

Disparities in outcomes for rare pediatric cancer suggest unequal access to primary care

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Disparities in outcomes for children with retinoblastoma—a rare eye tumor usually discovered in routine pediatric check-ups—suggest unequal access to primary care, researchers from Dana-Farber/Boston Children's Cancer and Blood Disorders Center report in a study published in the journal *JAMA Pediatrics*. Although virtually all the children in the study survived, Hispanic children and children who lived in disadvantaged areas were more likely to lose an eye due to late diagnosis.

White children and children who live in areas with a higher [socio-economic status](#) were more likely to have been diagnosed early enough that physicians could preserve their eye and vision. In a review of 830 cases recorded in the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) registries, researchers examined results for children under age 10 whose cases of retinoblastoma were recorded between January 1, 2000, and December 31, 2010. They looked at race and ethnicity and analyzed county-based data on poverty, educational attainment, language isolation, crowding, unemployment and proportion of immigrants.

The study found:

- At the time of diagnosis, the disease had spread beyond the eye in 33 percent of Hispanic children, compared with 20 percent of

non-Hispanic children.

- At diagnosis, disease had spread beyond the eye in 28 percent of children from high-poverty areas, compared with 20 percent of other children. Similar disparities were found in other measures of socio-economic status.
- Three-quarters (74.5 percent) of Hispanic children had the diseased eye surgically removed, compared with two-thirds (67.5 percent) of non-Hispanic children and less than two thirds (63 percent) of non-Hispanic white children. Among non-Hispanic black and Asian children, 74 percent had their eye removed.
- Three-quarters (76 percent) of children living in disadvantaged counties had their eye removed, compared to less than two-thirds (64 percent) who lived in advantaged counties.

Retinoblastoma is usually detected during a routine pediatrician visit with a so-called "red reflex" test: When the clinician flashes a light in the child's eye, a white reflection from the retina - rather than a healthy red reflection—indicates the possible presence of a tumor. The disease typically affects children under age 5, and most cases are diagnosed before age 2. Early diagnosis makes it easier for clinicians to salvage the eye, either through laser therapy or cryo- (cold) or thermo- (heat) therapy delivered by an ophthalmologist, or through chemotherapy delivered to the eye. If the tumor has spread deep into the eye socket or beyond, a surgeon must remove the affected eye.

"Because retinoblastoma is most often diagnosed during well-child visits, the disparities uncovered in this study raise questions about inequities in [primary care](#) that go beyond the few children who develop this rare cancer," said senior author Carlos Rodriguez-Galindo, MD, clinical director of the Solid Tumor Center at Dana-Farber/Boston Children's. "The findings also tell us that, despite the advances of recent decades in the care of children with cancer, disparities still exist. These disparities may impact children in different ways, depending on the type of cancer

and treatment received. It is very important to perform disease-specific studies of disparities to better assess the impact of this problem."

Many children with retinoblastoma lose an eye, regardless of race, ethnicity or socio-economic status, because most children present with advanced intraocular disease, notes co-author Paola Medina Friedrich, MD, a pediatric oncologist at Dana-Farber/Boston Children's. This, she says, suggests that there is room for improved awareness among pediatricians about screening children during routine visits or room for improvement in skills and conditions during clinic visits that would help pediatricians detect the tumor's characteristic white reflection at earlier stages of the disease.

"Even without considering disparities, most [children](#) present with large intraocular tumors. Ideally we should detect these tumors when they are small and have not compromised vision," Friedrich said. "The guidelines recommend routine vision checks, including the red reflex check on every well child visit. This is particularly important during the first two years."

Disparities in access to treatment may also contribute to outcomes that differ by race, ethnicity and [socioeconomic status](#), the researchers note. Salvaging a patient's eye requires access to sophisticated, multi-disciplinary care, as well as multiple clinic visits and treatment administration, all which may be more difficult for families facing economic, cultural or language barriers. "As treatments for retinoblastoma become increasingly complex," the study warns, "disparities may worsen."

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