

Adherence to Pediatric Ophthalmology Follow-Up After Completion of Retinopathy of Prematurity: A Retrospective Review

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Purpose: Retinopathy of prematurity is a leading cause of preventable childhood vision loss, and infants remain at risk of long-term ocular complications even after ROP screening concludes. However, adherence to recommended pediatric ophthalmology follow-up after ROP screening completion is not well characterized. This study aimed to evaluate adherence to pediatric ophthalmology follow-up visits after completion of ROP screening and identify factors associated with loss to follow-up in a tertiary care setting.

Patients and Methods: We performed a retrospective chart review of premature infants eligible for ROP screening at a single urban academic center between January 2018 and December 2021. All infants were screened by a single vitreoretinal specialist, with pediatric ophthalmology follow-up recommended at the time of ROP clearance within 4 to 6 months. The primary outcome was a documented follow-up visit with pediatric ophthalmology. Demographic, perinatal, and ROP-related factors were compared between those who did and did not follow up, using univariate and multivariate logistic regression analyses.

Results: Of 475 eligible infants, 223 (46.9%) completed at least one pediatric ophthalmology follow-up appointment. In multivariate analysis, outpatient discharge from ROP care (OR 0.66, 95% CI 0.45–0.97, $p = 0.035$) and higher gestational age (OR 0.92, 95% CI 0.84–1.00, $p = 0.041$) were significantly associated with lower adherence to follow-up. Timing of follow-up (pre-COVID-19 vs COVID-19 era), insurance status, race, ethnicity, number of comorbidities, and distance to the clinic were not significantly associated with follow-up adherence.

Conclusion: Fewer than half of infants completed their recommended pediatric ophthalmology follow-up appointments after ROP screening completion. Lower adherence among infants discharged from outpatient ROP care and those born at higher gestational ages highlights a critical care transition from ROP screening to pediatric ophthalmology. Interventions such as scheduling follow-up appointments prior to discharge and improving caregiver education may enhance continuity of care and reduce preventable vision loss in this vulnerable population.

Plain Language Summary:

Why was this study done?

Infants born prematurely (before their due date) often require eye exams to check for retinopathy of prematurity (ROP), a condition that can lead to blindness. Even after ROP screening is completed and acute disease risk decreases, these infants remain at risk for other vision problems related to prematurity and prior ROP, such as strabismus (eye misalignment), amblyopia (lazy eye), and refractive errors needing glasses. Clinical guidelines recommend a pediatric ophthalmology visit within 4 to 6 months after screening, but it is unclear how often families return.



What did the researchers do and find?

We reviewed the medical records of 475 infants who underwent ROP screening at one academic medical center in New York City between 2018 and 2021. Fewer than half (47%) of infants attended a pediatric ophthalmology visit after screening ended. Two key factors were associated with lower follow-up:

- Setting: Infants who completed ROP screening as outpatients were less likely to return than those who completed ROP screening while still in the neonatal intensive care unit (NICU).
- Gestational age: Infants born closer to full term (less premature) were also less likely to return.

Other factors, including race, ethnicity, insurance type, number of medical conditions, and whether follow-up was recommended before or during the COVID-19 pandemic, were not significantly linked to follow-up.

What do these results mean?

Many infants born prematurely do not receive recommended eye care after ROP screening. Simple steps such as scheduling appointments before discharge and providing parents with clear guidance may ensure timely detection of vision problems and reduce preventable vision loss.

Keywords: continuity of patient care, infant, premature, visual development, care transitions

Introduction

Retinopathy of prematurity (ROP) is a major global health concern and a leading cause of preventable blindness in premature infants.¹ It results from abnormal vascular development in incompletely vascularized retinas, with risk strongly tied to low birth weight and gestational age.² In severe cases, ROP can progress to retinal detachments (stages 4 and 5), resulting in irreversible vision loss if left untreated.²

Screening programs aim to detect ROP before progression to advanced stages, with serial eye examinations typically performed every 1–3 weeks until the retina is fully vascularized or disease regresses after treatment.² When advanced disease is identified, treatment with laser panretinal photocoagulation (PRP) of the retina or intravitreal anti-vascular endothelial growth factor (VEGF) therapy may be initiated to reduce the risk of retinal detachment and vision loss. Depending on the practice setting, these examinations are performed by vitreoretinal specialists or pediatric ophthalmologists.³ In the United States, approximately 14,000 infants are diagnosed with ROP each year.⁴ Recent national data demonstrate that the incidence of ROP among at-risk premature infants increased from 4.4% in 2003 to 8.1% in 2019, underscoring the growing population of infants at risk for ROP-related visual morbidity.⁵

Even after spontaneous regression or successful treatment, infants with a history of ROP or prematurity remain at increased risk for long-term ocular complications including retinal detachment, glaucoma, amblyopia, strabismus, and refractive errors (myopia, hypermetropia, astigmatism). These risks arise from a combination of ROP-related retinal changes and the broader effects of prematurity on visual development.^{6,7} The Early Treatment for Retinopathy of Prematurity (ETROP) study highlighted these risks by following infants with “high-risk prethreshold” ROP, a disease stage not yet meeting traditional treatment criteria but highly likely to progress.⁸ Among these infants, 1.9% developed cataracts by 6 months of age.⁹ By age 3, nearly 43% of treated eyes developed ≥ 1.00 D of astigmatism; by ages 4 to 6, 60–70% had myopia.^{10,11} By age 6, 1.67% of children had glaucoma and 42.2% had strabismus.^{12,13}

Adherence to follow-up during active ROP screening, whether in the neonatal intensive care unit (NICU) or outpatient setting, has been well studied and is generally high.^{14,15} In contrast, far less is known about adherence to recommended pediatric ophthalmology visits once ROP screening concludes, when care transitions from retinal disease surveillance to monitoring visual development and amblyopia risk.¹⁶ Several barriers to follow-up during active ROP screening have been identified, including limited access to care, competing medical needs, poor health literacy, language barriers, and poor parental social support and mental health.^{15,17–21} Lower birth weight has also been associated with poorer outpatient follow-up during active ROP screening.²²

Because infants with a history of ROP or prematurity remain at risk for visual impairment beyond screening completion, ongoing ophthalmic surveillance is recommended. Accordingly, the 2018 joint policy statement from the American Academy of Pediatrics (AAP), American Association of Pediatric Ophthalmology and Strabismus (AAPOS),

American Academy of Ophthalmology (AAO), and American Association of Certified Orthoptists (AACO) recommends that all infants who undergo ROP screening, regardless of whether treatment was required, be evaluated by a pediatric ophthalmologist within 4 to 6 months of completing ROP care.² Unlike ROP screening examinations, these visits focus on identifying ocular conditions affecting visual development rather than monitoring retinal vascularization.

During active screening, adherence is generally high due to frequent scheduled examinations, clear perceived urgency and dedicated ROP coordinators who help ensure appointments are scheduled and attended. However, this structured support often ends once ROP screening concludes, creating a point of care discontinuity in which responsibility shifts from coordinated retinal surveillance to family-driven pediatric ophthalmology follow-up.

Few studies have examined adherence to pediatric ophthalmology follow-up during this post-screening care transition. While vitreoretinal specialists primarily manage retinal disease surveillance, pediatric ophthalmologists assess a wide range of ocular disorders, often without the coordinated support systems to encourage follow-up present during active ROP screening.^{15,23} A recent multicenter study showed that only 53.5% of neonates completed pediatric ophthalmology follow-up after ROP screening completion.¹⁴ The present study aims to evaluate adherence to recommended pediatric ophthalmology follow-up after completion of ROP screening and to identify demographic and clinical factors associated with loss to follow-up using a retrospective review of medical records. By focusing on this understudied transition period, this work seeks to identify modifiable gaps in care continuity that may contribute to preventable visual impairment in premature infants.

Materials and Methods

Ethics

This study was approved by the institutional review board at Columbia University Irving Medical Center under protocol number IRB-AAAU5808, approved on 03/17/2023. All patient data were de-identified to ensure confidentiality and the study was conducted in accordance with Health Insurance Portability and Accountability Act regulations to protect patient privacy and maintain compliance with ethical standards. This study was conducted in accordance with the ethical principles of the Declaration of Helsinki.

Study Design and Setting

This study was a retrospective chart review. Electronic medical records of infants who underwent ROP screening at a single urban academic medical center between January 1, 2018, and December 31, 2021 were identified and reviewed. No participants were enrolled, and no prospective follow-up, longitudinal tracking or direct contact with patients or families was performed. All variables and outcomes were ascertained retrospectively from documentation available in the electronic medical record.

Inclusion criteria were infants eligible for ROP screening who completed screening at our institution and had a documented recommendation for pediatric ophthalmology follow-up. Infants were excluded if ROP screening or pediatric ophthalmology care occurred at an outside institution. Screening and follow-up adhered to guidelines from the AAP, AAO, AAPOS, and AACO.²

This study was conducted at NewYork-Presbyterian Morgan Stanley Children's Hospital, a large urban tertiary academic medical center with a Level IV neonatal intensive care unit (NICU). The MSCH NICU is a 70-bed unit that provides care to a high volume of critically ill and preterm infants, including those born at very low gestational ages and with complex medical and surgical needs. Infants eligible for ROP screening are routinely evaluated according to national guidelines. ROP screening at this institution is performed by a dedicated vitreoretinal specialist, with pediatric ophthalmology services available on-site for follow-up care. The center was selected because it provides continuity of ROP screening and pediatric ophthalmology follow-up within a single integrated health system, allowing assessment of care transitions after completion of ROP screening.

Electronic medical records were reviewed by study investigators (SXX, NH) using a standardized data abstraction form. Data were accessed through the institutional electronic health record system and included demographic, perinatal, and ophthalmic data documented during routine clinical care.

ROP Screening and Clearance Protocol

This section is included to describe the standardized clinical screening and discharge workflows in place during the study period and to contextualize how follow-up recommendations were generated. A single vitreoretinal specialist monitored infants with serial dilated fundus exams every 1–3 weeks until meeting criteria for safe discontinuation of ROP screening, as defined by the 2018 AAP/AAO/AAPOS/AACO joint statement. These included: (1) full retinal vascularization in close proximity to the ora serrata for 360°; (2) Zone III vascularization without prior Zone I or II disease; (3) postmenstrual age (PMA) of 45 weeks without type 1 ROP; or (4) regression of ROP without residual abnormal vascular tissue.² Retinal vascularization normally progresses from zone I to zone III and is typically complete by 40 weeks' gestational age in full term infants. Infants who did not require treatment continued routine clinical screening until they met these standard criteria. Those treated with laser photocoagulation were monitored until disease regression and scar stabilization, while those receiving anti-VEGF therapy were followed until vascularization was complete. During screening, the stage of ROP was documented at each visit as follows: Stage 0, incomplete vascularization; Stage 1, demarcation line at edge of vascularization; Stage 2, ridge at edge of vascularization; Stage 3, extraretinal neovascular proliferation; Stage 4, partial retinal detachment; Stage 5, total retinal detachment.

Pediatric Ophthalmology Referral and Follow-Up Process

Once an infant met ROP screening discharge criteria, the vitreoretinal specialist referred them to a pediatric ophthalmologist within the same institution, typically for at least one follow-up within 6 months to assess visual development, amblyopia risk and other ocular conditions. Infants discharged from the NICU on a weekday had their ophthalmology follow-up appointments scheduled by the NICU staff prior to discharge. Families of infants discharged on weekends were instructed to schedule follow-up independently. For infants completing ROP screening as outpatients, after discharge from the NICU, families were offered the opportunity to schedule pediatric ophthalmology follow-up at checkout from the final ROP screening visit in the vitreoretinal clinic. In cases of severe ROP requiring treatment, ROP coordinators followed up with families to ensure completion of the first pediatric ophthalmology appointment. All infants who qualified for ROP screening, regardless of their ROP stage, were referred for an evaluation with pediatric ophthalmology. While most were recommended to follow up in 6 months, the exact timing varied based on individual clinical findings and was noted in the vitreoretinal specialist's discharge plan (typically ranging from 4 to 6 months). Follow-up completion was defined as any documented visit with a pediatric ophthalmologist in the medical record after the final ROP visit with the vitreoretinal specialist, regardless of whether the visit occurred within the recommended timeframe. The flow of infants from ROP screening to pediatric ophthalmology follow-up is summarized in [Figure 1](#).

Study Variables

Study variables included demographic and social variables (sex, race and ethnicity, insurance type, primary language, distance traveled to the eye clinic), perinatal factors (gestational age, birth weight, length of NICU stay, number of comorbidities, multiple births), and ROP disease characteristics (highest ROP stage reached during screening, whether treatment was provided, and inpatient or outpatient discharge from ROP services). Distance to the eye clinic was calculated using the patient's recorded home zip code at the time of ROP screening and the clinic address. Number of comorbidities was determined by issues documented in the NICU discharge summary, including those managed during the NICU stay (ie, hyperbilirubinemia, respiratory distress syndrome) and those necessitating post-discharge follow-up (ie, inguinal hernia, small patent foramen ovale). No data were collected through direct contact or follow-up interviews with families.

Outcomes

The primary outcome was adherence to the initial pediatric ophthalmology follow-up visit, defined in this study as any documented visit with a pediatric ophthalmologist after discharge from ROP screening, regardless of whether the visit occurred within the recommended 4–6-month timeframe. This pragmatic definition was chosen to capture real-world engagement with follow-up care in a retrospective dataset and to minimize misclassification related to variability in

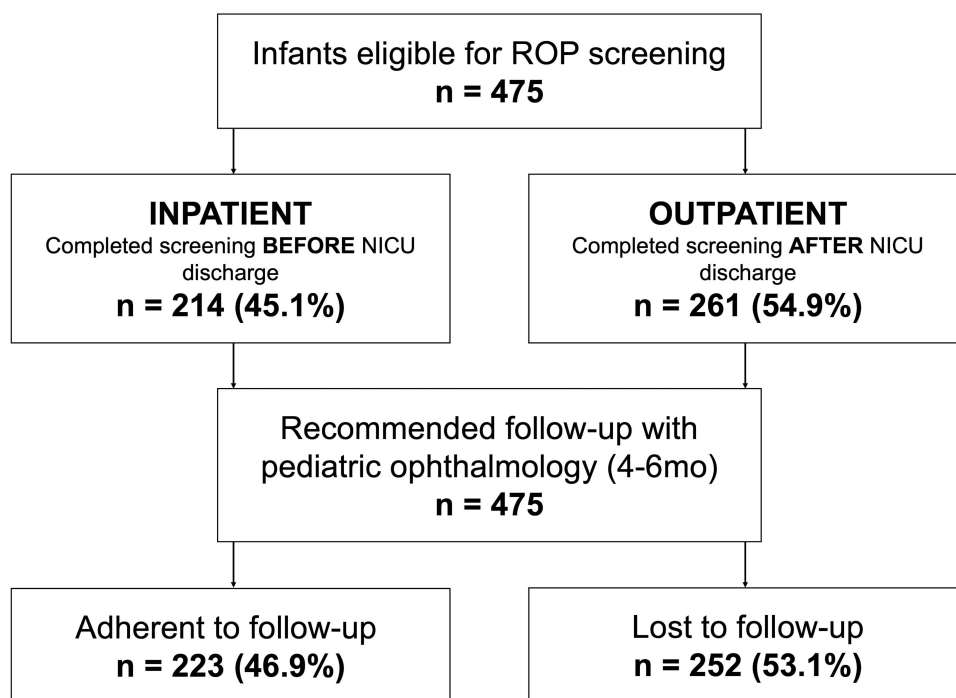


Figure 1 Study sample and follow-up adherence. Flowchart of infants eligible for retinopathy of prematurity (ROP) screening who underwent examination by a vitreoretinal specialist (top row). Screening completion is shown as inpatient (left; completed ROP screening before neonatal intensive care unit (NICU) discharge) or outpatient (right; completed ROP screening after NICU discharge in an outpatient setting) (second row). All infants were recommended pediatric ophthalmology follow-up within 4–6 months (third row). Final outcomes are adherence (left) or loss to follow-up (right) (fourth row). Bold text denotes care setting, timing relative to NICU discharge, and sample sizes at each stage.

recommended follow-up intervals and scheduling constraints. Secondary outcomes included identifying clinical and sociodemographic factors associated with follow-up adherence, as well as evaluating whether follow-up rates differed before and during the COVID-19 pandemic. Factors analyzed included gestational age, birth weight, length of NICU stay, number of comorbidities, ROP severity, multiple births, discharge setting (inpatient vs outpatient), and timing of recommended pediatric ophthalmology follow-up, categorized as pre-COVID (recommended follow-up between 1/1/2018 and 2/29/2020) and post-COVID (recommended to follow-up between 3/1/2020 and 12/31/2021).

Statistical Analysis

The final study sample was described with counts and percentages for categorical variables and means and standard deviations for numerical variables. Infants with and without documented pediatric ophthalmology follow-up in the medical record were compared with chi-squared contingency tests for categorical variables and Student's t-tests for numerical variables. Bonferroni correction was applied to univariate analyses to account for multiple comparisons. A backward stepwise logistic regression approach was used to identify independent factors associated with follow-up adherence while accounting for correlations among demographic and clinical variables. Results of logistic regression were described with odds ratios and 95% confidence intervals. A p-value of 0.05 was selected as the threshold for statistical significance. All analyses were conducted using Python.²⁴ Missing data were assessed for all variables and were limited primarily to race and ethnicity, which were categorized as “unknown” when not documented. The primary outcome and key clinical predictors were complete. A complete-case analysis was performed without imputation.

Results

A total of 475 electronic medical records met inclusion criteria and were included in the final analysis. 52.6% were male, 36.4% identified as Hispanic and 54.3% were insured through Medicaid. Mean gestational age was 28.8 ± 2.5 weeks, and mean birth weight was 1.10 ± 0.3 kg. Only 11 infants (2.3%) required treatment with either PRP or intravitreal anti-

VEGF injection, while over half (58.9%) were found to have no active ROP (designated “stage 0”) at any examination. Additional demographic and clinical characteristics are detailed in [Table 1](#).

For this study, follow-up was defined as completion of at least one pediatric ophthalmology visit, regardless of whether it occurred within the recommended 6-month period. By this definition, 223 infants (46.9%) followed up (mean

Table 1 Overall Characterization of Final Study Sample

Variable	Infants (n=475)
Sex, n, (%)	
Male	250 (52.6)
Female	225 (47.4)
Gestational age (weeks), mean \pm SD	28.8 \pm 2.5
Birth weight (kg), mean \pm SD	1.10 \pm 0.3
Length of NICU stay (days), mean \pm SD	73.1 \pm 41.0
Number of comorbidities, mean \pm SD	4.0 \pm 3.1
Highest ROP stage documented, n, (%)	
0	280 (58.9)
I-3	195 (41.1)
ROP treatment provided, n, (%)	11 (2.3)
Discharge from ROP services as an outpatient, n, (%)	261 (54.9)
Multiple births, n, (%)	196 (41.3)
Race, n, (%)	
White	264 (55.6)
Black	103 (21.7)
Asian	17 (3.6)
Other	14 (2.9)
Unknown	77 (16.2)
Ethnicity, n, (%)	
Hispanic	173 (36.4)
Non-Hispanic	225 (47.4)
Unknown	77 (16.2)
Insurance type, n, (%)	
Private	182 (38.3)
Medicare	29 (6.1)
Medicaid	258 (54.3)
Uninsured	6 (1.3)

(Continued)

Table 1 (Continued).

Variable	Infants (n=475)
English as primary language, n, (%)	316 (66.5)
Distance to eye clinic (km), mean \pm SD	48.6 \pm 291.2
Recommended follow-up during the COVID-19 era ^a , n, (%)	274 (57.7)
Adherence to follow-up ^b , n, (%)	223 (46.9)

Notes: ^aRecommended follow-up during the COVID-19 era was defined as having a recommended follow-up date on or after March 1, 2020. ^bAdherence to follow-up was defined as any documented encounter with a pediatric ophthalmologist in the medical chart after discharge from ROP services with the vitreoretinal specialist, regardless of whether the visit occurred within the recommended follow-up period.

Abbreviations: NICU, neonatal intensive care unit; ROP, retinopathy of prematurity; SD, standard deviation; km, kilometer.

interval between ROP screening completion and the first documented pediatric ophthalmology visit was 8.73 ± 5.12 months), while 252 infants (53.1%) were lost to follow-up.

Univariate Analysis

Infants who attended their pediatric ophthalmology follow-up visits differed significantly from those who did not in several key variables in the univariate analysis. Compared to those lost to follow-up, infants who returned for follow-up had significantly lower gestational age (28.5 ± 2.6 weeks vs 29.1 ± 2.3 weeks, $p = 0.0033$), lower birth weight (1.05 ± 0.4 kg vs 1.14 ± 0.3 kg, $p = 0.0021$), longer NICU stays (80.5 ± 42.1 days vs 66.7 ± 38.9 days, $p < 0.001$), and a higher number of comorbidities (4.5 ± 3.1 vs 3.6 ± 3.0 , $p = 0.0018$). These associations remained statistically significant after Bonferroni correction, as detailed in [Table 2](#).

Table 2 Demographic and Clinical Factors of Infants by Adherence with Pediatric Ophthalmology Follow-Up

Variable	Adherent to Follow-Up ^a (n=223)	Not Adherent to Follow-Up (n=252)	p-value
Sex, n, (%)			0.69
Male	120 (53.8)	130 (51.6)	
Female	113 (46.2)	122 (48.4)	
Gestational age (weeks), mean \pm SD	28.5 \pm 2.6	29.1 \pm 2.3	0.0033 ^{b,c}
Birth weight (kg), mean \pm SD	1.05 \pm 0.4	1.14 \pm 0.3	0.0021 ^{b,c}
Length of NICU stay (days), mean \pm SD	80.5 \pm 42.1	66.7 \pm 38.9	<0.001 ^{b,c}
Number of comorbidities, mean \pm SD	4.5 \pm 3.1	3.6 \pm 3.0	0.0018 ^{b,c}
Highest ROP stage documented, n, (%)			0.041 ^b
0	120 (53.8)	160 (63.5)	
1-3	103 (46.2)	92 (36.5)	
ROP treatment provided, n, (%)	8 (3.6)	3 (1.2)	0.15
Discharge from ROP services as an outpatient, n, (%)	110 (49.3)	151 (59.9)	0.026 ^b

(Continued)

Table 2 (Continued).

Variable	Adherent to Follow-Up ^a (n=223)	Not Adherent to Follow-Up (n=252)	p-value
Multiple births, n, (%)	79 (35.4)	117 (46.4)	0.019 ^b
Race, n, (%)			0.076
White	126 (56.5)	138 (54.8)	
Black	42 (18.8)	61 (24.2)	
Asian	10 (4.5)	7 (2.8)	
Other	11 (4.9)	3 (1.2)	
Unknown	34 (15.2)	43 (17.1)	
Ethnicity, n, (%)			0.73
Hispanic	85 (38.1)	88 (34.9)	
Non-Hispanic	104 (46.6)	121 (48)	
Unknown	34 (15.2)	43 (17.1)	
Insurance, n, (%)			0.26
Private	81 (36.3)	101 (40.1)	
Medicare	12 (5.4)	17 (6.7)	
Medicaid	129 (57.8)	129 (51.2)	
Uninsured	1 (0.4)	5 (2)	
English as primary language, n, (%)	150 (67.3)	166 (65.9)	0.82
Distance to eye clinic (km), mean ± SD	39.0 ± 277.8	57.1 ± 302.9	0.50
Recommended follow-up during the COVID-19 era ^d , n, (%)	127 (57.0)	147 (58.3)	0.83

Notes: ^aAdherence to follow-up was defined as any documented encounter with a pediatric ophthalmologist in the medical chart after discharge from ROP services with the vitreoretinal specialist, regardless of whether the visit occurred within the recommended follow-up period. ^bValues indicate $p < 0.05$. ^cValues that remained significant after Bonferroni correction. ^dRecommended follow-up during the COVID-19 era was defined as having a recommended follow-up date on or after March 1, 2020.

Abbreviations: NICU, neonatal intensive care unit; ROP, retinopathy of prematurity; SD, standard deviation; km, kilometer.

Other variables, including multiple births, highest ROP stage documented, and discharge from ROP services as an outpatient initially showed associations with follow-up adherence but did not remain significant after Bonferroni correction. No other demographic or clinical variables were significantly associated with follow-up adherence, including whether the date of recommended follow-up occurred before or during the COVID-19 pandemic.

Multivariate Logistic Regression Analysis

In the multivariate analysis using backward stepwise logistic regression (Table 3), higher gestational age was significantly associated with lower follow-up adherence (OR 0.92, 95% CI 0.84–1.00, $p = 0.041$). Discharge from ROP services as an outpatient was also significantly associated with lower follow-up adherence (OR 0.66, 95% CI 0.45–0.97, $p = 0.035$). This suggests that infants discharged from ROP services as outpatients were less likely to return for pediatric ophthalmology follow-up. Multiple births ($p = 0.081$) showed a trend toward association with lower follow-up adherence. Additional variables, including number of comorbidities and race, were included in the final model but did not reach statistical significance.

Table 3 Backward Stepwise Logistic Regression for Adherence to Follow Up in the Final Study Sample

Variable	Odds Ratio (95% CI)	p-value
Gestational age (weeks)	0.92 (0.84–1.00)	0.041 ^a
Number of comorbidities	1.06 (0.99–1.14)	0.10
Discharge from ROP services as an outpatient	0.66 (0.45–0.97)	0.035 ^a
Multiple births	0.71 (0.48–1.04)	0.081
Race (reference = White)		
Black	0.67 (0.41–1.07)	0.096
Asian	1.63 (0.57–4.63)	0.36
Other	3.46 (0.92–13.0)	0.067
Unknown	0.76 (0.45–1.28)	0.30

Note: ^aValues indicate $p < 0.05$.

Abbreviations: ROP, retinopathy of prematurity; CI, confidence interval.

Discussion

This study evaluated adherence to pediatric ophthalmology follow-up among infants screened for ROP as they transitioned from care by ROP specialists. Unlike prior studies focused on adherence during active ROP surveillance, this study isolates the post-screening transition period, when structured screening systems are no longer in place. Ongoing monitoring by pediatric ophthalmologists is essential for these children, who are thought to be at a higher risk for long-term visual complications associated with ROP and prematurity. Although guidelines recommend a pediatric ophthalmology visit within 6 months of ROP clearance, fewer than half (46.9%) of infants at our institution returned for any visit after discharge from ROP services. This finding is similar to the 53.7% rate reported in a multicenter study in California, but markedly lower than the near-universal adherence observed during active ROP screening (93.6% in California, 89.6% in Taiwan).^{15,23} Because many of these conditions are asymptomatic early in life, delayed follow-up may result in missed opportunities for timely intervention.

One potentially modifiable factor contributing to this drop-off in care was how appointments were scheduled. At our institution, infants discharged from the NICU on a weekday typically had their pediatric ophthalmology appointment scheduled by hospital staff. In contrast, families whose infants were discharged from ROP services in an outpatient setting were simply advised to make the follow-up appointment themselves during checkout and had to schedule the follow-up appointment on their own before leaving the clinic. Our analysis found that these families were significantly less likely to complete their follow-up appointment, suggesting that assigning a specific appointment with a date and time, rather than leaving scheduling up to the caregiver, may improve adherence. Caregivers may perceive less urgency after ROP resolution, particularly if unaware of the long-term ocular risks of prematurity.^{6,19}

Additionally, infants discharged from ROP services in the NICU often receive more structured communication and nurse-led education, whereas families seen in outpatient settings may receive less comprehensive guidance due to high patient volumes in ophthalmology clinics. Prior studies have shown that providing educational materials about ROP and emphasizing the importance of follow-up significantly enhances the perceived value of follow-up care and improves active ROP screening compliance.^{20,25} Similar educational materials could be developed and implemented to improve pediatric ophthalmology follow-up adherence and ensure caregivers are fully informed of the ongoing need for monitoring. The use of patient navigators and social workers has also been shown to increase adherence to follow-up care in the literature for other ophthalmic conditions, such as glaucoma, and might have a role in improving the adherence of premature infants, especially those discharged from ROP screening after they have left the NICU.^{26,27}

The multivariate analysis also demonstrated that infants with lower gestational age were more likely to follow up with pediatric ophthalmology. In addition, in the univariate analysis, infants with low birth weight, higher number of comorbidities, and prolonged NICU stay were more likely to adhere to follow-up with pediatric ophthalmology. Although these variables did not reach statistical significance in the multivariate model, they highlight areas for further investigation. These results align with previous studies which found that infants with longer NICU stays and more days on oxygen had higher follow-up compliance after NICU discharge and that infants at risk for ROP with lower mean gestational age and lower birth weights were more likely to adhere to outpatient follow-up during active ROP screening.^{21,28} Higher acuity infants may have better adherence because their frequent medical needs keep families more engaged with follow-up care.

There was also a trend toward lower adherence among infants from multiple births, suggesting that the additional medical needs and family burdens associated with multiparity may contribute to reduced adherence. This finding aligns with a previous study, which found lower NICU follow-up adherence among multiple-gestation infants, attributing this to the increased stress on family resources when caring for multiple sick newborns.²⁸ A study of patients with cerebral palsy similarly found that mothers with multiple children cited challenges in keeping appointments due to the competing demands of caregiving, including minimizing siblings' time in the hospital.²⁹

Race, ethnicity, insurance status, and distance to clinic were not significantly associated with adherence. A multicenter study in California similarly found no significant associations between race and ethnicity with adherence to pediatric ophthalmology follow-up but did report that public insurance was associated with lower adherence.¹⁵ Our institution's affiliated pediatric ophthalmology clinics accept public insurance, which may explain the difference in our findings. Distance from the infant's home zip code to the clinic was not significantly correlated with adherence, possibly due to New York City's extensive public transportation, which mitigates transportation barriers found in other studies.^{28,29}

Nickell et al recently found that infants with stage 1 or milder ROP tend to have a rate of long-term sequelae, such as amblyopia, refractive error, and strabismus, that is much closer to the general population.³⁰ The authors argue that these infants could potentially be monitored through other safety nets, such as school screenings or routine pediatrician visits.³⁰ Given the workforce shortage in pediatric ophthalmology, optimizing screening processes could reduce clinic burden. However, AAP guidelines still recommend follow-up for all ROP-screened infants and many institutions, including ours, continue to follow these recommendations.³¹ Furthermore, our data demonstrate that poor follow-up adherence is not limited to infants with low-stage ROP, underscoring the value of our study and the need for continued efforts to identify barriers to follow-up.

Because our study sample included infants recommended to follow up both before and during the COVID-19 pandemic, we conducted an additional analysis to assess its impact. We found no significant difference in follow-up rates between the pre-COVID (Jan 2018 – Feb 2020) and post-COVID (Mar 2020 – Dec 2021) periods, suggesting that the pandemic did not substantially affect pediatric ophthalmology follow-up adherence in our sample. This finding reinforces the validity of our original analysis, indicating that follow-up rates remained low regardless of the pandemic.

Limitations and Future Directions

This study has limitations. Because this was a retrospective chart review, follow-up was assessed solely based on documentation within the electronic medical record, and care received outside the institution may not have been captured, potentially underestimating true follow-up rates. Additionally, selection of participants from a single tertiary academic medical center may introduce selection bias, which may limit generalizability.

In our sample, traditional barriers such as insurance coverage and distance to care were not significantly associated with poor adherence. This may reflect institutional factors, as the pediatric ophthalmology service accepts all hospital insurance plans and offers care for uninsured children. However, this study focused primarily on patient-level factors, and unmeasured health system characteristics such as clinic capacity, scheduling availability, and staffing constraints may also influence follow-up adherence but could not be directly assessed in this retrospective review.

Follow-up adherence was defined broadly as any documented pediatric ophthalmology visit after completion of ROP screening, regardless of timing. Although this pragmatic definition may overestimate clinically timely follow-up, it was

chosen to reflect real-world patterns of care engagement. Similarly, the backward stepwise regression approach was exploratory in nature and may be subject to model instability and overfitting. As such, identified associations should be interpreted cautiously and not as causal.

As with all retrospective studies, this analysis is subject to bias from incomplete documentation and missing data; however, missingness was limited primarily to sociodemographic variables, and key clinical predictors and outcomes were complete for the study sample. Multicenter studies are recommended to validate these findings and improve generalizability. Future studies should prospectively evaluate these interventions to determine their effectiveness in improving follow-up adherence and reducing preventable vision loss. In addition, future research should explore long-term ocular outcomes of infants who fail to follow up, to better understand how to tailor recommendations for those at highest risk of ocular disease.

Conclusion

In conclusion, this study identified key factors influencing follow-up adherence in ROP-screened infants transitioning to pediatric ophthalmology care. Fewer than half of infants completed a recommended pediatric ophthalmology visit after ROP screening, with lower adherence observed among infants discharged from outpatient ROP care and those born at higher gestational ages. Follow-up adherence is influenced by multiple factors and understanding them is key to designing interventions that improve post-ROP care and reduce long-term vision risks in premature infants. Simple interventions, such as scheduling follow-up appointments before discharge and enhancing caregiver education, may improve adherence. Future studies should prospectively evaluate these interventions to determine their effectiveness in improving follow-up adherence and reducing preventable vision loss. In addition, future research should explore long-term ocular outcomes of infants who fail to follow up, to better understand how to tailor recommendations for those at highest risk of ocular disease.

Abbreviations

AAP, American Academy of Pediatrics; AAPOS, American Association of Pediatric Ophthalmology and Strabismus; AAO, American Academy of Ophthalmology; AACO, American Association of Certified Orthoptists; CI, confidence interval; D, diopter; ETROP, Early Treatment for Retinopathy of Prematurity; HIPAA, Health Insurance Portability and Accountability Act; IRB, Institutional Review Board; NICU, neonatal intensive care unit; OR, odds ratio; PMA, postmenstrual age; PRP, panretinal photocoagulation; ROP, retinopathy of prematurity; SD, standard deviation; VEGF, vascular endothelial growth factor.

Data Sharing Statement

All data supporting the findings of this study are available from the corresponding author Sonali Dalal Talsania upon reasonable request. The study adhered to institutional and ethical guidelines for data privacy and research conduct.

Ethics Approval and Informed Consent

This study was approved by the Institutional Review Board of Columbia University Irving Medical Center (IRB-AAAU5808) on 3/17/2023. Given the retrospective nature of the study and use of de-identified data, the requirement for informed consent was waived by the IRB.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically

reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors declare that they have no competing financial or non-financial interests related to the content of this manuscript.

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