

Original Article

Barriers to Screening Infants for Retinopathy of Prematurity after Discharge or Transfer from a Neonatal Intensive Care Unit

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OBJECTIVE:

To assess neonatal intensive care unit (NICU) practices affecting screening and follow-up for retinopathy of prematurity (ROP).

METHODS:

Retrospective study of infants at risk for ROP, eligible for back transport, admitted to a regional NICU from January 1, 1999 until May 31, 2002. Patients failed to receive needed follow-up for ROP after discharge or transfer from a NICU, if we could not verify their ROP screening follow-up within 1 month.

RESULTS:

A total of 74 infants were identified to need follow-up eye care. Infants who did not receive the follow-up care had greater mean gestational age (mean SD; 30.7 ± 2.3 vs 29.6 ± 2.5 weeks, $p = 0.05$) and birth weights (mean SD; 1581 ± 366 vs 1360 ± 508 g, $p = 0.007$), compared to infants who received the recommended care. Infants transported back to the community hospital were significantly more likely to miss follow-up eye care compared to infants discharged from the regional center (relative risk 2.81, 95% confidence interval (CI) (1.09 to 7.20)). Infants not screened for ROP in the NICU had greater risk for missing follow-up care compared to infants who had their first retinal examination in the NICU (relative risk 4.25, 95% CI (1.42 to 12.73)).

CONCLUSIONS:

Infants transferred back or discharged from the NICU before ROP screening represent a high-risk group for not receiving follow-up eye care. *Journal of Perinatology* (2005) **25**, 36–40. doi:10.1038/sj.jp.7211203
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INTRODUCTION

Retinopathy of prematurity (ROP) is a retinal neovascularizing disorder affecting premature infants that potentially may lead to blindness. Timely intervention with cryotherapy¹ or laser therapy² can remarkably decrease ROP progression. Carefully timed retinal examinations of premature infants at risk for ROP can help decrease risk of vision loss.^{3,4} The usual initial examination is recommended at 42 days of age or 32 weeks postconceptional age, whichever comes later.⁵ Complications of ROP may also involve a medicolegal risk.⁶ However, appropriate delivery of retinal examinations to this group of high-risk infants following discharge from a neonatal intensive care unit (NICU) can be difficult, and many infants do not receive the recommended care.⁷

Regionalization of neonatal care has been shown to improve outcome of high-risk infants.^{8,9} In a regionalized neonatal care system, infants who are recovering and no longer require tertiary care are frequently transferred back to their community level I or II nurseries, until they are ready to be discharged home. The back transfer process may add unintentional complexity to their follow-up eye care. We conducted this study to evaluate the effects of NICU practices on the delivery of ophthalmology care for infants eligible for back transfer to a referring community hospital.

METHODS

This study is a retrospective cohort study conducted after obtaining project approval from the Institutional Review Boards at the University of Michigan Health System (UMHS) in Ann Arbor, Michigan and Foote Hospital in Jackson, Michigan. We collected demographic and clinical data during care of infants in a regional subspecialty perinatal health-care center NICU, a 37-bed unit, and in a community, level II, 10-bed unit, special care nursery (SCN) from January 1, 1999 until May 31, 2002. Level of the perinatal care was assigned according to the perinatal care guidelines of the American Academy of Pediatrics.¹⁰

Infants whose parents resided in the SCN catchment's area who were admitted to the UMHS NICU during the study period and survived to hospital discharge were potential study subjects. The SCN catchment's area was defined as the county where the SCN is located as well as areas defined by zip codes in the surrounding counties that the community hospital's business office considered as their service area.

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Study Population and Criteria for ROP Examinations

The study group included all premature infants (born at less than 36 weeks of gestation) treated in the NICU, living in the SCN catchment area, and were eligible for ROP screening examinations. We further analyzed the information obtained on infants in the study group who needed follow-up eye examinations after their discharge or transfer from the NICU. These infants were either directly discharged home, transferred back to the SCN, or transferred to the general pediatric service (PS) within the regional center. Infants whom needed the follow-up care included those infants who needed ophthalmology screening for ROP and infants who had retinal examinations in the NICU and were diagnosed with any degree of ROP or had incomplete vascularization of the retina for who the ophthalmologists recommended further follow-up. Infants who were screened for ROP in the NICU and did not need follow-up care were not included in the follow-up analysis.

We used the criteria as practiced in the NICU and the SCN over the study duration to screen premature infants (less than 36 weeks) for ROP.^{11,12} From January 1999 till September 2001, all infants with birth weight <1300 g or <30 weeks of gestation, and infants with birth weights <1800 g if they required oxygen supplementation beyond the delivery room resuscitation were eligible to have ROP screening. After September 2001, all infants with birth weights <1500 g or gestational age of ≤ 28 weeks and those infants with birth weights between 1500 and 2000 g with an unstable clinical course were considered at risk for ROP as recommended by the American Academy of Pediatrics.¹²

Data Collected

We reviewed the medical records during the NICU course of the potential study population to determine if an infant was assessed to be at risk for ROP. Demographic and clinical data were abstracted from the medical records. Among infants with birth weights that fell in the range that required clinical judgment to assess risk of ROP, the medical record was abstracted for comments regarding need for ROP screening. We also evaluated discharge summaries for recommendations regarding ophthalmology follow-up appointment, and checked scheduling records to determine whether the appointments were arranged prior to discharge from the NICU, the SCN, or the PS. The pediatric ophthalmology service at the regional center serves as the main provider to screen and treat ROP for the study population. A patient was classified as failing to receive follow-up eye care, if we could not verify their attendance at an ophthalmology appointment within 1 month of the recommended time for screening or a recommended follow-up visit after a prior retinal examination.

Analysis

Data are reported as means with standard deviations (SD) or medians with 25th and 75th quartiles as appropriate. The Wilcoxon rank sum test was used to compare the medians of continuous

variables between groups. χ^2 Fisher's exact test and relative risk ratio (RR) with 95% confidence interval (CI) were used to compare categorical data. Owing to relatively small sample size and common occurrence of the outcome, we used stratification rather than a logistic regression model since the adjusted odds ratio did not approximate the RR. Statistical significance was defined as $p \leq 0.05$. Data were managed and analyzed using the SAS Release 8.02 statistical software (SAS Institute, Inc., Cary, NC) and EPI Info 2000 Version 1.1.2. (CDC, Atlanta, GA).

RESULTS

During the study duration, 366 infants from the catchment area of the community hospital received care in the regional center. A total of 82 infants survived until hospital discharge qualified for ROP screening. Four infants had their initial screening eye examination in the NICU, their retinas were fully vascularized, and did not need further eye follow-up. In all, 29 infants had their eye examinations in the NICU but still needed further follow-up examinations following their discharge or transfer. In total, 49 infants were transferred or discharged from the NICU before having screening examinations for ROP. Of the 78 infants who required eye examinations following their discharge or transfer from the NICU, four patients underwent treatment for severe ROP during their stay in the NICU. These four patients were discharged home from the regional center and had timely attendance of the recommended follow-up appointments after discharge. They were excluded from the analysis because their condition may represent postoperation follow-up. Selected demographic and social factors of the remaining 74 patients are presented in Table 1.

We verified that 46 infants (62%) received the needed follow-up ophthalmologic evaluation within a month of the recommended appointment time. Infants who did not receive the follow-up care had greater gestational age (mean SD; 30.7 ± 2.3 vs 29.6 ± 2.5 weeks, $p = 0.05$) and birth weights (mean SD; 1581 ± 366 vs 1360 ± 508 g, $p = 0.01$) compared to infants who received follow-up care. There were no statistical differences between the two groups when comparing their race, maternal marital status, insurance coverage, or site of birth. Infants who did not receive follow-up care had significantly younger mothers (mean SD; 24.6 ± 6.4 vs 26.9 ± 5.8 years, $p = 0.04$) with a higher fraction of the women below 21 years old (32 vs 13%, $p = 0.04$).

Hospital practices that may affect screening for ROP are summarized in Table 2. In total, 43 (58%) infants were transferred back to the SCN, 23 (31%) infants were discharged home from the NICU, while eight (11%) infants were discharged home from the UMHS after their transfer to the general pediatrics service. Infants transported back to the community hospital were significantly more likely to not receive recommended eye care compared to

Table 1 Demographics Features of Infants Requiring Ophthalmology Follow-Up

Infants required ophthalmology follow-up care	Overall, <i>N</i> = 74	Did not receive follow-up care, <i>N</i> = 28	Received follow-up care, <i>N</i> = 46	<i>p</i>
<i>Gestational age</i> (weeks), mean ± SD	30.0 ± 2.5	30.7 ± 2.3	29.6 ± 2.5	0.05
<i>Birth weight</i> (g), mean ± SD	1444.1 ± 496	1581 ± 366	1360.6 ± 508	0.01
<i>Race, N (%)</i>				
Black	11 (14.9)	4 (14.3)	7 (15.2)	NS
White	59 (79.7)	23 (82.1)	36 (78.3)	
Other	4 (5.4)	1 (3.6)	3 (6.5)	
<i>Race, N (%)</i>				
Nonwhite	15 (20.3)	5 (17.9)	10 (20.7)	NS
White	59 (79.7)	23 (82.1)	36 (78.3)	
<i>Apgar scores</i>				
5 minute, median (quartile range)	7 (7, 8)	8 (7, 8)	7 (7, 8)	NS
<i>Mothers</i>				
Age (years) mean ± SD	26.0 ± 6.1	24.6 ± 6.4	26.9 ± 5.8	0.04
Less than 21 years, <i>N (%)</i>	15 (20.3)	9 (32.1)	6 (13.0)	0.04
Not married, <i>N (%)</i>	39 (52.7)	15 (53.6)	24 (52.2)	
Married, <i>N (%)</i>	35 (47.3)	13 (46.4)	22 (47.8)	NS
<i>Insurance, N (%)</i>				
Medicaid	37 (50.0)	17 (61.7)	20 (43.5)	NS
Non Medicaid	37 (50.0)	11 (39.3)	26 (56.5)	
<i>Place of birth, N (%)</i>				
Inborn	41 (55.4)	13 (46.4)	28 (60.9)	NS
Outborn	33 (44.6)	15 (53.6)	18 (39.1)	

infants discharged from UMHS (RR 2.16, 95% CI (1.05 to 4.44)). Infants discharged home from the SCN tended to have higher risk of not receiving the recommended appointments compared to infants discharged home from the NICU (RR 2.18, 95% CI (1.09 to 7.2)), but had similar risk compared to infants discharged from the PS at UMHS (RR 1.3, 95% CI (0.51 to 3.35)).

Infants who were due to have their first eye examination following their discharge from the NICU were more likely to miss their recommended eye care than infants with any degree of ROP or with incomplete vascularization diagnosed during their stay in the NICU (RR 4.25, 95% CI (1.42 to 12.73)).

In our study population, most of the transferred back infants (81%) did not have an eye examination when they were in the NICU. Among infants not screened for ROP in the NICU, those back transferred to a community hospital were slightly more likely (57%) not to receive eye screening examinations compared to those discharged from the UMHS (36%); however, this difference did not achieve statistical significance (RR 1.6, 95% CI (0.75 to 3.42)).

Among infants screened for ROP in the NICU, those back transferred to a community hospital had similar low risk to miss

their follow-up eye care compared to those discharged from the regional center (RR, 1.06, 95% CI (0.11 to 10.7)).

Written recommendation for an examination in the discharge summary (RR 0.29, 95% CI (0.18 to 0.47)) and scheduling the retinal examinations at the time of discharge from the NICU, SCN or the PS (RR 0.13, 95% CI (0.06 to 0.28)) were associated with improved rates of follow-up retinal examinations (Table 2).

Of the 28 patients who did not have an eye examination by 1 month of the recommended date, 15 patients were either examined in the ophthalmology clinic later or seen in other clinics, and did not have serious vision problems. We could not verify follow-up information on the remaining 13 patients.

DISCUSSION

Only about two-thirds of infants who needed retinal examinations after their transfer or discharge from a subspecialty NICU, received eye care within a month of the recommended time. Although this low rate highlights room for improvement, it is similar to

Table 2 Factors Related to Not Receiving ROP Follow-Up Care

Variable	Overall, <i>N</i> = 74	Did not receive follow-up care, <i>N</i> = 28	Received follow- up care, <i>N</i> = 46	Relative risk for not receiving follow-up care (95% confidence interval)	<i>p</i>
<i>Place of discharge, N (%)</i>					
Transported back (SCN)	43 (58.1)	21 (75.0)	22 (47.9)	2.16 (1.05–4.44)	0.03
Not transported back (NICU or PS)	31 (41.9)	7 (25.0)	24 (52.1)		
<i>Service at discharge,* N (%)</i>					
NICU	23 (31.1)	4 (14.3)	19 (41.3)		
PS or SCN	51 (68.9)	24 (85.7)	27 (58.7)	2.71 (1.06–6.91)	0.02
PS	8 (11)	3 (10.7)	5 (10.9)	2.16 (0.61–7.62)	NS
SCN	43 (58.1)	21 (75.0)	22 (47.9)	2.81 (1.09–7.20)	0.01
<i>ROP screening in the NICU</i>					
Screened for ROP and needed follow-up	25 (33.8)	3 (10.7)	22 (47.8)		
Not screened for ROP in NICU	49 (66.2)	25 (89.2)	24 (52.2)	4.25 (1.42–12.73)	<0.001
<i>At discharge to home</i>					
<i>Arrangement at discharge, † N (%)</i>					
Eye Appointment was arranged	50 (67.6)	6 (21.4)	44 (95.7)	0.13 (0.06–0.28)	<0.0001
Eye Appointment was not arranged	24 (32.4)	22 (78.4)	2 (4.3)		
<i>Recommending the plan in the discharge summary, N (%)</i>					
Plan mentioned in DS	59 (79.7)	15 (53.6)	44 (95.7)	0.29 (0.18–0.47)	<0.0001
Plan was not mentioned in DS	15 (20.3)	13 (46.4)	2 (4.3)		

NICU = neonatal intensive care unit, PS = pediatric service, SCN = special care nursery, DS = discharge.
 *Relative risks were calculated with discharge from the NICU as the reference.
 †Appointments were arranged by hospital personnel at discharge.

previously reported rates.⁷ In this report, we evaluated practices in the NICU that could affect the delivery of appropriate follow-up care. We evaluated the possibility that transferring the care of recovering infants between hospitals and services adds layers of complexity, and may be an unintended barrier to the delivery of appropriate ROP care. However, transport back is common and is part of regionalized perinatal services so unexpected negative consequences require countermeasures so that the global process can serve the needs of high-risk newborns.^{10,13,14}

In our study, infants transported back to the community hospital or transferred to a PS in the regional center were at a higher risk of not getting the recommended eye care compared to infants discharged home directly from the NICU. As expected, we also found significantly better follow-up rates among infants diagnosed with any degree of ROP prior to their transfer or discharge compared to those who were due to have their first eye examination after they left the NICU.

The appropriateness¹⁵ and cost effectiveness of the recommended cutoff gestational ages and birth weights to screen

for ROP¹⁶ are debated. Subsequently, variation from the institutional and national guidelines may occur based on the interpretation of the cutoff points in the screening tests. Primary care physicians taking care of the infants after their transfer or discharge from the NICU may rely on the NICU staff to make recommendations regarding appropriate eye care. Given the good parental compliance with the prescheduled ophthalmology appointments in our study population, the NICU physicians' judgment on whether an infant met the cutoff criteria for ROP screening, and actions of recommending and scheduling the appointments are important factors to improve the rate for ophthalmology follow-up. The higher birth weights and gestational ages of the infants who failed to have ophthalmology follow-up may reflect a physician bias that bigger infants had low or no risk.

In our study, most of the transferred back infants did not have an eye examination when they were in the NICU. They were transferred before meeting the age criteria for time of the first screening. The relative risk estimate for getting follow-up retinal care suggested a trend toward lower compliance among transported

back infants compared to infants discharged home from the NICU. The back transfer process per se may simply require better communication between the neonatology staff and the accepting pediatricians to ensure appropriate eye care needs are delivered. Since this study was done, more procedures were placed in the study sites to improve the rate of scheduling appointments and communicating the ROP screening plans to the primary care physicians when discharging or transferring at risk infants from the NICU.

A total of 28 premature infants did not have screening examinations and may have clinically significant untreated retinal disease. Although the risk for severe disease is greatest in infants with very low or extremely low birth weight, larger infants still have some risk.¹⁵ The incidence of Stage III or IV disease in a large recent study by Conrath et al.¹⁷ was 0.7% among infants less than 33 weeks gestation or less than 1501 g. In our study, infants of higher gestational age tended to be more likely to miss their eye follow-up.

This study has several limitations. The regional center is located approximately 1 hour from the community hospital. The pediatric retinal specialists serve a large geographical area; however, infants could receive eye care at other centers or have moved away from the area shortly after hospital discharge. Exploring the role of the distance of the ophthalmology clinic as a barrier to ROP screening is an important question, but it was not feasible in our retrospective study. We doubt that the distance was a barrier in this study population given the patients' excellent compliance with prearranged appointments.

Having the eye examinations within a month of the recommended time for follow-up would not be labeled appropriate follow-up for ROP. These infants need to be evaluated within a week of the recommended time. However, appointments are frequently rescheduled, and some parents needed reminders when they missed the appointment even when appropriate steps were taken by the discharging hospital.⁷ Since our goal was to evaluate for NICU practices related to not getting follow-up, we defined not receiving the follow-up care within a month of the recommended time as failure to receive care.

We reason that arranging for the retinal examination appointments before infants leave the NICU, would improve the ROP screening process. Our study shows that failure to make these arrangements is associated with substantial failures to receive needed eye care. Scheduled appointments may also be helpful to the primary care physicians who rely on the neonatologists' interpretation of the significance of the ROP weight and gestational age cutoff points and the significance of the clinical course that the infant had in the NICU. Our findings lend support for the AAP's recommendations emphasizing the importance of arranging follow-up eye examinations prior to transfer or discharge of infants with or at risk for ROP.¹²

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