Area deprivation index predicts follow-up in retinopathy of prematurity

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BACKGROUND The risk of progression or development of retinopathy of prematurity (ROP) persists after hospital discharge, and successful outpatient follow-up requires extensive coordination. This study aimed to evaluate the impact of social drivers of health on attendance at outpatient ROP examinations using an area deprivation index (ADI), a census-based composite score indicating neighborhood affluence and opportunity.

METHODS The medical records of infants evaluated for ROP between January 1, 2016, and May 1, 2023, at the University of Chicago Medical Center were reviewed. The following demographic data were extracted from the record: birth weight, gestational age, sex, race, ethnicity, and insurance status. ADI was calculated based on available maternal demographic data. Univariate and multivariable logistic regressions were performed to evaluate predictors of missed first outpatient appointment.

RESULTS A total of 540 infants who were evaluated during the study period required additional ROP examinations after discharge. Of these, 174 patients (32%) missed their first outpatient appointment, and 14 (2.6%) did not complete their ROP evaluations. For each level increase in ADI, adjusted odds of missing initial follow-up increased by 17% (95% CI, 7%-28%; $P < 0.001$). Although race/ethnicity was associated with missed follow-up on unadjusted analyses, the apparent relationship became nonsignificant after adjusting for ADI (OR = 1.21; 95% CI, 0.51-2.88; $P = 0.663$).

CONCLUSIONS In our study cohort, patients with high ADI scores, indicating neighborhood disadvantage, were at higher risk of missed outpatient follow-up during the acute phase of ROP evaluation. (J AAPOS 2025;29:104227)

Retinopathy of prematurity (ROP) can lead to retinal detachment and poor visual outcomes if not recognized in a timely fashion. Surprisingly, despite advances in prevention, screening, and treatment of ROP, this condition remains the leading cause of legal blindness among children in the United States.[1] ROP care is a litigious area of ophthalmology, not only because of risk of permanent visual impairment but also because of complexities involved in coordinating examinations following discharge.[2] A retrospective study by Mahmud and colleagues[3] determined that public insurance in certain hospital systems was a significant risk factor for insufficient long-term follow-up with pediatric ophthalmology following ROP screening, despite a 94% rate of follow-up to complete retinal vascularization among all study participants. There was no association between follow-up and other social factors, such as household income.[3] Our study aimed to explore potentially modifiable risk factors to delayed follow-up that may contribute to disparate outcomes in an urban population. Beyond race, ethnicity, and insurance type, composite scores such as the area deprivation index (ADI), derived from census indicators, attempt to capture the many social and structural drivers of health outcomes in order to better assess health disparities on a population level.[4,5] In this study, we used ADI to investigate the impact of social drivers of health on the critical transition point between inpatient and outpatient ROP evaluations.

Methods

This retrospective study was approved by the University of Chicago Institutional Review Board and was compliant with the US Health Information Portability and Accountability Act of 1996 and the Declaration of Helsinki.

Study Population

The medical records of all infants evaluated for ROP at the University of Chicago Medical Center between January 1, 2016, and May

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1, 2023, because of birth weight (BW) of <1500 g, gestational age (GA) of ≤31 weeks, or discretionary criteria determined by the neonatology service, were reviewed. Participants for whom maternal zip code or address was not available during the hospital encounter were excluded. Demographic data were compiled by the Center for Research Informatics at the University of Chicago including: BW, GA, sex, race, ethnicity, insurance, and ADI. Race and ethnicity were obtained from the electronic health record, where they are recorded as separate variables. At our institution, neonatal race and ethnicity are based on the maternal self-reported race and ethnicity, which are obtained during intake. Race and ethnicity were analyzed as a combined variable (denoted as "race/ethnicity"): non-Hispanic White, non-Hispanic Black, Hispanic or Latino, or other (American Indian or Alaska Native, Asian Indian, Asian/Mideast Indian, other Pacific Islander, more than one race, none of the above, patient declines to respond, unknown, or patient unable to respond). Infants were divided into two cohorts, based on active ROP lists maintained by the senior author: those with type 1 ROP who received treatment and all other infants evaluated for ROP at our institution, which included infants with any ROP that was less severe than type 1 ROP and those with no ROP. Type 1 ROP was defined according to the Early Treatment for Retinopathy of Prematurity (ETROP) study.[6]

Initial outpatient appointments for ROP evaluation were arranged prior to patient discharge, or in some cases made by the Ophthalmology Department via contact with family members if patients were discharged prior to this appointment being made. Outpatient ROP appointments were scheduled to occur at the interval designated by the examiner at the last inpatient examination, or at the appropriate age as determined by guidelines published by the American Academy of Pediatrics[7] if the patient had received no examinations while inpatient. Appointments were completed in an outpatient ophthalmology clinic adjacent to the children's hospital that houses the neonatal unit.

The primary outcome was failure to attend the initial outpatient ophthalmology appointment following discharge, which was confirmed by manual chart review. Failure to attend this appointment triggered a process to reschedule by phone calls to family members, with escalation to letters and/or assistance from social workers if needed. The secondary outcome was failure to complete the final ROP examination, indicating graduation from the acute screening phase and transition to the long-term follow-up phase, as determined by the examiner.

Patients were excluded if vascularization was determined mature prior to hospital discharge, if they expired prior to discharge, or if they transferred to another institution during the acute phase of ROP examinations. In addition, some patients were transferred to long-term care facilities where they continued to undergo examinations by our ophthalmology service. These patients were not considered lost to follow-up. Similarly, patients who received laser for ROP during the inpatient stay were considered to have completed the ROP evaluation process and were scheduled for comprehensive follow-up examinations.

Area Deprivation Index

ADI is a measure of neighborhood disadvantage created by the US Health Resources and Services Administration. It is an aggregate marker of resources and conditions available in metropolitan areas across the United States that impact health outcomes and disease. It is used to compare expected outcomes between neighborhoods; the lower the ADI, the more affluent the neighborhood. ADI is composed of 17 measures, including education, employment, housing quality, and poverty, that are drawn from US Census and American Community Survey data using nine-digit zip codes. It has been made publicly available by the University of Wisconsin School of Medicine and Public Health (www.neighborhoodatlas.medicine.wisc.edu).[5] ADI scores in this study were obtained from the 2020 ADI dataset, which is derived from the American Community Survey 5-year data from 2016 to 2020.

ADI was obtained for the home address on file for each patient and recorded in deciles from 1 to 10. Each successive increase in ADI (eg, from 1 to 2) refers to an increase in 10 percentage points. ADI was also analyzed as a dichotomous variable to determine a cut-off point at which the ADI conferred greatest risk for missed follow-up.

Statistical Analysis

Statistical analyses were performed using Stata version 17.0 (StataCorp LP, College Station, TX). For baseline data, Pearson χ^2 test or the Fisher exact test was used to evaluate categorical data. The Wilcoxon rank-sum test was used to compare continuous variables with skewed distribution; the t test was used for continuous variables with normal distribution. Univariate and multivariable logistic regressions were used to evaluate predictors of missed first outpatient appointment. Factors with significance <0.10 were included on the multivariable analyses. Because of the small number of missed final appointments, only univariate analyses were performed. P values <0.05 were considered statistically significant.

Results

A total of 1,032 infants were evaluated for ROP, of whom 903 had sufficient data for determination of ADI. Of those 903 patients, 540 required continued ROP examinations as an outpatient. The majority of infants who required outpatient follow-up were non-Hispanic and Black (70%). Median ADI in the cohort was 7 (IQR, 5-9) and ADI was heavily skewed toward higher numbers in our population. Eighty percent of patients had Medicaid insurance. Of the patients who required follow-up after hospital discharge, 41 patients (7.6%) were treated for type 1 ROP.[6]

Thirty-two percent of patients (n = 174) missed the initial ophthalmology appointment following hospital discharge. On univariate analysis, ADI was significantly associated with missed follow-up ($P < 0.001$). The odds of missing the initial appointment increased by 21% (95% CI, 12%-32% [$P < 0.001$]) for each unit increase in ADI. An ADI above 7 was found to be particularly high risk, with a 2.31 times increased odds of missed follow-up (95% CI, 1.60-3.34 [$P < 0.001$]).

In addition, higher BW, Medicaid insurance coverage, and race/ethnicity were associated with missing the first outpatient appointment on univariate analysis (Table 1).

Table 1. Factors associated with missed outpatient follow-up

Study parameter	First outpatient appointment		*P* value[a]
	Missed (n = 174)	Attended (n = 366)	
BW, g, median (IQR)	1118 (815-1343)	1025 (765-1330)	0.048
GA, weeks, median (IQR)	29 (26-30)	28 (26-30)	0.246
ADI, decile, median (IQR)	8 (6-9)	7 (4-8)	<0.001
Race/ethnicity, no. (%)			<0.001
Non-Hispanic White	8 (4.6)	38 (10)	
Non-Hispanic Black	143 (82)	232 (63)	
Hispanic or Latino	15 (8.6)	81 (22)	
Other	8 (4.6)	15 (4.1)	
ROP severity, no. (%)			0.082
Type 1 ROP[b]	8 (4.6)	33 (9.0)	
All other patients[c]	166 (95.4)	333 (91)	
Insurance coverage, no. (%)			
Medicaid	130 (92)	262 (75)	<0.001
Private	12 (8.5)	8 (25)	

ADI, area deprivation index; *BW*, birth weight; *GA*, gestational age; *IQR*, interquartile range; *ROP*, retinopathy of prematurity.
[a]χ^2 test for categorical variables, rank-sum for continuous variables with skewed distribution, and *t* test for continuous variables with normal distribution.
[b]As defined by ETROP.[6]
[c]Including any ROP less severe than type 1 ROP and patients with no ROP.

However, after adjusting for ADI, race/ethnicity was no longer associated with a missed appointment (OR = 1.21; 95% CI, 0.51-2.88; $P = 0.663$).

We also assessed for an interaction between race/ethnicity and ADI, and we found that race/ethnicity does not modify the relationship between ADI and follow-up (OR = 1.03; 95% CI, 0.89-1.18 [$P = 0.660$]). Since race/ethnicity was a categorical variable, we also used indicator variables to represent the different categories and test for various interaction effects, and none of the interaction terms were statistically significant.

On adjusted analysis, only ADI and insurance remained significantly associated with increased odds of missing the first follow-up after hospital discharge. After adjusting for insurance, race/ethnicity, birth weight, and treatment for ROP, the likelihood of missing the first appointment after discharge increased by 17% (95% CI, 7%-28%) per unit increase in ADI (Table 2).

Fourteen patients (2.6%) were permanently lost to follow-up prior to complete retinal vascularization despite multiple attempts to reach family members by phone, certified letter, or with assistance from a social worker. All 14 patients who failed to complete ROP examinations also missed the first outpatient appointment. Among these patients, no other factors were identified to predict failure to complete a final ROP evaluation.

Table 2. Adjusted and unadjusted odds of missed initial outpatient appointment

Study parameter	OR (95% CI)	*P* value	Adjusted OR[a] (95% CI)	*P* value
ADI, per unit increase	1.21 (1.12-1.32)	<0.001	1.17 (1.07-1.28)	0.001
Race/ethnicity				
Non-Hispanic White	Reference		Reference	
Non-Hispanic Black	2.93 (1.33-6.45)	0.008	1.21 (0.51-2.88)	0.663
Hispanic or Latino	0.88 (0.34-2.25)	0.789	0.49 (0.18-1.34)	0.164
Other[b]	2.53 (0.80-7.98)	0.112	1.83 (0.46-7.28)	0.87
Birth weight, per 100g	1.05 (1.00-1.12)	0.048	1.01 (0.95-1.08)	0.703
Medicaid insurance	3.60 (1.90-6.82)	<0.001	2.91 (1.48-5.73)	0.002
Type 1 ROP[c]	2.05 (0.93-4.55)	0.075	1.80 (0.75-4.30)	0.187

ADI, area deprivation index; *CI*, confidence interval; *OR*, odds ratio; *ROP*, retinopathy of prematurity.
[a]Adjusted for BW, race/ethnicity, ADI (per unit increase), insurance, and treatment for ROP.
[b]Including American Indian or Alaska Native, Asian Indian, Asian/Mideast Indian, other Pacific Islander, more than one race, none of the above, patient declines to respond, unknown, or patient unable to respond.
[c]As defined by ETROP.[6]

Discussion

ROP is a source of both acute and long-term morbidity in premature infants, and, based on data from the IRIS registry, it remains the leading cause of vision loss in US children.[1] The transition to outpatient evaluation is critical because of the ongoing risk of development or progression of ROP after discharge. In addition to potential legal risks, missed or delayed appointments in the outpatient setting also remain a possible cause of poor visual outcomes for high-risk patients after discharge.[2,8,9]

In this study, higher ADI independently predicted failure to complete the first outpatient ROP examination during this transition point, and every patient who failed to complete ROP evaluations to vessel maturation had missed the first outpatient examination. There was likely insufficient power to detect an association between ADI and missed final appointment due to the small number of patients who missed the final appointment (n = 14). All of these patients were determined to be low risk by the screening ophthalmologist after multiple attempts to contact them by phone messages and certified and uncertified letters.

Although previous studies have identified insurance status as a relevant predictor of follow-up in this population,[3] this factor was less informative in our study, where the majority of patients had Medicaid insurance. While Medicaid coverage was still significantly associated with missed follow-up, it did not render ADI insignificant on adjusted analysis. ADI may, in fact, be a more useful marker for identifying patients at risk of missed follow-up because it allows for meaningful stratification, whereas Medicaid insurance—held by 80% of patients in our study—applies to the majority and offers less differentiation.

In addition to insurance status, race/ethnicity was also associated with follow-up in unadjusted analyses. However, the relationship between race/ethnicity and follow-up was not significant after adjusting for ADI, and no interaction was found between race/ethnicity and ADI—meaning that the effect of ADI on follow-up did not differ by racial/ethnic group. Given that structural racism contributes to residential segregation and socioeconomic deprivation, the apparent relationship between race and follow-up may be mediated through neighborhood-level disadvantage, as represented by ADI. Race and ethnicity have commonly been relied upon to draw population-based conclusions in epidemiological research despite lack of biological basis and risk of encouraging unconscious bias.[10] ADI, which does not include race or ethnicity in its calculation, provides a more comprehensive assessment of socioeconomic deprivation in a given neighborhood that may capture the effects of structural racism and socioeconomic factors in general that co-vary with race and ethnicity. As a result, the use of ADI has the potential to reduce confounding compared with reporting on racial composition alone. In addition, the collection of race and ethnicity data is often inherently flawed and prone to errors, particularly in pediatric populations.[11]

Limitations of this study include lack of generalizability due to particularly high ADI scores overall as well as poor rates of appointment attendance. Notably, ADI is limited insofar as it obtains its data from the census, which may over or undercount some populations. In addition, our study used the 2020 ADI, although our data collection extended to 2023. We were not able to evaluate the relationship between ROP severity and follow-up in this population because of a lack of granular data on ROP stage. Finally, as discussed above, the collection of race and ethnicity data was flawed in our patient population. In this retrospective dataset, an infant's race and ethnicity were recorded based on maternal race and ethnicity data that were self-reported during intake at the time of delivery admission. In the future, mothers will likely have the opportunity to identify the race and ethnicity of their child independently at our hospital. However, this dataset limitation may have resulted in inaccurate assumptions about race and ethnicity, further supporting the argument for prioritizing an independent measure such as ADI in drawing conclusions from this study.

Our cohort, drawn from a level IV neonatal intensive care unit on the south side of Chicago that serves a large regional area across state lines, had a median ADI of 7, indicating a high level of socioeconomic adversity. We found that 32% of patients missed the first scheduled appointment, although the great majority (97.4%) of patients ultimately resumed screening and were graduated from the acute screening phase. This gap highlights the burden placed on both physicians and support staff as well as caretakers of premature infants due to the complex and time-consuming efforts required to reschedule time-sensitive appointments. This burden is likely outsized in disadvantaged populations, as evidenced by our unusually high rate of missed appointments. Additional resources may be especially valuable in these settings to optimize outcomes for vulnerable patients, although these findings may not generalize to hospitals in areas of less socioeconomic hardship.

Patients with an ADI above 7 were at particularly high risk of missing follow-up, putting them at risk of poor long-term outcomes. In this high-risk group, modifiable barriers to follow-up should be addressed prior to discharge through a multidisciplinary effort. Interventions might include providing culturally sensitive education in multiple languages at a reasonable reading level, offering transportation assistance, providing flexible appointment times, and strengthening communication and coordination among healthcare providers to ensure seamless transitions of care. From a policy perspective, expanding social services for families from disadvantaged neighborhoods can ensure those with higher ADI receive the necessary support to effectively follow up, narrowing potentially lifelong disparities in health. Tools such as ADI quantify neighborhood disparities and provide valuable insight for policymakers, public health advocates, and clinicians in order to address social and health inequities. Further research

is needed to determine which interventions are most impactful in reducing barriers to follow-up among patients with high ADI scores. By incorporating objective measurements of neighborhood-level deprivation, researchers and practitioners can develop targeted and effective strategies that surpass the limitations of traditional proxy indicators for socioeconomic status.

References

1. Lim HW, Pershing S, Moshfeghi DM, Heo H, Haque ME, Lambert SR, IRIS® Registry Analytic Center Consortium. Causes of childhood blindness in the United States using the IRIS® registry (Intelligent Research in Sight). Ophthalmology 2023;130:907-13.
2. Wiggins RE Jr, Gold RS, Menke AM. Twenty-five years of professional liability in pediatric ophthalmology and strabismus: the OMIC experience. J AAPOS 2015;19:535-40.
3. Mahmud F, Karmouta R, Strawbridge JC, et al. A multicenter study of retinopathy of prematurity follow-up adherence. Retina 2023;43:1780-87.
4. Jastrzembski BG, VanderVeen D, Oke I. Social conditions and the rate of severe retinopathy of prematurity among a diverse cohort of infants. JAMA Ophthalmol 2023;141:104.
5. Kind AJH, Buckingham WR. Making neighborhood-disadvantage metrics accessible—the neighborhood atlas. N Engl J Med 2018;378:2456-2458. AND University of Wisconsin School of Medicine Public Health. 2015 Area Deprivation Index v2.0, https://www.neighborhoodatlas.medicine.wisc.edu/. Accessed September 12, 2023.
6. Early Treatment for Retinopathy of Prematurity Cooperative Group. Revised indications for the treatment of retinopathy of prematurity: results of the early treatment for retinopathy of prematurity randomized trial. Arch Ophthalmol 2003;121:1684-94.
7. Fierson WM. American Academy of Pediatrics Section on Ophthalmology; American Academy of Ophthalmology; American Association for Pediatric Ophthalmology and Strabismus; American Association of Certified Orthoptists. Screening examination of premature infants for retinopathy of prematurity. Pediatrics 2018;142:e20183061. Erratum in: Pediatrics 2019;143:e20183810.
8. Day S, Menke AM, Abbott RL. Retinopathy of prematurity malpractice claims: the Ophthalmic Mutual Insurance Company experience. Arch Ophthalmol 2009;127:794-8.
9. Moshfeghi DM. Top five legal pitfalls in retinopathy of prematurity. Curr Opin Ophthalmol 2018;29:206-9.
10. Flanagin A, Frey T, Christiansen SL, AMA Manual of Style Committee. Updated guidance on the reporting of race and ethnicity in medical and science journals. JAMA 2021;326:621-7.
11. Salhi RA, Macy ML, Samuels-Kalow ME, Hogikyan M, Kocher KE. Frequency of discordant documentation of patient race and ethnicity. JAMA Netw Open 2024;7:e240549.