RESEARCH ARTICLE

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Retinoblastoma Incidence in Saudi Arabia: A 20-Year Analysis

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Abstract

Background: Retinoblastoma (Rb) represents the most frequent primary intraocular cancer in the pediatric population; yet comprehensive national data are limited in Saudi Arabia due to incomplete cancer registry coverage and underreporting. The present study systematically investigates the incidence, distribution, and trends of retinoblastoma across Saudi Arabia over two decades, utilizing robust data from the Saudi National Cancer Registry (SCR), a nationwide surveillance system overseen by the Ministry of Health. **Methods:** This retrospective population-based analysis included all children diagnosed with Rb in Saudi Arabia between January 1, 2000, and December 31, 2019. The study examined incidence rates and temporal patterns by age, regional location, and tumor histology. **Results:** Out of 542 documented cases (258 females, 284 males), the age-standardized incidence rate (ASIR) for children aged 0–4 years demonstrated an initial increase, peaking at 1.26 per 100,000 in 2003, followed by a gradual decline to 0.93 per 100,000 by 2019. Higher incidence rates were detected in major urban centers, especially Riyadh and Makkah, likely reflecting demographic density, enhanced diagnostic practices, and more accessible specialized care. Most tumors were either undifferentiated (Grade IV) or not otherwise specified (NOS, 63%), while diffuse retinoblastoma was rare (2%). Diagnosis was predominantly confirmed by histopathological evaluation (88.3%). **Conclusion:** This study offers the most comprehensive picture to date of retinoblastoma incidence and patterns in Saudi Arabia. The observed rising incidence, together with regional disparities, emphasizes the need for more refined cancer surveillance, equitable resource allocation, and accelerated early detection strategies, particularly in underserved areas. These findings provide essential baseline metrics to inform national cancer control policies and optimize equitable resource distribution.

Keywords: Cancer incidence, cancer registry, ocular oncology, pediatric cancer, Saudi Arabia, Retinoblastoma

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Introduction

Retinoblastoma (Rb) is recognized as the leading primary intraocular malignancy in children under the age of 15 with an incidence of 3.7 cases per million [1]. Globally, the ASIR for Rb showed an overall increasing trend, rising from 0.08 per 100,000, in 1990 to 0.09 per 100,000 in 2021 [2]. Retinoblastoma serves not only as a clinical challenge but also as a sensitive indicator of health system efficacy in the early detection and management of pediatric malignancies. Globally, Rb incidence is disproportionately higher in lower-resource settings where diagnosis is often delayed and outcomes can be poor [3].

Assessing the epidemiologic burden and temporal patterns of retinoblastoma is fundamental to the practice of pediatric ocular oncology. Accurate data support efforts to prioritize public health interventions, allocate diagnostic and treatment resources, and shape national policies intended to optimize survival and quality of life for affected children. Moreover, understanding variations in disease patterns helps direct attention to disparities in healthcare access and ensures efficient targeting of early screening and awareness programs [4, 5].

In Saudi Arabia, progress in establishing cancer registration systems has improved the landscape of pediatric cancer tracking. However, retinoblastoma-specific data have remained fragmented, often overshadowed by broader studies encompassing general pediatric or adult oncologic populations. The Saudi National Cancer Registry (SCR), operational since 1994 [6], has expanded its coverage and now represents a unique source of population-based incidence data, including information on tumor morphology, grade, laterality, and diagnostic modalities. Despite these advances, prior research has generally failed to address the specific epidemiology of Rb or has lacked granularity in reporting long-term, regionally

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detailed trends [7, 8]. This study aims to examine temporal and regional trends in retinoblastoma incidence in Saudi Arabia between 2000–2019.

Materials and Methods

Study Design and Data Source

This retrospective cohort study analyzed retinoblastoma (Rb) incidence trends in Saudi Arabia from January 1, 2000, and December 31, 2019. Data were extracted from the Saudi Cancer Registry (SCR), a population-based national registry maintained by the Saudi Ministry of Health. The SCR collects comprehensive cancer data from hospitals, clinics, pathology laboratories nationwide, and oncology centers across all regions of Saudi Arabia, ensuring robust representation of cancer cases, including pediatric malignancies such as Rb. However, the utilization of retrospective registry data inherently introduces potential selection biases and the risk of underreporting, particularly from remote or lower-resource rural facilities where case ascertainment and pathology documentation may be less consistent. The registry adheres to standardized coding protocols, including the International Classification of Diseases for Oncology (ICD-O-3), to ensure consistency in case ascertainment.

Study Population and Inclusion Criteria

All patients with a histopathologically or clinically confirmed Rb diagnosis, based on ICD-O-3 codes (C69.2 for retinoblastoma), during the study period were included, as recorded in the SCR. Patients of all ages were included to capture both typical pediatric cases and rare instances of Rb in older individuals, which may reflect late diagnoses or atypical presentations. Cases with incomplete or missing data on key variables, such as site, tumor characteristics, or disease stage (intraocular vs. extraocular), were excluded to ensure data quality. To account for potential underreporting, a sensitivity analysis was conducted to assess the impact of missing data on incidence estimates.

Data Collection and Variables

Data extracted from the SCR included patient demographics (age at diagnosis, sex, and region of residence), tumor characteristics (site, mode of diagnosis, histopathology, grade and stage at diagnosis), and year of diagnosis. Population estimates for Saudi Arabia, stratified by age group and calendar year, were sourced from the General Authority for Statistics (GASTAT) to calculate incidence rates [9]. To ensure accuracy, data were cross-verified with hospital-based registries where available, and duplicate entries were removed based on unique patient identifiers.

Statistical Analysis

Statistical analyses were performed using IBM SPSS Statistics (Version 27.0; IBM Corp, Armonk, NY, USA). Age-standardized incidence rates (ASIRs) were computed using the direct standardization method, with the Saudi 2020 census population and according to the World Health Organization (WHO) standard population as the reference. Incidence rates were computed separately for two pediatric age groups (0–4 years and 5–9 years) to reflect the typical age distribution and geographic region of Rb and expressed per 100,000 populations. Demographic variables (age, sex, region) and tumor characteristics (morphology, laterality, differentiation grade) were summarized using frequencies, proportions, and medians with interquartile ranges. Temporal trends in Rb incidence were analyzed using joinpoint regression modeling to identify significant shifts in ASIRs over the 20-year study period. The best-fitting log-linear model was selected to detect statistically significant joinpoints ($p < 0.05$) marking distinct phases in incidence trends. For each identified segment, the annual percent change (APC) and its corresponding 95% confidence interval (CI) were calculated to quantify the magnitude and direction of the change. Subgroup analyses by sex, region, and laterality were conducted to explore demographic, geographic, and clinical disparities. A p-value of <0.05 was considered statistically significant for all analyses.

Quality Control

To ensure data reliability, a random sample of 10% of cases was manually reviewed for consistency in coding and completeness. Discrepancies were resolved through consultation with SCR data managers. Additionally, the study accounted for potential under-diagnosis in rural regions by comparing regional incidence rates with national averages.

Results

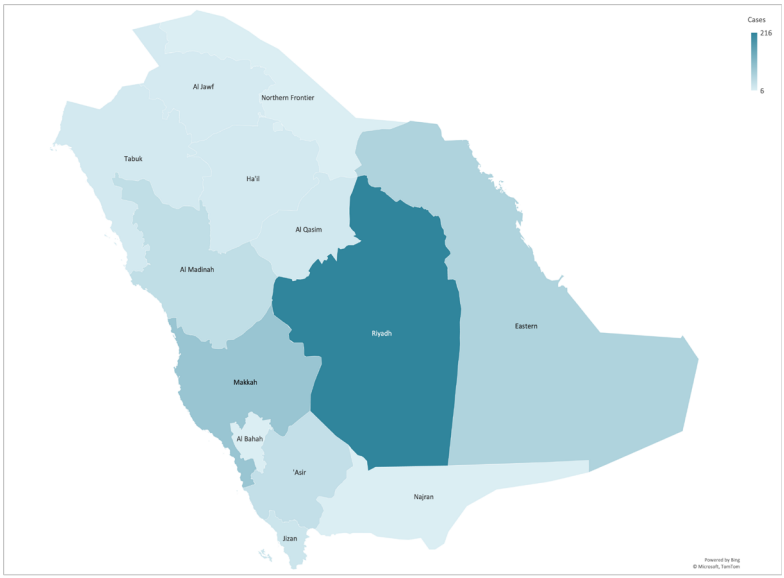
Patient Characteristics

A total of 542 patients with retinoblastoma (Rb) were identified from the Saudi Cancer Registry (SCR) between January 1, 2000, and December 31, 2019. The sociodemographic characteristics of these patients are summarized in Table 1. Of the total cohort, 284 (52.4%) were male and 258 (47.6%) were female, indicating a slight male predominance (male-to-female ratio: 1.1:1). The majority of diagnoses (n=195, 36.0%) occurred in children aged less than 1 year, consistent with the typical early onset of Rb. The age distribution of diagnoses shows 96.3% of cases occurring in children aged 0–4 years, reflecting the disease's predominance in early childhood.

Geographically, Rb cases were disproportionately concentrated in urban centers, with Riyadh accounting for 39.9% of cases, and Makkah for 16.2%, collectively representing over half of all cases. In contrast, the regions of Najran, Northern, and AlBaha each reported only six cases (1.1%), suggesting significant population density, regional disparities in either disease occurrence or diagnostic capabilities, or access to healthcare facilities, across regions (Figure 1).

Incidence of Retinoblastoma

Over the 20-year period (2000–2019), the age-standardized incidence rate (ASIR) of retinoblastoma among Saudi children aged 0–4 years averaged 1.05 per 100,000, with low variability (SD: 0.10). An early uptrend peaked at 1.26 per 100,000 in 2003, followed by a gradual



Regions include Riyadh, Makkah, and other provinces as recorded by the SCR.

Figure 1. Geographic Distribution of Retinoblastoma Cases Across Saudi Arabia Regions

decline to 0.91 per 100,000 in 2017–2018, and a slight rebound to 0.93 in 2019.

Variance analysis indicated overall stability in rates, but with two distinct temporal phases. Joinpoint regression analysis identified a single statistically significant joinpoint in 2004, marking a shift from a period of increasing rates (2000–2004) with an estimated annual percent change (APC) of approximately +6.3% per year ($p < 0.05$) to a declining phase from 2004–2019, during which the APC was approximately –2.0% per year ($p < 0.05$). This pattern suggests an initial rise in incidence during the early 2000s, potentially reflecting changes in case detection or reporting, followed by a sustained reduction in rates over the subsequent 15 years (Figure 2).

Table 1. Sociodemographic Characteristics of Retinoblastoma Patients

Variable	Category	No.	%
Gender	Female	258	47.6
	Male	284	52.4
Age Category	<1 year	195	36
	One year	158	29.2
	Two years	91	16.8
	≥ Three years	98	18.1
Region	Riyadh	216	39.9
	Makkah	88	16.2
	Eastern	60	11.4
	Madinah	39	7.2
	Asir	35	6.5
	Jazan	24	4.4
	Qassim	18	3.3
	Hail	16	3
	Tabouk	15	2.8
	Jouf	13	2.4
	AlBaha	6	1.1
	Najran	6	1.1
	Northern	6	1.1

Tumors characteristics

The analysis of the tumors' characteristics focused on five key areas: site, mode of diagnosis, histopathology, tumor grade, and extension as shown in Table 3. Left-eye involvement was the most common presentation of the disease, accounting for 39.3% of cases. Right-eye involvement was less frequent at 30.6%, with bilateral disease affecting both eyes observed in 30.1% of patients. Histological analysis was the primary diagnostic method, accounting for 88.3% of cases. Other approaches, such as clinical examination, medical imaging and cytology, were used far less frequently.

Based on tumor histopathology, the most common variant was Not Otherwise Specified (NOS), which accounted for 62.9% of cases (341 patients). The undifferentiated subtype was the next most prevalent, with 143 cases. Differentiated tumors were observed in 47 patients, while diffuse retinoblastoma was the least common, representing a mere 2% of the total, with only 11 cases. In contrast, tumor grade showed less variation. The majority of cases were Grade IV, comprising 30.6% (166 patients), closely followed by cases where the grade information was unavailable, at 29.7% (161 patients). The remaining grades I, II, and III showed an almost equal distribution. Local tumor extension was the most common presentation, accounting for 55.5% of cases. Regional extension was less frequent at 31.9%, while distant metastasis was rare, observed in only 4.1% of cases.

Discussion

This nationwide investigation provides a 20-year overview (2000-2019) of retinoblastoma (Rb) in Saudi Arabia using data from the Saudi Cancer Registry (SCR), documenting 542 pediatric cases. The analysis

Table 2. Annual Age-Standardized Incidence Rates (ASIRs) of Retinoblastoma Among Saudi Children by Age Group, 2000–2019

Year	No. cases (0–4 yrs)	% (0–4 yrs)	No. cases (5–9 yrs)	% (5–9 yrs)	ASIR (0–4 yrs)	ASIR (5–9 yrs)
2000	19	86.4	3	13.6	0.98	0.12
2001	25	96.2	1	3.8	0.99	0.04
2002	26	92.9	2	7.1	1.16	0.09
2003	23	95.8	1	4.2	1.26	0.05
2004	26	92.9	2	7.1	1.23	0.09
2005	26	96.3	1	3.7	1.2	0.04
2006	24	100	0	0	1.15	0
2007	29	100	0	0	1.14	0
2008	24	100	0	0	1.11	0
2009	23	100	0	0	1.1	0
2010	26	100	0	0	1.04	0
2011	23	92	2	8	1.02	0.09
2012	32	94.1	2	5.9	1	0.09
2013	31	96.9	1	3.1	0.98	0.04
2014	27	100	0	0	0.96	0
2015	29	100	0	0	0.94	0
2016	27	96.4	1	3.6	0.92	0.04
2017	28	93.3	2	6.7	0.91	0.08
2018	25	96.2	1	3.8	0.91	0.04
2019	29	96.7	1	3.3	0.93	0.04
ASIR					1.05	0.04

Note: ASIR, Age-standardized incidence rate (per 100,000); yrs, years.

identifies demographic distributions, geographic patterns, tumor characteristics, and temporal shifts, which are contextualized with national, regional, and global findings. Incidence remained stable in the early years but rose in the latter decade, a trend likely attributable to population growth, improved registry coverage, heightened public awareness, and expanded pediatric oncology capacity. Such patterns align with observations from other middle-income countries undergoing healthcare system strengthening [3, 4].

Demographic Analysis

Retinoblastoma (Rb) predominantly affects young children globally, typically manifesting before age five, driven by genetic factors such as RB1 mutations and its aggressive pathology [3, 10, 11]. The Saudi dataset aligns with this pattern, with most cases occurring in children under five, emphasizing the need for early screening and

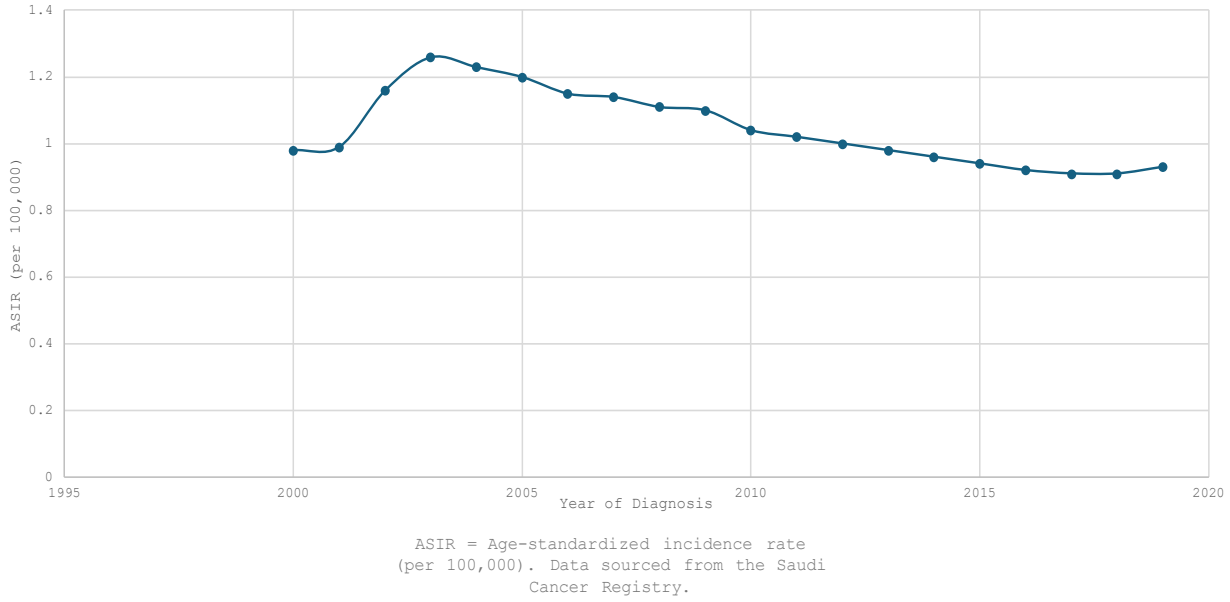


Figure 2. Annual Age-Standardized Incidence Rates (ASIR) of Retinoblastoma Among Saudi Children (2000–2019).

Table 3. Tumor Characteristics of the Retinoblastoma Patients

Variable	Category	No.	%
Site	Right Eye	166	30.6
	Left Eye	213	39.3
	Bilateral	163	30.1
Mode of Diagnosis	Clinical	56	10.3
	Cytology	4	0.7
	Histology	478	88.3
	Unknown	4	0.7
Histopathological types	NOS	341	62.9
	Differentiated	47	8.7
	Undifferentiated	143	26.4
	Diffuse	11	2
Tumor Grade	Grade I	74	13.7
	Grade II	65	12
	Grade III	76	14
	Grade IV	166	30.6
	Unknown	161	29.7
Extension	Localized	301	55.5
	Regional	173	31.9
	Distant	22	4.1
	Unknown	46	8.5

vigilant primary care to improve outcomes [3]. Analysis of the cohort revealed a modest male predominance (52.4% male vs. 47.6% female, ratio 1.1:1), consistent with global trends showing a slight male bias [12]. Of the cases, 96.3% were diagnosed in children aged 0–4 years, with 36.0% identified before their first birthday, reflecting the early onset characteristic of Rb worldwide [13]. This age profile is comparable to findings in other Middle Eastern nations, such as Lebanon, where over 90% of diagnoses occurred before age five [14]. In contrast, high-income countries like the United States benefit from robust neonatal screening, enabling earlier detection of bilateral cases, whereas the median age at diagnosis in Saudi Arabia suggests delays in identifying unilateral cases, potentially due to limited healthcare access [15].

Regional Disparities

The analysis of Rb incidence in Saudi Arabia revealed substantial regional variations, with urban centers such as Riyadh (39.9%) and Makkah (16.2%) accounting for the majority of cases, while rural regions like Najran, Northern Borders, and Al-Baha each contributed only 1.1%. This urban-centric distribution likely reflects greater population density and enhanced access to specialized facilities, such as the King Khalid Eye Specialist Hospital in Riyadh, rather than inherent differences in disease prevalence [16]. Comparable trends are observed in other Middle Eastern countries; for example, Lebanon exhibits lower reported Rb incidence in rural and refugee populations due to limited diagnostic capabilities [14]. Globally, low- and middle-income countries (LMICs) mirror this pattern, with urban areas showing higher Rb rates due to centralized oncology services, as seen in regions like sub-Saharan Africa and South Asia [5]. Saudi-based research supports these findings, highlighting increased case referrals from central regions equipped with advanced healthcare infrastructure [8]. Socioeconomic challenges and a shortage of specialized personnel in remote areas significantly contribute to these disparities, compounded by cultural reluctance toward treatments like enucleation, a common issue in the Middle East [17, 18].

In Saudi Arabia, the predominance of Rb cases in central and western regions, particularly Riyadh, which accounts for nearly 40% of referrals, is likely driven by dense populations, efficient cancer registries, and proximity to specialized care centers [4, 11, 19]. In contrast, rural areas such as Jazan, Asir, and Northern Borders report notably fewer cases, reflecting under diagnosis due to inadequate healthcare infrastructure and barriers to accessing medical services rather than a true absence of disease [6, 17]. Although Saudi Arabia's healthcare and registry systems produce age-adjusted Rb incidence rates comparable to global standards, regional inequities persist due to uneven distribution of resources and referral patterns [4, 20, 21]. These findings emphasize persistent challenges in ensuring equitable healthcare access across urban and rural areas, aligning with broader regional and global trends.

Temporal Trends

The incidence of Rb in Saudi Arabia demonstrated an initial rise in the early 2000s, peaking in 2003–2004, followed by a sustained, gradual decline through 2019. For children aged 0–4 years, the average age-standardized incidence rate (ASIR) was 1.05 per 100,000 (approximately 10.5 per million), translating to about 1 in 16,000–18,000 live births. This rate aligns with global estimates but reflects an upward trend, consistent with worldwide increases in reported Rb cases from 1990 to 2021, driven by enhanced registries and greater awareness [11, 22]. Earlier Saudi studies reported incidence rates ranging from 1 in 11,580 to 1 in 16,667 live births, with occasional declines possibly linked to improved preventive measures or reporting variations [7, 23]. Joinpoint analysis identified a pivotal shift in 2004, with an initial rise (APC +6.3%) followed by a decline (APC -2.0%), likely reflecting improved Saudi Cancer Registry (SCR) coverage. Globally, Rb ASIRs have increased (AAPC 0.67 from 1990–2021), with mortality decreasing in high-income countries but remaining a challenge in LMICs, including parts of the Middle East influenced by high-burden regions [5, 11, 22]. These trends suggest stability in incidence rates, with potential influences from improved diagnostics, reporting, and public health interventions, as seen in Table 2.

Tumor Characteristics

In Saudi Arabia, left eye involvement in retinoblastoma was more frequent (39.3%), and bilateral cases accounted for 30.1%, consistent with global rates (20–30%). This distribution highlights a notable predisposition for the disease to manifest unilaterally in the left eye, which is a significant finding in clinical epidemiology. The high rate of bilateral cases suggests a significant role of

genetic factors, likely influenced by Saudi Arabia's high consanguinity rates, which increase the risk of heritable retinoblastoma due to germline RB1 mutations [24]. In the context of retinoblastoma (Rb) diagnosis in Saudi Arabia, biopsy-based methods remain the predominant approach, accounting for 88.3% of cases, which aligns with global standards. However, there is a growing trend toward the use of advanced imaging techniques, such as MRI and ultrasound, particularly in well-equipped medical facilities [16]. These observations highlight the importance of establishing uniform diagnostic criteria and enhancing pathology reporting practices to ensure consistency and accuracy in Rb management across Saudi Arabia. Such improvements could further optimize early detection, treatment planning, and overall patient outcomes.

The Rb cohort in Saudi Arabia exhibited a predominance of the not otherwise specified (NOS) tumor morphology (62.9%), with undifferentiated tumors at 26.4%, differentiated at 8.7%, and diffuse subtypes at 2.0%. This distribution mirrors global patterns where NOS classifications prevail due to diagnostic limitations, yet contrasts with some Saudi studies noting a higher prevalence of diffuse Rb (up to 7.9%) [4]. The significant share of high-grade (Grade IV) tumors (30.6%) points to aggressive disease, potentially tied to RB1 gene mutations linked to poor differentiation in hereditary cases [24]. Incomplete tumor grade documentation in 29.7% of cases highlights persistent challenges in standardized pathology reporting. This is likely attributable to inconsistent reporting practices across regional centers during the registry's earlier years, as well as cases diagnosed purely clinically without enucleation, which inherently limits the ability to comprehensively correlate incidence trends with tumor severity, a concern in global registries [3, 10].

Most cases presented as localized disease (55.5%), followed by regional (31.9%) and distant (4.1%) extension, suggesting earlier detection than in many low- and middle-income countries (LMICs), where extraocular disease often exceeds 50% [25]. However, localized disease is less common than in high-income settings like the US, where it reaches 70-80% due to advanced diagnostics [15]. This distribution suggests that the disease is typically identified and treated before it progresses to advanced stages, which is a positive prognostic indicator for patient outcomes.

Retinoblastoma Detection

This study highlights advancements in Rb detection in Saudi Arabia, driven by progress in pediatric oncology and cancer registry systems. However, regional disparities and challenges in early diagnosis persist, particularly in rural areas. Saudi Arabia's Rb incidence trends, which are stable-to-increasing, align with global patterns, showing improved outcomes compared to many LMICs but falling short of high-income nations in terms of globe preservation and metastasis prevention [26]. The reliance on registry data introduces limitations, as underreporting in remote regions likely underestimates true incidence, while the absence of post-2020 data limits insights into the impact of the COVID-19 pandemic. Furthermore, the lack of genetic and environmental data, such as RB1 mutations and consanguinity patterns, restricts understanding of etiological factors.

Limitations, and Future Directions in Saudi Arabia

Key limitations include inconsistent pathology reporting, with nearly 30% of cases lacking defined tumor grades, and incomplete registry coverage, particularly in rural areas, which likely underestimates the national Rb burden. Based on the available data, key limitations of the study are the absence of clinical information on signs and symptoms. This indicates that the data analysis was restricted to other variables and did not include patient-reported or physician-observed clinical manifestations. The absence of genetic and familial data hinders the identification of hereditary Rb cases, while limited prospective outcome tracking and minimal integration of socioeconomic or environmental factors further constrain the study's scope [4, 10, 21]. Furthermore, the registry inherently lacks comprehensive survival data and specific access-to-care metrics, which limits our ability to fully evaluate long-term patient outcomes and the distinct socioeconomic barriers influencing delayed diagnoses in rural areas. These challenges are not unique to Saudi Arabia, as similar issues with data quality and interpretability are noted in Middle Eastern and global Rb registries [3, 4, 17].

Public Health Implications

The geographic concentration of retinoblastoma cases in major urban centers, contrasted with the substantial proportion of unclassified tumor grades, highlights critical gaps in decentralized pediatric ocular care. To improve survival and outcomes, national cancer control strategies must prioritize equitable resource distribution across all provinces. This requires the implementation of targeted early screening initiatives and the standardization of primary referral pathways in rural and underserved regions. By equipping peripheral healthcare facilities with advanced diagnostic capabilities and standardized pathology protocols, the health system can bridge the current geographic divide, accelerating early detection and ensuring timely, specialized interventions for all at-risk pediatric patients.

In conclusion, Rb in Saudi Arabia reflects global and regional demographic and incidence patterns but is marked by distinct challenges, including inadequate rural reporting, limited access to care, inconsistent pathology documentation, and underutilization of genetic diagnostics. While enhanced registry systems demonstrate national progress, regional inequities underscore the need for targeted health system interventions. Priorities include region-specific educational campaigns, expanded outreach programs, strengthened early detection efforts, increased investment in genetic diagnostics, and the adoption of standardized pathology reporting protocols. This study provides essential baseline data for future national screening strategies and international epidemiologic comparisons.

Author Contribution Statement

SS, AB, and MB coordinated the study, contributed to data acquisition, analyzed and interpreted the data, and drafted the manuscript. MB, AA, RA, YA, WK, and IK analyzed and interpreted the data and revised the manuscript for important intellectual content. AA, SS, HJ, and WK coordinated the study, contributed to data acquisition, interpreted the data, and revised the manuscript for important intellectual content. SS, AB, MB, WK, HJ, and IK designed the study, contributed to the methodology, and revised the manuscript for important intellectual content. All authors read and approved the final manuscript.

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Study approval and thesis status

This research was conducted as part of an approved medical student research project at Almaarefa University.

Ethical considerations

Ethical approval was obtained from the Institutional Review Board (IRB) of Almaarefa University (Ref No. IRB24-077). All data extracted from the Saudi Cancer Registry were de-identified to protect patient confidentiality, and the study adhered to the principles of the Declaration of Helsinki and national data protection regulations.

Availability of data

Data can be obtained by an official request to the Saudi Cancer Registry.

Study registration

The study was not registered in a clinical trial or systematic review database, as it is a retrospective population-based registry analysis.

Reporting guidelines

The manuscript was prepared in accordance with the REPCAN (Guideline for REporting Population-based CANcer Registry Data) [27] to ensure comprehensive reporting.

List of abbreviations

Retinoblastoma (Rb), General Authority for Statistics (GASTAT), Saudi Cancer Registry (SCR), annual percent change (APC), not otherwise specified (NOS), Age-Standardized Incidence Rates (ASIRs), low- and middle-income countries (LMICs),

Competing interests

The authors declare no competing interests.

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