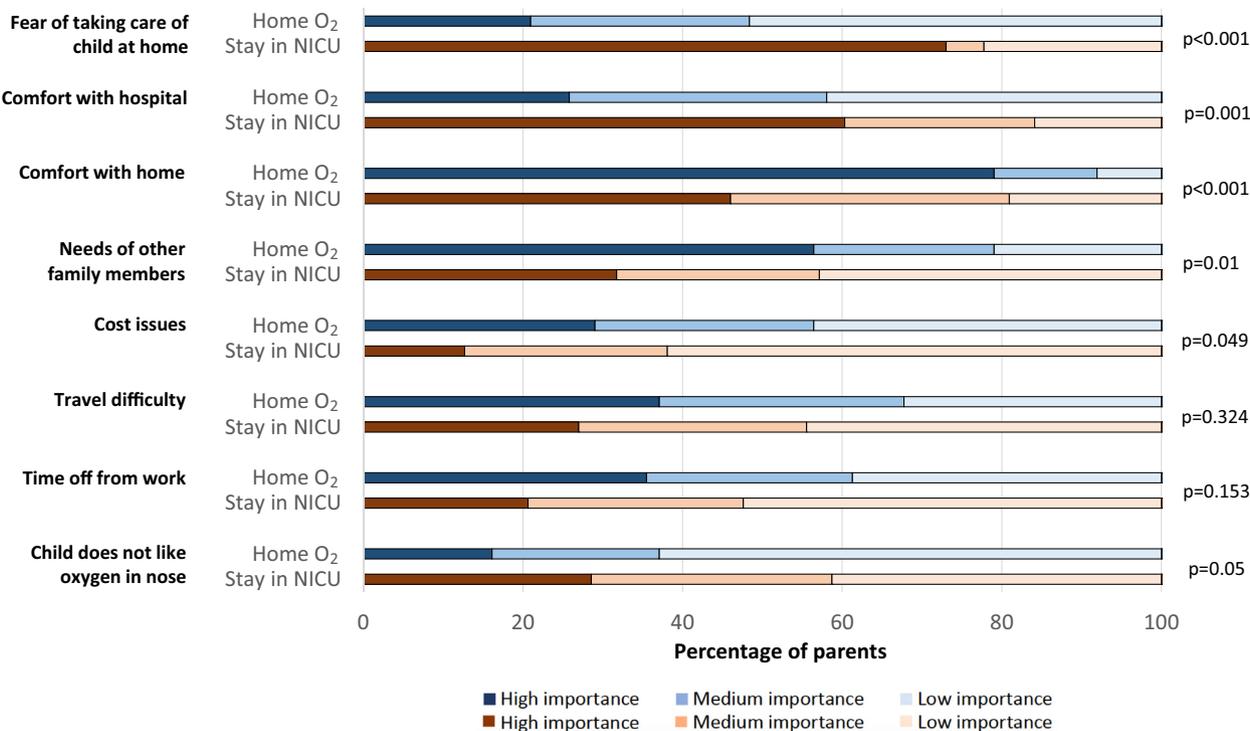


Figure 3. Ranked importance of factors influencing initial preference. Parent responses to the question, “Can you rank all of the following factors from 1 to 8, with 1 being the most important factor in making your initial home oxygen preference decision?” The y-axis lists the factors that parents were given to choose from, and the x-axis shows the proportion of parent responses. Importance rankings were grouped: high importance = ranks 1-3; medium importance = ranks 4-5; low importance = ranks 6-8. The P values indicate χ^2 tests for difference in ranked importance between groups by initial preference for home oxygen (home O₂) vs staying longer in the NICU (stay in NICU).

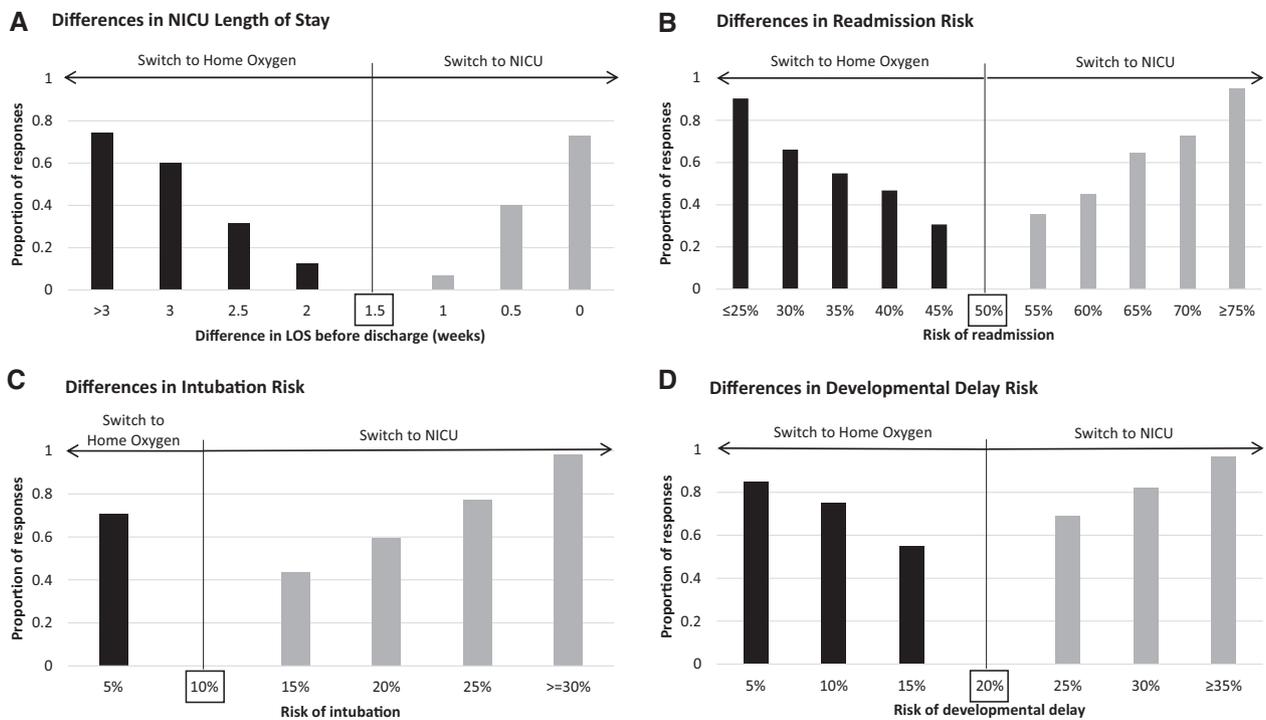


Figure 4. Cumulative proportion of parents willing to switch preference during the threshold technique. The cumulative proportion of parents who switched preference as outcomes were systematically manipulated for each of 4 outcomes: **A**, NICU length of stay, **B**, readmission, **C**, reintubation, and **D**, developmental delay. For each figure, the y-axis shows the cumulative proportion of parents in their respective initial preference group who would switch preference (switch to home oxygen = black bars; switch to NICU = gray bars); the x-axis shows the switch point for each outcome. The starting risk in the initial scenario is highlighted by a box on the x-axis.

any length of stay difference. Some parents who chose to not switch preference commented that they knew that their child was going to go home on home oxygen and were not convinced that another weaning attempt would change anything. Another parent chose not to switch because she had previously experienced her child desaturating on a previous room air attempt and was frightened at the thought of attempting another oxygen wean. For parents who preferred to stay in the NICU, 20 (32%) would switch preference to home oxygen if the difference in length of stay were increased by 1 week; 16 (25%) would not switch for any difference in length of stay.

For the outcome of readmission risk (**Figure 4, B**), the original scenario reflected a 50% readmission risk at 1 year for both home oxygen and stay in the NICU groups.^{4,30} For parents who preferred home oxygen, 59 (95%) would switch preference at some threshold of increased readmission risk; 22 (36%) would switch their preference to stay in the NICU with a 5% increase in absolute risk. Similarly, for parents who preferred to stay in the NICU, 57 (90%) would switch preference to stay in the NICU at some threshold of readmission risk; 20 (31%) would switch their preference to home oxygen for a 5% decrease in absolute risk.

For the outcome of reintubation risk (**Figure 4, C**), the original scenario reflected a 10% reintubation risk for both

groups.¹² For parents who preferred home oxygen, 53 (85%) of parents would switch their preference to stay in the NICU at some threshold, with 27 (44%) switching their preference to stay in the NICU with a 5% increase in intubation risk. For parents who preferred to stay in the NICU, 45 (71%) would switch their preference to home oxygen with a 5% decrease in intubation risk.

For the outcome of developmental delay (**Figure 4, D**), the original scenario reflected a 20% risk of delay at 2 years of age.^{11,25} One hundred fourteen parent (91%) would switch at some threshold of increased risk of developmental delay, with the majority of parents switching their preference at the smallest increment of risk difference. The few parents who chose to not switch their preference commented that they did not believe that the presence or absence of home oxygen would have any effect on their child's neurologic development.

At 3 months after discharge, participants were asked to reconsider their initial theoretical preference for home oxygen vs staying in the NICU. Of the 110 infants (73%), 80 had been discharged with home oxygen. Of 43 parents whose infants were discharged with home oxygen who had initially chosen to stay in the NICU, 26 (61%) would switch their preference to earlier discharge with home oxygen. Of 37 parents whose infants were discharged with home oxygen who initially chose home oxygen, only 1

would switch to stay in the NICU. **Table III** (available at www.jpeds.com) displays parents' rationale for keeping or switching preference, as well as the initial factors ranked most important in their initial theoretical preference.

Discussion

This study was designed to determine parent preferences for a longer NICU stay vs earlier discharge with home oxygen in infants with BPD. We made the following observations.

Fear and comfort determine parent preferences for discharge with home oxygen; apart from gestational age, no other infant or parent characteristics were associated with differences in parent preference. Parents weigh modest differences in NICU length of stay similarly to modest differences in readmission risk. After discharge, most parents preferred earlier discharge with home oxygen.

We observed that the strongest predictor of parent preference for home oxygen vs staying in the NICU was fear and comfort with surroundings in the NICU vs comfort at home. We did not find any parent demographics or measures of respiratory illness severity that were associated with differences in parent preference. We did find that parents of infants with BPD born at later gestational ages were more likely to prefer earlier discharge with home oxygen over staying longer in the NICU to wean oxygen, in contrast with parents of infants born at earlier gestational ages. Because we would expect that gestational age would be correlated with infant illness, it is unclear whether this represents a statistical artifact or true differences. Parents of infants born at <28 weeks of gestation have had prenatal conversations about the likelihood of mortality followed by a long, difficult NICU stay; as a result, they could be more anxious about discharge than parents who have had a different experience of prematurity and neonatal intensive care.³²⁻³⁴ Interventions to increase parent confidence in caring for their infants have been shown to impact feeding outcomes,^{35,36} and may also impact parent preferences for earlier discharge with home oxygen, although we did not ask parents to specify what they meant by comfort at home or in the NICU. Because hospitals using more home oxygen have a shorter NICU length of stay,¹⁰ and most parents in our study preferred home oxygen after their actual experience with this therapy, proactively addressing parents' fears may allow earlier discharge for infants with BPD.

When evaluating outcomes that affect parent preferences, we found that 30%-40% of parents switched preference if the difference in NICU stay was changed by 1 week, and a similar proportion of parents switched preference if the absolute difference in readmission were increased or decreased by 5%. As expected, more parents switched preference for small differences in developmental delay or reintubation outcomes, indicating that parents understood the threshold technique exercise.

Understanding how parents view the balance between NICU length of stay and risks associated with home oxygen use is important in the context of practice variation in

home oxygen use across the US. A prior study found that infants discharged from centers with higher rates of home oxygen use had a 1.5-week earlier postmenstrual age at discharge than infants in centers with lower rates of home oxygen use, adjusted for illness severity.¹⁰ Readmission is still a broadly used quality measure despite its limitations in pediatrics, whereas NICU length of stay is not generally viewed as a quality measure.^{37,38} If parents view modest risk differences in these outcomes similarly, it suggests that clinicians and health systems should consider both NICU length of stay and potential hospital readmission when planning discharge strategies.

When parents of infants discharged with home oxygen were interviewed 3 months after discharge, we found that 97% of parents who initially preferred home oxygen still preferred discharge with home oxygen, and 60% of those who initially preferred to stay in the NICU would switch their preference to earlier discharge with home oxygen. This study took place in a single center with a high proportion of home oxygen use for infants with BPD, a dedicated BPD clinic with a standard protocol for outpatient management of home oxygen, and relative ease of obtaining home nursing and durable medical equipment. Palm et al have previously noted that weaning oxygen in the outpatient setting rarely follows a standardized protocol; differences in outpatient management strategies may affect parent preferences and infant experiences with durable medical equipment at home.³⁹ In addition to varied outpatient strategies, center-specific practices like dedicated BPD teams, insurance coverage issues, and clinicians' perceptions of parent capabilities all likely impact clinician recommendations and subsequent parent preferences. Given the high cost of NICU care, future research should determine how different system approaches impact parent preferences for issues like home oxygen use. Proactive parent education combined with comprehensive outpatient and community support might allow safe reductions in NICU length of stay that are cost effective and align with parent preferences.

The inclusion of parent preferences is increasingly important in pediatric research, because parent satisfaction and understanding increase the probability of treatment adherence and the effective use of resources. The threshold technique has been used previously to elicit parent preferences, and our study expands its use to the NICU.^{23,24,40} We chose the threshold technique over other elicitation methods to isolate how each change in outcome affected parent preferences. Conjoint analysis techniques allow for the calculation of utility, but can be lengthy or difficult with multiple outcomes and levels of attributes.^{24,41,42} Study participants accepted the interview technique and found it understandable. During the interviews, some parents stated that they appreciated having risks for each outcome set in front of them and having an opportunity to process which risks they were willing to accept.

The strengths of this study include the prospective enrollment and preference elicitation before and after NICU discharge, the clinical and demographic diversity of the study cohort, and the high proportion of follow-up. The interview

script was extensively tested before beginning the study, including literacy level, parent understanding of clinical scenarios, and parent and nurse agreement with the relevance of the included clinical attributes.

This study has several limitations. Despite constructing visual aids and standardized scripts to provide balanced outcomes descriptions, communication of risk is difficult.⁴³ When responding to a hypothetical clinical scenario, some potential outcomes in the interview were difficult for parents to imagine, which may have affected their responses. We tried to mitigate this factor by qualitatively documenting reasons why parents did not switch preferences. Although we designed the clinical scenario and attributes based on the available literature with input from nurses and families, we provided a limited set of clinical outcomes, which may or may not reflect the outcomes of greatest importance to all families. We did not ask parents about their preferences or perspectives on other types of durable medical equipment such as feeding tubes. As a single-center study with a high proportion of home oxygen use, parent preferences could be affected by the surrounding clinical conversations with physicians and nurses.

In conclusion, for parents of infants with BPD, preferences are initially divided between earlier NICU discharge with home oxygen vs staying in the NICU longer to attempt to wean oxygen. Other than gestational age, clinical and demographic factors do not affect this choice as much as perceptions of fear and comfort in the hospital vs at home. By 3 months after NICU discharge, most parents prefer earlier discharge with home oxygen. Earlier intervention to facilitate parent confidence with infant cares and medical equipment, combined with appropriate outpatient support, may be effective in safely decreasing NICU length of stay for infants with BPD. ■

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50 Years Ago in *THE JOURNAL OF PEDIATRICS*

Congenital Rubella: Immune Response of the Neonate and Diagnosis by Demonstration of Specific IgM Antibodies

Vesikari T, Vaheri A, Pittay O, Kunnas M. *J Pediatr* 1969; 75:658-64.

Fifty years ago, it had been recently established that accurate laboratory methods could separate the IgM fraction from the IgG fraction in serum and that IgM did not cross the placenta. The study by Vesikari et al in *The Journal* demonstrated the usefulness of measuring total IgM content and specific rubella hemagglutination inhibiting (HI) antibody in the IgM fraction in serum of newborns as valid (confirmed by virus isolation) diagnostic tests for intra-uterine rubella infection. With this small study, the authors also began to elucidate both the risks of maternal-to-fetal infection as well as the effects of fetal infection as determined by stage of pregnancy at the time of infection.

They studied 15 infants born to mothers with recognized rubella during pregnancy. In 6 infants, maternal infection occurred during the first 12 weeks; 5 had findings of congenital rubella, and all newborns had elevated total IgM ≥ 75 mg/dL, rubella HI IgM antibodies detected, and isolation of virus at birth. In 9 infants, maternal infection occurred after 12 weeks; no infant had findings of congenital rubella, elevated total IgM, rubella HI IgM in serum, or isolation of virus. Unlike infants who were congenitally infected, these infants had postnatal decay of passively acquired rubella HI IgG antibodies (similar to 8 control infants). Although investigations of larger numbers of cases of maternal rubella showed infrequent cases of IgM antibody-negative congenital rubella when infection occurred extremely early in pregnancy, and cases of transplacental transmission of virus during later stages of pregnancy, the observations of Vesikari et al were both novel and spot-on.

Timo Vesikari went on to be, and continues to be, a giant in international research on infectious diseases and their prevention through vaccination—research that has saved millions of children from erstwhile fatal or highly morbid infections.

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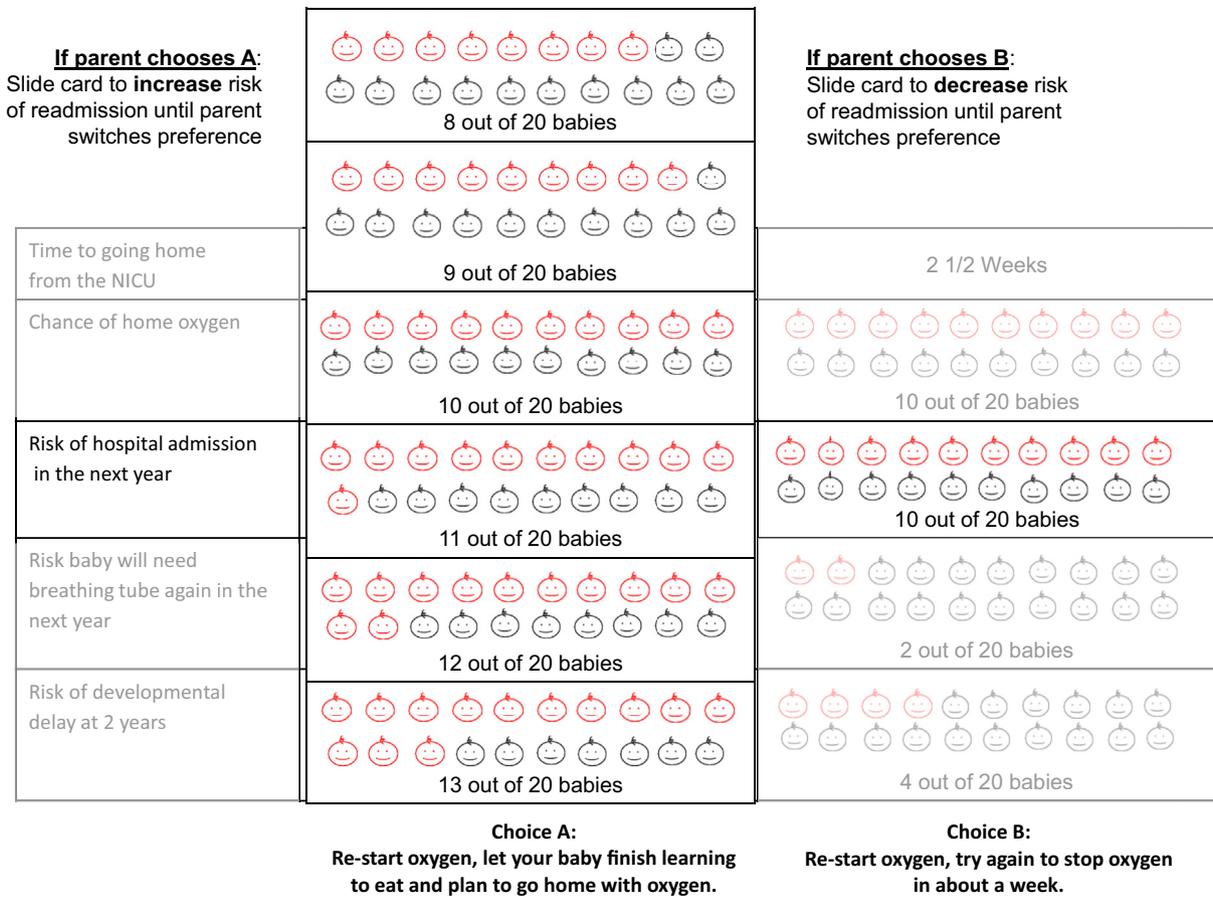


Figure 2. Sliding cards for the threshold technique interview. During the interview, the 4 outcomes of length of NICU stay, risk of hospital admission, risk baby will need breathing tube again in the next year, and risk of developmental delay at 2 years were systematically varied, with the direction of changing risk dependent upon the parent’s initial preference.

Table II. Parent and infant factors by initial preference for home oxygen vs staying in the NICU

Variables	Initial preference		P value
	Home oxygen (n = 62), n (%)	Stay in NICU (n = 63), n (%)	
Parent demographics			
Sex			
Female	58 (94)	59 (94)	.981
Male	4 (6)	4 (6)	
Age, years			
<20	7 (11)	2 (3)	.173
21-35	44 (71)	52 (83)	
>35	11 (18)	9 (14)	
Race			
Black	15 (24)	14 (22)	.331
Hispanic	5 (8)	8 (13)	
White	40 (65)	36 (57)	
Asian	1 (2)	5 (8)	
American Indian/ Alaska Native	1 (2)	0 (0)	
Education			
Less than high school	2 (3)	3 (5)	.356
High school graduate	13 (21)	11 (17)	
Some college or technical school	18 (29)	13 (21)	
College/technical school graduate	23 (37)	22 (35)	
Graduate school	6 (10)	14 (22)	
Number of other children			
0	30 (48)	24 (38)	.168
1	18 (29)	15 (24)	
≥2	14 (23)	24 (38)	
Number of adults in home			
Single parent	8 (13)	4 (6)	.100
2	42 (68)	53 (84)	
≥3	12 (19)	6 (10)	
Minutes to hospital			
<30	30 (48)	38 (60)	.212
30-60	19 (31)	11 (17)	
>60	13 (21)	14 (22)	
Staying at Ronald McDonald house			
Yes	18 (29)	11 (17)	.125
No	44 (71)	52 (83)	
Childcare plans after discharge			
Parent at home	38 (61)	29 (46)	.216
Relative or nanny	16 (26)	21 (33)	
Daycare center	8 (13)	13 (21)	
Car			
Yes	54 (87)	52 (83)	.478
No	8 (13)	11 (17)	
Infant illness characteristics			
Insurance type			
Private	28 (45)	34 (54)	.325
Public	34 (55)	29 (46)	
Sex			
Female	27 (44)	29 (46)	.780
Male	35 (56)	34 (54)	
Gestational age, weeks			
22-24	16 (26)	15 (24)	.004
25-28	25 (40)	41 (65)	
29-31	21 (34)	7 (11)	
Birth weight, g			
<1000	35 (56)	43 (68)	.395
1000-1499	23 (37)	17 (27)	
≥1500	4 (6)	3 (5)	
Birth location			
Inborn	35 (56)	39 (62)	.535
Outborn	27 (44)	24 (38)	

(continued)

Table II. Continued

Variables	Initial preference		P value
	Home oxygen (n = 62), n (%)	Stay in NICU (n = 63), n (%)	
Antenatal steroids			
Yes	58 (94)	58 (92)	.271
No	2 (3)	5 (8)	
Birth mode			
Cesarean delivery	44 (71)	45 (71)	.931
Vaginal	17 (27)	18 (29)	
Multiple birth			
Yes	16 (26)	14 (22)	.639
No	46 (74)	49 (78)	
IVH grade			
0	42 (68)	48 (76)	.553
1-2	13 (21)	10 (16)	
3-4	6 (10)	4 (6)	
ROP stage			
0-2	41 (66)	45 (71)	.607
3-5	19 (31)	17 (27)	
ROP surgery			
Yes	6 (10)	6 (10)	.977
No	56 (90)	57 (90)	
NEC stage 2+			
Yes	2 (3)	3 (5)	.661
No	60 (97)	60 (95)	
PDA management			
No treatment	38 (61)	40 (63)	.876
Medical	12 (19)	13 (21)	
Surgical ligation	12 (19)	10 (16)	
Surfactant use			
Yes	60 (97)	55 (87)	.084
No	2 (3)	7 (11)	
Steroids for chronic lung disease			
Yes	31 (50)	22 (35)	.088
No	31 (50)	41 (65)	
Respiratory support at 28 days of life			
Mechanical ventilation	26 (42)	26 (41)	.971
Noninvasive positive pressure	22 (35)	23 (37)	
Nasal cannula	14 (23)	13 (21)	
Mechanical ventilation days			
0	15 (24)	13 (21)	.273
1-25	21 (34)	30 (30)	
26-50	8 (13)	6 (10)	
51-75	15 (24)	8 (13)	
>75	3 (5)	6 (10)	
Total days of supplemental oxygen			
0-25	7 (11)	8 (13)	.839
26-50	9 (15)	7 (11)	
>50	46 (74)	48 (76)	
Pulmonary hypertension			
Yes	5 (8)	6 (10)	.730
No	57 (92)	57 (90)	
BPD severity			
Mild	9 (15)	17 (27)	.196
Moderate	27 (44)	26 (41)	
Severe	26 (42)	20 (32)	
Discharge feeding type			
All oral	46 (74)	53 (84)	.375
Nasogastric tube	7 (11)	5 (8)	
Gastrostomy tube	9 (15)	5 (8)	
Corrected gestational age at interview, weeks			
34-37	13 (21)	14 (22)	.964
38-42	31 (50)	32 (51)	

(continued)

Table II. Continued

Variables	Initial preference		P value
	Home oxygen (n = 62), n (%)	Stay in NICU (n = 63), n (%)	
>42	18 (29)	17 (27)	
Respiratory support at interview			
Room air	6 (10)	10 (16)	.358
Nasal cannula	44 (71)	42 (67)	
Noninvasive positive pressure	12 (19)	11 (17)	
Oral feeding at interview			
All oral	16 (26)	10 (16)	.202
>50% oral	12 (19)	6 (10)	
<50% oral	17 (27)	23 (37)	
All nasogastric	17 (27)	24 (38)	

IVH, intraventricular hemorrhage; NEC, necrotizing enterocolitis; PDA, patent ductus arteriosus; ROP, retinopathy of prematurity.
 BPD is defined as mild if required >21% after day of life 28, moderate if required <30% FiO₂ at 36 weeks gestational age, and severe if required ≥30% FiO₂ and/or positive pressure at 36 weeks gestational age. An infant is inborn if the birth and discharge hospital is the same. Parent and infant characteristics of the study sample, by parent home oxygen preference. The P values indicate χ^2 or Fisher exact tests for differences between proportions.

Table III. Initial preference vs stated preference at 3 months after discharge

Theoretical → postdischarge preference, n (%)	Most important reason for theoretical preference	n	Comments at 3 months after discharge	n	
Home oxygen → home oxygen, 36 (45%)	Comfort at home	23	Benefit of home outweighs difficulties	7	
	Family needs	3	Closer to support system	5	
	Cost	3	Better bonding with child	3	
	Comfort in hospital	2	Home oxygen seemed inevitable	2	
	Fear	2			
	Child doesn't like oxygen	2			
	Time off work	1			
Home oxygen → Stay in NICU, 1 (1%)	Comfort at home	1	More cords/equipment than expected	1	
	Fear	17	Not as scary as I thought it would be	10	
Stay in NICU → Home oxygen, 26 (33%)	Travel difficulty	2	Was initially intimidated by machine	7	
	Child doesn't like oxygen	2	Better bonding with child	4	
	Cost	2	NICU room air wean attempt led to frightening desaturation	1	
	Comfort at home	1			
	Comfort in hospital	1			
	Stay in NICU → Stay in NICU, 17 (21%)	Fear	8	Immobility and isolation with equipment	3
		Comfort in hospital	3	Continued fear	2
Comfort at home		2	Didn't feel trained enough	2	
Child doesn't like oxygen		2	Can wean oxygen faster in hospital	2	
Family needs		1			
Cost		1			

Comment counts do not add up to the total number of parents in a given category because some parents did not comment and others made multiple comments.