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Parental Awareness and Social Determinants Influencing Early Detection of Retinoblastoma

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ABSTRACT

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Background: Retinoblastoma is the most common primary intraocular malignancy in children and requires early diagnosis to improve survival and preserve vision. However, delayed detection remains common in developing regions due to limited parental awareness and various social determinants such as education level, socioeconomic status, and accessibility to healthcare services.

Aim: To evaluate parental awareness and identify social factors influencing the early detection of retinoblastoma in paediatric patients.

Materials and Methods: A cross-sectional observational study was conducted over four months from October 2025 to January 2026. A total of 280 parents of paediatric patients attending a tertiary healthcare institution were included. Data were collected using a structured questionnaire, and healthcare-seeking behaviour. Statistical analysis was performed using descriptive statistics and chi-square tests, with a p-value <0.05 considered statistically significant.

Results: Out of 280 participants, 134 (47.9%) were aware of retinoblastoma as a childhood eye cancer, while 146 (52.1%) had no prior knowledge. Awareness of leukocoria was reported by 112 parents (40.0%) and strabismus by 86 (30.7%). Parental education showed a significant association with awareness ($\chi^2 = 16.82$, $p = 0.001$). Socioeconomic status also significantly influenced awareness levels ($\chi^2 = 12.47$, $p = 0.002$). Early medical consultation within one month of symptom recognition was reported by 118 parents (42.1%), with urban residence associated with earlier healthcare-seeking behaviour ($\chi^2 = 18.03$, $p < 0.001$).

Conclusion: Parental awareness and social determinants significantly influence early detection of retinoblastoma. Public awareness programs and improved healthcare accessibility are essential to promote early diagnosis and better treatment outcomes.

Keywords: Retinoblastoma, Parental Awareness, Early Detection, Paediatric Ocular Cancer

INTRODUCTION

Retinoblastoma is the most common primary intraocular malignancy occurring in children and represents a critical condition in pediatric ophthalmology. The tumor originates from immature retinal cells and usually develops during early childhood, particularly before the age of five years. Globally, the disease occurs in approximately one out of every 15,000–20,000 live births and contributes to a significant proportion of childhood ocular cancers. Although retinoblastoma is relatively rare, it remains a life-threatening condition if diagnosis and treatment are delayed. Advances in modern ophthalmology, including improved diagnostic imaging and targeted therapies, have significantly enhanced survival rates in high-income countries, where early diagnosis allows effective management and eye-preserving treatment strategies. ^[1] The clinical presentation of retinoblastoma often includes recognizable ocular signs that can be observed by caregivers or parents. The most common presenting feature is leukocoria, commonly described as a white pupillary reflex or “cat’s eye reflex,” which may be visible in photographs or under specific lighting conditions. Other signs

include strabismus, redness of the eye, visual impairment, and ocular swelling. Studies have reported that leukocoria accounts for more than half of initial presentations of retinoblastoma cases, followed by strabismus and inflammatory ocular changes. Early recognition of these symptoms is essential because prompt diagnosis significantly improves survival and visual outcomes.^[2] Despite the availability of advanced diagnostic technologies, delayed diagnosis remains a major challenge, particularly in low- and middle-income countries. Several studies have shown that many children with retinoblastoma are diagnosed at advanced stages of the disease due to delays in symptom recognition and referral to specialized healthcare facilities. In developing regions, factors such as limited awareness, poor access to specialized ophthalmic services, and socioeconomic barriers often contribute to late presentation of the disease. Consequently, children in these regions frequently require more aggressive treatment approaches, including enucleation or systemic chemotherapy.^[3]

Parental awareness plays a crucial role in the early detection of retinoblastoma because parents are usually the first individuals to observe abnormal changes in their child's eyes. Research indicates that a large proportion of retinoblastoma cases are initially detected by family members rather than healthcare professionals. Early recognition of warning signs by parents and prompt consultation with medical professionals can significantly reduce diagnostic delays and improve treatment outcomes. Conversely, limited knowledge about ocular cancer symptoms may lead parents to ignore early signs or misinterpret them as minor eye problems.^[4] Educational background and access to reliable health information strongly influence parental awareness regarding childhood diseases.

Parents with higher educational levels are generally more likely to recognize abnormal ocular signs and seek timely medical advice. They are also more likely to obtain information about childhood cancers through healthcare providers, digital media, and public health campaigns. In contrast, parents with limited education or restricted access to health information may lack awareness about early symptoms of retinoblastoma, which may delay medical consultation and diagnosis.^[5] Socioeconomic conditions also play an important role in determining how quickly families seek healthcare services. Financial constraints, long travel distances to healthcare facilities, and limited availability of specialized ophthalmology services can significantly delay diagnosis. Studies have demonstrated that children from rural or economically disadvantaged communities are more likely to present with advanced stages of retinoblastoma compared with those from urban

populations with better healthcare access.^[6] In addition to socioeconomic factors, cultural beliefs and social perceptions about illness may influence parental health-seeking behavior. In certain communities, parents may initially rely on traditional remedies or local healers before seeking professional medical care. Such practices may further delay the detection and treatment of serious conditions such as retinoblastoma. Addressing these cultural and social barriers through community education and public health awareness programs is essential to promote early detection.^[7]

Early diagnosis of retinoblastoma is associated with improved survival rates, reduced treatment complexity, and greater chances of preserving vision. When the disease is detected in its initial stages, treatment options such as focal laser therapy, cryotherapy, and localized chemotherapy can effectively control tumor growth while preserving the eye. However, if diagnosis occurs at a late stage, more aggressive interventions such as enucleation may be required to prevent metastasis and ensure patient survival.^[8] Family experience with retinoblastoma also influences early detection. Families with a history of the disease often demonstrate increased vigilance and are more likely to seek early screening for subsequent children. Research has shown that children from such families are frequently diagnosed at earlier stages due to improved parental awareness and proactive medical monitoring.^[9]

Public health initiatives aimed at educating parents about early warning signs of retinoblastoma can significantly improve early diagnosis rates. Awareness campaigns through hospitals, pediatric clinics, community health programs, and digital platforms can help parents recognize symptoms such as leukocoria and strabismus and encourage timely medical consultation. Early screening during routine pediatric examinations may further contribute to earlier detection and improved treatment outcomes.^[10] Given the strong influence of parental awareness and social determinants on early detection of retinoblastoma, it is important to evaluate these factors in different populations. Understanding how education, socioeconomic status, healthcare accessibility, and cultural beliefs affect parental knowledge and health-seeking behavior can help develop targeted awareness programs and improve pediatric eye health services.^[11] Therefore, this study aims to assess parental awareness regarding retinoblastoma and to identify the social factors that influence the early detection of this pediatric ocular malignancy. By identifying knowledge gaps and barriers to healthcare access, the study seeks to support the development of effective strategies that promote early diagnosis and improve clinical outcomes in children affected by retinoblastoma.^[12-15]

Aim of the Study: To assess the level of parental awareness and identify social factors influencing the early detection of retinoblastoma in paediatric patients.

MATERIALS AND METHODS

Study Design: A cross-sectional observational study was conducted to assess parental awareness of retinoblastoma and identify social determinants influencing its early detection.

Study Duration: The study was conducted over four months, from October 2025 to January 2026.

Ethical Considerations: Ethical approval was obtained from the Institutional Ethics Committee, School of Health Sciences, Brainware University, Kolkata (Approval No.: BWU/AHS/NOC/DSC/2024/037). The study followed the Declaration of Helsinki. Written informed consent was obtained from all participants, with confidentiality and voluntary participation ensured.

Study Population and Sample Size: The study included 280 parents or legal guardians of children attending the ophthalmology and radiology departments of a tertiary care hospital for pediatric ocular conditions, including suspected or confirmed retinoblastoma.

Inclusion Criteria: Parents or legal guardians of children aged 0–10 years who provided informed consent and could adequately complete the questionnaire were included.

Exclusion Criteria: Individuals who declined participation or provided incomplete or unreliable responses due to communication or cognitive limitations were excluded.

Data Collection: Data were collected using a structured, pre-validated questionnaire administered through face-to-face interviews. The questionnaire assessed demographic and socioeconomic characteristics, awareness of retinoblastoma and its early signs, and health-seeking behaviors related to diagnosis.

Statistical Analysis: Data were coded and analyzed using descriptive statistics. Frequencies and percentages were calculated, and findings were presented in tables and narrative form to assess parental awareness and factors associated with early detection.

RESULTS

A total of 280 parents or legal guardians participated in the study during the four-month study period (October 2025 to January 2026). The collected data were analyzed to assess parental awareness regarding retinoblastoma and to identify social factors influencing early detection. Descriptive statistics, chi-square tests, and p-values were used to determine the statistical significance of the observed associations.

Demographic Characteristics of Participants: Among the 280 respondents, the majority of parents were

between 26–35 years of age ($n = 124$, 44.3%), followed by 36–45 years ($n = 96$, 34.3%), while 60 parents (21.4%) were younger than 25 years. In terms of educational status, 102 parents (36.4%) had completed secondary education, 98 (35.0%) had higher education (graduate or postgraduate level), and 80 (28.6%) had only primary education. Regarding residence, 162 participants (57.9%) were from urban areas and 118 (42.1%) belonged to rural regions (**Figure:1**).

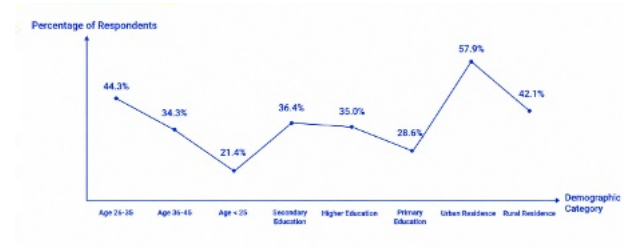


Figure: 1. Demographics of Parents in the Study

Awareness of Retinoblastoma: Out of the total participants, 134 parents (47.9%) reported that they had heard about retinoblastoma as a childhood eye cancer, whereas 146 parents (52.1%) had no prior knowledge of the disease. Awareness regarding early symptoms varied among participants. Leukocoria (white pupillary reflex) was recognized by 112 parents (40.0%), while strabismus as a potential symptom was identified by 86 parents (30.7%). Only 74 participants (26.4%) were aware that early diagnosis could significantly improve treatment outcomes and survival (**Figure: 2**).

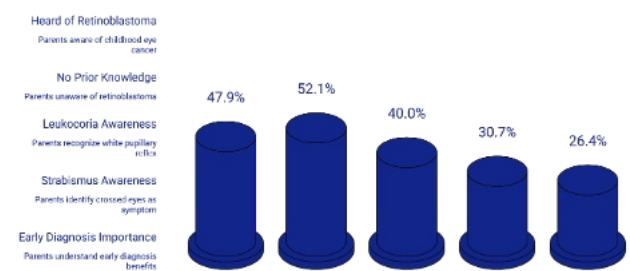


Figure: 2. Parental Awareness of Retinoblastoma

Statistical analysis demonstrated a significant association between parental education level and awareness of retinoblastoma. Parents with higher education showed significantly greater awareness compared with those with primary education ($\chi^2 = 16.82$, $p = 0.001$).

Influence of Socioeconomic Factors on Awareness: The relationship between socioeconomic status and awareness level was also evaluated. Parents belonging to higher socioeconomic groups showed greater knowledge about the disease compared with those from lower socioeconomic backgrounds. Among parents with higher monthly household income, 68 out of 110 participants

(61.8%) were aware of retinoblastoma, while only 66 out of 170 parents (38.8%) from lower income groups reported awareness (**Figure-3**). This difference was found to be statistically significant ($\chi^2 = 12.47$, $p = 0.002$).

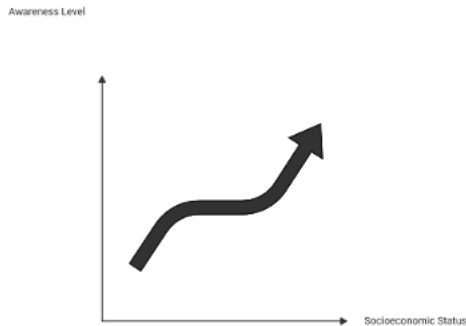


Figure: 3. Awareness of Retinoblastoma Increases with Socioeconomic Status

Health-Seeking Behavior: The time interval between noticing ocular symptoms and seeking medical consultation was analyzed to understand health-seeking behavior. Among the participants, 118 parents (42.1%) reported that they sought medical consultation within one month of noticing abnormal ocular signs. However, 92 parents (32.9%) waited between one to three months, while 70 parents (25.0%) delayed medical consultation for more than three months (**Figure-4**). A significant association was observed between awareness level and early healthcare consultation. Parents who were aware of retinoblastoma symptoms were more likely to seek medical advice within one month compared with unaware parents ($\chi^2 = 14.65$, $p = 0.001$).



Figure: 4. Health-Seeking Behaviour for Ocular Symptoms

Impact of Residence on Early Detection: Residential location also showed a notable influence on early detection. Among urban participants ($n = 162$), 86 parents (53.1%) sought medical consultation within one month of symptom recognition, whereas only 32 parents (27.1%) from rural areas sought early medical care. This difference was statistically significant ($\chi^2 = 18.03$, $p < 0.001$), indicating better access to healthcare facilities and information among urban populations (**Figure: 5**).

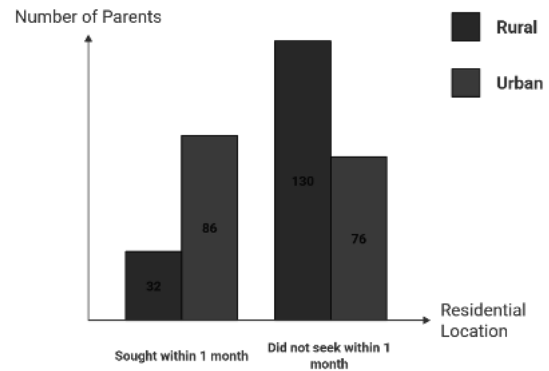


Figure: 5. Early Medical Consultation by Residential Location

Sources of Health Information: Participants reported various sources of information related to eye health and childhood diseases. The most common sources included healthcare professionals (38.6%), internet and social media (26.8%), community awareness programs (18.2%), and family or friends (16.4%). Parents who obtained information from healthcare professionals demonstrated significantly higher awareness levels compared with other sources ($\chi^2 = 10.94$, $p = 0.004$).

DISCUSSION

The present study aimed to evaluate parental awareness and the influence of social factors on the early detection of retinoblastoma in pediatric patients. Early identification of retinoblastoma plays a crucial role in improving survival rates and preserving vision. The findings of this study demonstrate that parental awareness, education level, socioeconomic status, and accessibility to healthcare services significantly influence the early recognition and timely diagnosis of this childhood ocular malignancy. In the current study, less than half of the participants (47.9%) reported prior awareness of retinoblastoma as a childhood eye cancer. This indicates a substantial gap in public knowledge regarding pediatric ocular tumors. Similar findings have been reported in previous studies where limited awareness among parents contributed to delayed diagnosis and late presentation of retinoblastoma. In many developing regions, parents often recognize ocular abnormalities but may not associate them with serious diseases, resulting in delayed medical consultation. Increasing awareness about early symptoms such as leukocoria and strabismus is therefore essential to facilitate timely diagnosis and treatment. One of the key observations of this study was the significant association between parental education level and awareness of retinoblastoma. Parents with higher educational backgrounds demonstrated greater knowledge of early symptoms and the importance of early medical evaluation. Education enhances access to health-related

information through digital media, healthcare professionals, and educational resources. Consequently, educated parents are more likely to recognize abnormal ocular signs and seek medical advice promptly. These findings are consistent with earlier research indicating that parental education is one of the strongest predictors of early detection of childhood cancers.

Socioeconomic status also emerged as an important determinant influencing parental awareness and health-seeking behaviour. The results showed that parents belonging to higher income groups had significantly greater awareness of retinoblastoma compared with those from lower socioeconomic backgrounds. Financial limitations often restrict access to healthcare facilities, specialized ophthalmology services, and diagnostic imaging, which can delay clinical evaluation. In many low-income families, healthcare visits are postponed due to economic constraints, transportation difficulties, or lack of nearby medical services. As a result, children from economically disadvantaged families may present with more advanced stages of retinoblastoma at the time of diagnosis. Another important finding of this study was the difference in healthcare-seeking behaviour between urban and rural populations. Parents residing in urban areas were more likely to seek medical consultation within one month of noticing ocular symptoms compared with those living in rural regions. Urban populations typically benefit from better healthcare infrastructure, availability of specialized medical professionals, and greater exposure to health awareness campaigns. In contrast, rural communities often face challenges such as limited healthcare facilities, fewer ophthalmologists, and longer travel distances to tertiary care hospitals. These barriers contribute to delayed diagnosis and highlight the need for improved healthcare accessibility in rural areas.

The study also identified that healthcare professionals were the most common source of reliable information regarding childhood eye diseases. Parents who obtained information from medical professionals demonstrated significantly higher awareness levels compared with those relying on informal sources such as family members or social media. This emphasizes the important role of healthcare providers in educating parents about early warning signs of ocular diseases during routine pediatric visits. Pediatricians, ophthalmologists, and community health workers can contribute significantly by promoting awareness of leukocoria and other warning signs during child health programs and immunization visits. The findings of this study highlight the importance of community-based awareness programs and public health education to improve early detection of retinoblastoma. Educational campaigns through schools, community health centers, social media, and mass communication platforms can help increase parental

knowledge about childhood eye cancers. In addition, routine eye examinations during pediatric health check-ups may aid in the early identification of suspicious ocular signs. Such preventive strategies can significantly reduce diagnostic delays and improve treatment outcomes. Early detection of retinoblastoma not only improves survival but also allows the use of less aggressive treatment approaches. When the tumor is diagnosed at an early stage, treatment modalities such as focal laser therapy, cryotherapy, and localized chemotherapy can be used to control tumor growth while preserving the eye and vision. However, delayed diagnosis often requires more invasive treatments, including enucleation or systemic chemotherapy, which can have significant physical and psychological impacts on both the child and the family. Although the present study provides valuable insights into parental awareness and social determinants affecting early detection, certain limitations should be considered. The study was conducted in a single tertiary healthcare setting, which may limit the generalizability of the findings to other populations. Additionally, the assessment of awareness was based on self-reported responses, which may be influenced by recall bias. Future research involving larger multicenter studies and community-based surveys may provide a more comprehensive understanding of parental awareness and its impact on early diagnosis.

CONCLUSION

Retinoblastoma is a potentially curable childhood malignancy when diagnosed at an early stage, and it is already well established that parental awareness, educational status, socioeconomic conditions, and healthcare accessibility play critical roles in its timely detection. The existing literature indicates that parents are often the first to recognize early clinical signs such as leukocoria and strabismus, and delays in diagnosis are commonly associated with limited awareness and restricted access to healthcare services, particularly in low- and middle-income settings. The present study adds to this body of knowledge by providing quantitative, region-specific evidence demonstrating that less than half of the participants were aware of retinoblastoma, with significantly lower awareness observed among parents with lower educational and socioeconomic status. Furthermore, the study identifies statistically significant associations between awareness levels and early healthcare-seeking behaviour, as well as notable urban-rural disparities in timely medical consultation. An important novel finding is the identification of healthcare professionals as the most reliable and influential source of information for improving parental awareness compared with informal or digital sources. Overall, these findings highlight that despite existing knowledge, substantial gaps persist in awareness and

access, necessitating targeted public health strategies, including structured awareness programs, community-based education, and improved accessibility to specialized paediatric ophthalmic services, to promote early diagnosis and improve clinical outcomes.

DECLARATION

Data Availability Statement: The datasets generated and/or analysed during the current study are available from the corresponding author on reasonable request.

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Contributors' Statement

Raman Vats: Conceptualization and design of the study; literature review; development of study methodology; data collection and analysis; interpretation of findings.

Santosh Singh: Manuscript drafting, revision, and final approval of the manuscript for publication. All authors take responsibility for the integrity and accuracy of the work.

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