

UNDERSTANDING DELAYS IN RETINOBLASTOMA DIAGNOSIS IN CHILDREN: INSIGHTS FROM A TERTIARY CARE HOSPITAL IN PAKISTAN

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Abstract: Retinoblastoma, a rare but life-threatening pediatric ocular malignancy, requires early diagnosis and treatment to ensure better outcomes. However, many children, especially in developing countries like Pakistan, present late due to various socio-economic, cultural, and healthcare access barriers. Understanding these factors is critical to improving early detection and timely treatment. **Objective:** This study aims to identify the factors contributing to the delayed presentation of retinoblastoma in children at a tertiary care hospital in Pakistan. A cross-sectional survey utilizing a structured questionnaire. The study was conducted at the Pediatric Ophthalmology Department, Nishtar Hospital, Multan, from January 2024 to July 2024. **Methods:** A total of 90 mothers of children diagnosed with retinoblastoma were surveyed. Data were collected on patient demographics, initial symptoms, and time intervals between symptom onset and hospital presentation. The study examined factors such as the time to consult a general practitioner and the time lapse before reaching the tertiary care center, alongside variables like gender, age, disease laterality, socioeconomic background, and access to medical care. An oncologist performed a general physical examination, while a pediatric ophthalmologist performed a detailed eye examination under anesthesia. Statistical analysis was conducted using SPSS version 20, and Pearson's Chi-square test was used to determine the significance of the factors associated with delays. **Results:** Of the 90 participants, 63% (n=57) presented with delayed diagnosis and treatment. The key contributing factors were residence in rural areas (48%, n=43), financial constraints (58%, n=52), social pressure (22%, n=20), lack of awareness about the severity of the disease (55%, n=50), limited transportation (49%, n=44), fear of enucleation (39%, n=35), and reliance on non-medical or alternative treatments (29%, n=26). Additionally, a significant number of participants (36%, n=32) reported that superstition played a role in delaying medical consultation, with many initially seeking help from religious figures for dua or dam (prayers or spiritual healing) as a means of resolving the condition. All these factors contributed statistically significantly to delays in diagnosis and treatment ($p < 0.05$). **Conclusion:** The study identifies significant barriers to timely diagnosis and treatment of retinoblastoma in children. Addressing these issues, particularly in rural areas, through improved healthcare infrastructure and public awareness could promote earlier diagnosis and better treatment outcomes for children in Pakistan.

Keywords: Retinoblastoma, delayed diagnosis, pediatric oncology, healthcare access, rural health, Pakistan

Introduction

Retinoblastoma, the most common primary intraocular malignancy in children, represents a significant public health challenge, especially in low- and middle-income countries (LMICs) like Pakistan. (1). The global incidence of retinoblastoma is estimated at 1 in 15,000 to 20,000 live births, with a higher prevalence observed in countries with limited access to healthcare. (2). Early diagnosis and timely intervention are crucial for managing retinoblastoma, significantly impacting survival rates and visual outcomes. (3). However, delays in diagnosis and treatment often result in advanced disease presentation, leading to poorer prognosis, increased mortality, and a greater likelihood of enucleation, which affects the child's quality of life and psychological well-being (4).

In Pakistan, delayed presentation of retinoblastoma is common and is often linked to several socio-cultural, economic, and healthcare access factors (5). Studies have shown that factors such as residing in rural areas, financial constraints, and lack of awareness about retinoblastoma symptoms contribute to late presentation (6, 7). Moreover,

limited access to specialized pediatric ophthalmology services in rural regions exacerbates these delays (8). A critical gap in the healthcare infrastructure means that many families face challenges in reaching tertiary care centers, where proper diagnosis and treatment can be administered (9).

Cultural beliefs and practices also play a role in the delayed presentation, as many families initially seek traditional healers or spiritual remedies before consulting a medical professional (9). Addressing these barriers requires targeted interventions, including public awareness campaigns, improving healthcare access in rural areas, and providing financial support to families in need. Such measures could significantly improve the prognosis of children diagnosed with retinoblastoma in Pakistan.

Methodology

This study employed a cross-sectional survey design to investigate the factors contributing to the delayed presentation of retinoblastoma in children. The research was

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conducted at the Pediatric Ophthalmology Department of Nishtar Hospital, Multan, and a tertiary care center in Pakistan. The study duration spanned from January 2024 to July 2024.

The study targeted mothers of children diagnosed with retinoblastoma. A total of 90 participants were selected using a purposive sampling technique. Eligible participants included mothers of children aged 0-10 years who were newly diagnosed with retinoblastoma during the study period. Exclusion criteria included children with a previous history of retinoblastoma diagnosis or those who had already received treatment at another medical facility.

A structured questionnaire was designed based on existing literature and expert input from pediatric oncologists and ophthalmologists. The questionnaire was pre-tested on a small sample (n=10) to ensure clarity and relevance. It included sections on demographics (age, gender, and socioeconomic status), initial symptoms, time intervals between symptom onset and hospital presentation, and factors influencing delays in seeking medical care (e.g., financial constraints, cultural beliefs, and access to transportation).

Data collection was conducted through face-to-face interviews with the mothers of children diagnosed with retinoblastoma. The interviews were carried out in a private setting within the hospital to ensure confidentiality and encourage open responses. Interviewers were trained medical staff fluent in the local language to facilitate effective communication and minimize any language barriers.

The time intervals recorded included:

Time from symptom onset to first consultation with a general practitioner.

Time from the initial consultation to referral to a tertiary care center.

Time from the referral to the actual presentation at the Pediatric Ophthalmology Department of Nishtar Hospital.

All children underwent a comprehensive eye examination under anesthesia, performed by a pediatric ophthalmologist. This included indirect ophthalmoscopy and imaging studies to confirm the diagnosis and assess the extent of the disease. A general physical examination was conducted by an oncologist to evaluate any systemic involvement. The findings of these examinations were documented to correlate clinical presentation with the time of diagnosis.

Ethical approval was obtained from the Institutional Review Board (IRB) of Nishtar Hospital, Multan. Informed consent was secured from all participants before data collection, ensuring their understanding of the study's purpose, procedures, potential risks, and benefits. Participants were assured of the confidentiality of their responses, and they had the right to withdraw from the study at any time without any repercussions.

Data were analyzed using SPSS version 20. Descriptive statistics, such as means, standard deviations, frequencies, and percentages, were used to summarize demographic characteristics and factors contributing to delays. Pearson's Chi-square test was employed to assess associations between independent variables (e.g., socioeconomic status, rural vs. urban residence) and delayed presentation. A p-value of <0.05 was considered statistically significant. Multivariate logistic regression analysis was performed to identify the factors most strongly associated with delays in presentation, adjusting for potential confounders.

Results

A total of 90 mothers of children diagnosed with retinoblastoma participated in the study. The data analysis focused on demographic characteristics, factors contributing to delayed presentation, and the time intervals between symptom onset and hospital presentation. The key findings are presented below, along with detailed tables to support the analysis.

Table 1 shows the demographic characteristics of the study participants. Most children (57.8%) were male, with a predominant age group of 3-5 years (45.6%). The majority of the participants resided in rural areas (58.9%), and over half (57.8%) belonged to low-income families.

Table 2 summarizes the time intervals between symptom onset and hospital presentation. The mean time from symptom onset to the first consultation with a general practitioner was approximately 24.5 days, while the total delay from symptom onset to presentation at the tertiary care center averaged 50.6 days.

Table 3 presents the factors contributing to delayed presentation. Financial constraints (57.8%) and lack of awareness about the severity of the disease (55.6%) were the most frequently reported factors. Other significant factors included residence in rural areas (47.8%) and limited transportation (48.9%).

Table 4 shows the association between residence (urban vs. rural) and delayed presentation. The majority of cases with delayed presentation were from rural areas (68.4%), which was statistically significant (p < 0.05).

Table 5 presents the results of the multivariate logistic regression analysis. Significant predictors of delayed presentation included rural residence (OR = 2.45, p = 0.01), financial constraints (OR = 3.14, p = 0.002), lack of awareness (OR = 2.76, p = 0.005), and limited transportation (OR = 1.88, p = 0.04).

Table 1: Demographic Characteristics of the Study Participants (N=90)

Variable	Frequency (n)	Percentage (%)
Child's Gender		
Male	52	57.8
Female	38	42.2
Child's Age (years)		
0-2	26	28.9
3-5	41	45.6
6-10	23	25.5
Residence		
Urban	37	41.1
Rural	53	58.9
Socioeconomic Status		
Low-income	52	57.8
Middle-income	29	32.2
High-income	9	10.0

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Table 2: Time Intervals between Symptom Onset and Hospital Presentation

Time Interval	Mean ± SD (days)	Range (days)
Symptom onset to first consultation	24.5 ± 11.2	10 - 60
First consultation to referral to tertiary care	15.3 ± 7.8	5 - 35
Referral to the actual hospital presentation	10.8 ± 6.5	3 - 28
Total delay (symptom onset to presentation)	50.6 ± 14.9	18 - 120

Table 3: Factors Contributing to Delayed Presentation

Contributing Factors	Frequency (n)	Percentage (%)
Residence in rural areas	43	47.8
Financial constraints	52	57.8
Lack of awareness about severity	50	55.6
Limited transportation	44	48.9
Fear of enucleation	35	38.9
Reliance on non-medical treatments	26	28.9
Superstition and spiritual beliefs	32	35.6

Table 4: Association between Residence and Delayed Presentation

Residence	Delayed Presentation (n=57)	Non-delayed Presentation (n=33)	p-value
Urban	18 (31.6%)	19 (57.6%)	<0.05
Rural	39 (68.4%)	14 (42.4%)	

Table 5: Multivariate Logistic Regression Analysis of Factors Associated with Delayed Presentation

Variable	Odds Ratio (OR)	95% CI	p-value
Rural residence	2.45	1.22 - 4.91	0.01
Financial constraints	3.14	1.58 - 6.24	0.002
Lack of awareness	2.76	1.35 - 5.64	0.005
Limited transportation	1.88	1.01 - 3.52	0.04
Reliance on non-medical treatments	1.67	0.85 - 3.27	0.12
Superstition and spiritual beliefs	1.94	1.02 - 3.72	0.03

Discussion

The findings of this study reveal a significant prevalence of delayed presentation among children diagnosed with retinoblastoma at a tertiary care center in Pakistan, with 63% of the participants experiencing delays in seeking medical attention (10). This delay, averaging around 50.6 days from symptom onset to hospital presentation, is particularly concerning given the aggressive nature of retinoblastoma and the critical importance of early intervention in improving survival rates and visual outcomes (3).

The study identified multiple contributing factors to the delayed presentation, with rural residence, financial constraints, lack of awareness, and cultural beliefs being among the most prominent (11). These results align with previous research highlighting similar barriers in LMICs like Pakistan. For instance (8). reported that rural populations face greater challenges in accessing specialized healthcare services, leading to delays in the diagnosis and treatment of pediatric cancers (12). In their study, financial difficulties and limited transportation options were identified as major obstacles to timely medical consultations, consistent with our findings (13).

A critical issue identified in this study is the role of cultural beliefs and practices in delaying medical care. Approximately 36% of the participants indicated that superstition and reliance on spiritual healing played a role

in their decision to seek non-medical remedies before consulting a healthcare professional (14). This finding echoes the results of (8). Who highlighted that many families in Pakistan initially turn to religious figures or traditional healers when confronted with severe illnesses. Such practices are deeply embedded in the cultural context Of the region and pose significant challenges to early medical intervention. Addressing this issue requires culturally sensitive health education programs that respect traditional beliefs while emphasizing the importance of medical care for serious conditions like retinoblastoma.

The socioeconomic disparities revealed in our study are particularly significant. Low-income families accounted for 57.8% of the delayed cases, which correlates with the findings of (7).who documented that financial constraints are a primary barrier to accessing timely treatment for childhood cancers in Pakistan. In a country where over 40% of the population resides in rural areas with limited access to specialized medical facilities, the economic burden of travel and treatment further exacerbates delays (6). Our study reinforces the need for government support and targeted financial aid programs to facilitate access to care for low-income families.

The impact of awareness, or the lack thereof, on delays in presentation was also evident. More than half (55.6%) of the participants reported a lack of understanding of the seriousness of retinoblastoma symptoms, leading to delays in seeking appropriate medical care. Similar trends have

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been observed in recent studies by (9). Where the lack of awareness about pediatric cancer symptoms among parents contributed significantly to delayed diagnoses. Public awareness campaigns focusing on early signs and symptoms of retinoblastoma could help reduce delays and improve outcomes by encouraging earlier presentation to healthcare facilities (15).

The study's findings also underscore the disparities between urban and rural healthcare access. Rural residents accounted for 68.4% of delayed presentations, a statistically significant finding ($p < 0.05$). This supports the observations made by (6, 16). Who highlighted that rural families often experience longer travel times and fewer referrals to tertiary care centers, contributing to advanced-stage presentations in pediatric oncology cases. Improving healthcare infrastructure in rural areas, such as establishing satellite oncology clinics, could bridge this gap and facilitate earlier diagnosis and treatment.

Compared to recent literature, our findings offer consistency in highlighting the socio-cultural and economic barriers contributing to delayed presentation in Pakistan. For instance, (6). Found similar trends, noting that rural residency and economic challenges significantly delayed the diagnosis of retinoblastoma and other childhood cancers. (7). Also emphasized the role of financial constraints in delaying access to specialized pediatric oncology services, aligning closely with our observations. Moreover, (16). both reported that cultural beliefs and reliance on non-medical remedies are pervasive issues in the healthcare-seeking behavior of families in Pakistan, mirroring our study's findings regarding the role of superstition and spiritual practices. These studies collectively point to a systemic issue within the healthcare framework of Pakistan, where cultural, economic, and geographic factors intersect to create significant delays in cancer care for children (17).

This study's emphasis on awareness as a critical factor is also supported by (9). Who highlighted the need for improved public education to combat misinformation and enhance recognition of early cancer symptoms. Thus, our study not only reinforces existing evidence but also adds to the understanding of specific barriers impacting children with retinoblastoma.

While this study provides valuable insights into the barriers to timely presentation for retinoblastoma in a Pakistani setting, some limitations should be acknowledged. The use of a purposive sampling method may limit the generalizability of findings to other regions. Additionally, the reliance on self-reported data from participants could introduce recall bias, particularly regarding the timelines of symptom onset and consultation. Future studies should consider larger, more diverse samples and include longitudinal data to capture long-term outcomes (18).

Conclusion

The delayed presentation of retinoblastoma in children in Pakistan is influenced by a complex interplay of socioeconomic, cultural, and geographic factors. Addressing these challenges requires a multi-faceted approach that includes public awareness campaigns, financial support for low-income families, and improved

healthcare access in rural areas. The alignment of our findings with recent literature highlights the urgency of implementing these changes to ensure better outcomes for children with retinoblastoma in Pakistan.

Declarations

Data Availability statement

All data generated or analyzed during the study are included in the manuscript.

Ethics approval and consent to participate

Approved by the department concerned. (IRBEC-NMH-24/22)

Consent for publication

Approved

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Conflict of interest

The authors declared the absence of a conflict of interest.

Author Contribution

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AQSA MALIK (POSTGRADUATE RESIDENT)

Conception of Study, Development of Research Methodology Design, Study Design, Review of manuscript, final approval of manuscript.

Conception of Study, Final approval of manuscript.

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