What is Retinoblastoma ? Evaluate the Knowledge and Awareness of General Population and Health Provider in Saudi Arabia

Abdulrahman Alamri, MD* Jawaher Hassan Ali Hazazi, MBBS** Sarah Ibrahim summan , MBBS** Shahd Abdulhakeem Al Hamdan, MBBS** Waad Saber Alharthy, MBBS** Bayader Manea Alraqea, MBBS** Waad Khalid A Albadawi, MBBS** Nada Abdullah Ali Asiri, MBBS** Rozan Abdulaziz Alghamdi, MBBS** Renad Mohammed Abdullah Alshehri, MBBS** Reem Thalib Hadhir Alalyani**

ABSTRACT

Study Design: Cross sectional

Background: Retinoblastoma represents around 3% of all malignancies in children under the age of 15, making it the most common primary intraocular tumor in childhood. The retinoblastoma tumor-suppressor gene (RB1 gene) biallelic mutation that causes it to begin, with a propensity for cone development, is the source of the condition's primitive retinoblastoma origins.

Methods: Data for this cross-sectional study were gathered using a specially designed questionnaire. A demographic questionnaire with questions about knowledge and awareness of RB. The questionnaire was created following a series of conversations amongst the panel of experts, which included linguists, researchers, and subject specialists. The questionnaire's Cronbach alpha coefficient was computed. The research will be carried out in Saudi Arabia's

Result: Table 2, 27.78% of the respondents were in direct connection with larger number of kids, 41.67% opted yes in response of the questions that malignant tumor can effect eyes, 23.89% have heard before about RB, 55.56% opted that tumor can effect both eyes, hereditary (25.93%) was the major cause of this diseases ,protrusion (40.93%) was the major symptoms, 64.81% agreed to visit doctor.

Conclusion: It is recommended that policymakers aid in the raising of awareness regarding retinoblastoma by launching campaigns during a designated time each year. In addition, governments are in charge of supplying the required screening to medical professionals.

Keywords: Retinoblastoma, Tumor, Healthcare, Awareness

INTRODUCTION

Retinoblastoma represents around 3% of all malignancies in children under the age of 15, making it the most common primary intraocular tumor in childhood. The retinoblastoma tumor-suppressor gene (RB1 gene) biallelic mutation that causes it to begin, with a propensity for cone development, is the source of the condition's primitive retinoblastoma origins. Leukocoria (60%) is the most frequent presenting and warning indication in children with retinoblastoma, followed by strabismus (20%). The remaining twenty percent exhibit abnormal symptoms such as orbital cellulites, glaucoma, hemorrhage, uveitis, and ocular revascularization. These symptoms are, therefore, regarded as late warning indicators with a dismal outlook for survival and global salvage. Extra ocular involvement with proptosis is the most common presenting symptom in emerging nations[1-3].

About 45% of instances of retinoblastoma are heritable, making it the first cancer to be identified as a hereditary illness. The general population's incredibly low incidence of retinoblastoma makes mass screening programs less practical and cost-effective. Screening children who have a high chance of getting retinoblastoma, such as siblings and first- and second-degree relatives of the affected children, is an alternate but workable technique known as "targeted screening." Precise clinical screening of relatives and potential progeny is made possible through constitutional DNA genetic testing. In order to identify minor, easily treatable cancers, all at-risk children should have numerous examinations under anesthesia (EUA) throughout the first three years of life, even in the absence of genetic testing[4-5].

Retinoblastoma is always present in the world, with one instance for every 15,000–20,000 livebirths, or roughly 9000 new cases year. There is no verified population or geographic hotspots for the disorder. The largest illness load is found in regions with high birth rates and sizable populations, including Asia and Africa Retinoblastoma, for instance, is the most prevalent eye tumor and one of the top five children cancers in Nigeria. The highest mortality rates are found in areas with the highest prevalence: in Asia and Africa, 40–70% of children with retinoblastoma pass away, while just 3–5% do so in Europe, Canada, and the United States[6-7].

In Canada, 25 children receive a new diagnosis of retinoblastoma (RB), a pediatric eye cancer. A tumor can grow in one or both eyes as a result of a biallelic mutation in the RB1 gene. As a result of the disease's

* Department of Ophthalmology
College of Medicine, King Khalid university
Saudi Arabia.
E-mail: amamri@gmail.com
** College of Medicine, King Khalid university

course and treatment, children may experience visual impairment in one or both eyes. The main objective of this study is to Evaluate the knowledge and awareness of general population and health provider in Saudi Arabia.

METHODS

Data for this cross-sectional study were gathered using a specially designed questionnaire. A demographic questionnaire with questions about knowledge and awareness of RB. The questionnaire was created following a series of conversations amongst the panel of experts, which included linguists, researchers, and subject specialists. The questionnaire's Cronbach alpha coefficient was computed. The research will be carried out in Saudi Arabia's

Following data collection, the information was coded and input into the SPSS ver.20 program to analyze descriptive statistics, which included computing mean standard deviation, frequencies, and percentages.

Regression analysis is done at the 5% level of significance in order to calculate the significance differences. Using an electronic version of the questionnaire, information was gathered from members of the public, healthcare professionals, and other sources. Saudi Arabia's King Khalid University provided ethical approval. The time frame for the study was January 2022–April 2022.

RESULTS

The cronbach alpha of the questionnaire was 0.82. Total respondent was 540, the mean (SD) of the age was 33.5(12.8) 55.56% were males while 44.44% were females, 30.56% had Masters and above level of education.29.26% had education sector experience ,15.56% had healthcare experiences. 44.4% had monthly income above 15000 SAR. (Table 1)

Table 1: Demographics

Variable		Freq.	Percentage
Age	18-30	128	23.70%
	31-50	289	53.52%
	above 50	123	22.78%
Gender	Male	300	55.56%
	Female	240	44.44%
Education	Elementary	120	22.22%
	Secondary	75	13.89%
	College	180	33.33%
	Master and above	165	30.56%
Profession	Education sector	158	29.26%
	Industry sector	298	55.19%
	Health profession	84	15.56%
Monthly income in SAR	Less than 5000	100	18.52%
	5000-15000	200	37.04%
	above 15000	240	44.44%

Table 2: Awareness and Practices

Are you in direct connection with large amount of children?	Freq.	%
Yes	150	27.78%
No	400	74.07%
Did you know that malignant tumors may affect the eye?		
Yes	225	41.67%
No	315	58.33%
Have you ever heard of retinoblastoma, which may affect children and appear shortly after birth?		
Yes	129	23.89%
No	211	39.07%
I don't know	200	37.04%
Tumor in the eye , choose an answer from the following:		
The tumor only affects one eye.	125	23.15%
The tumor can affect both eyes.	300	55.56%
I don't know the answer	115	21.30%
What is the cause of the tumor in your opinion		
hereditary	140	25.93%
for no reason	126	23.33%
diseases during pregnancy for mother	75	13.89%
drugs or treatments during pregnancy	74	13.70%
I don't know	45	8.33%
Multiple options	80	14.81%
What are the symptoms that you may see on a child to suspect the presence of a tumor		
Pupil is white	125	23.15%
protrusion in the eye	221	40.93%
inflammation of severe eye does not respond to treatment	84	15.56%
I don't know	31	5.74%
Multiple options	79	14.63%
Do you think that any of the above symptoms need to see a doctor as soon as possible?		
Yes	350	64.81%
No	90	16.67%
I don't know	100	18.52%

As per table 2, 27.78% of the respondents were in direct connection with larger number of kids, 41.67% opted yes in response of the questions that malignant tumor can effect eyes, 23.89% have heard before about RB, 55.56% opted that tumor can effect both eyes, hereditary (25.93%) was the major cause of this diseases ,protrusion (40.93%) was the major symptoms, 64.81% agreed to visit doctor.

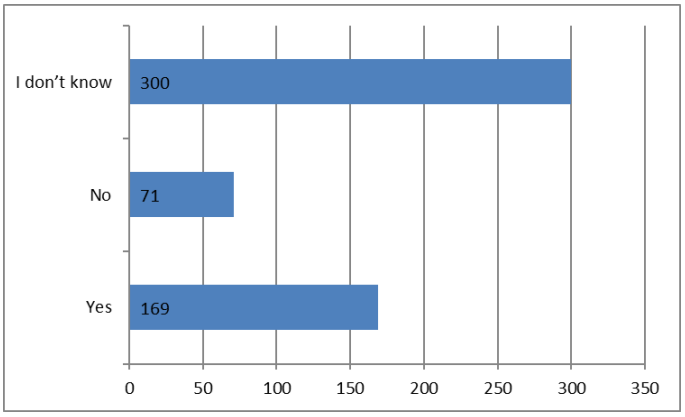

Figure 1: Is there a specialized oncology center in your country?

As per Figure 1169 respondents agreed that , their country have specialized oncology center.

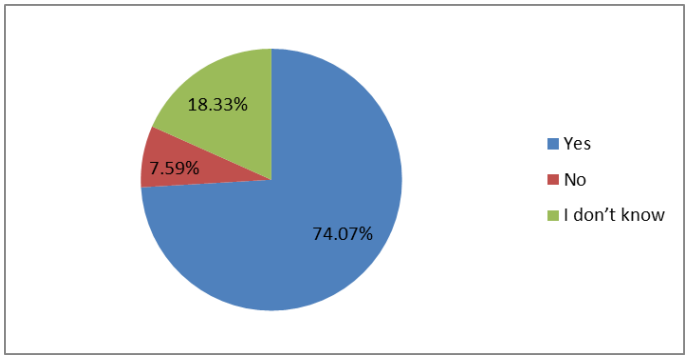

Figure 2: Routine examination of eyes of children recommended by you

As per figure 2, 74.07% agreed that routine examination from doctor is essential

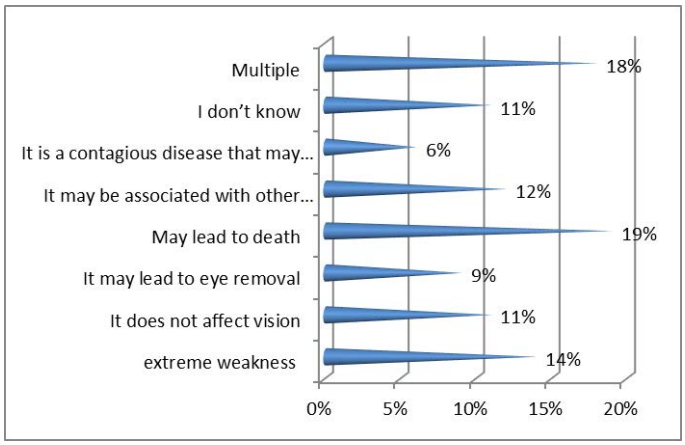

Figure 3: Complications

As per figure 3 extreme weakness is one of the major complication followed by eye removal and death.

Table 3: Regression Analysis

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	0.979	0.11		8.926	0
	Educational level?	0.012	0.028	0.019	0.422	0.674
	Gender	0.121	0.045	0.125	2.718	***0.001***
	Profession	0.005	0.011	0.026	0.43	0.668
	Monthly income	15	0.015	-43	-979	0.28

As per table 3, we have observed the significant gender differences with the awareness.

DISCUSSION

Retinoblastoma diagnosis has significant long-term effects on the person receiving the diagnosis as well as their family members and caregivers. Retinoblastoma patients have a special chance for knowledge sharing and co-creation of research since they frequently have long-standing links with the medical and scientific communities. Because of their personal experiences with the disease, patients and their families acquire a particular level of competence and understanding about retinoblastoma. This encompasses inclinations, perspectives on danger, principles, customs, and actions[8-10].

In our study we have observed significant gender difference regarding the awareness, while The majority of the patients (84.7%) in the Global Retinoblastoma Study Group, a recent large multinational study involving 4351 newly diagnosed patients with retinoblastoma recruited from 278 retinoblastoma centers in 153 countries, were from low- and middle-income countries, according to the study's authors.15 Additionally, they discovered that children in low- and middle-income countries (LMICs) received their diagnoses at a later age (30.5 months on average) than children in high-income countries (HICs) (14.1 months on average)[11].

Numerous research found that there is a need to increase healthcare practitioners' understanding of cancer and related health conditions, Numerous research emphasized the necessity of taking the right actions to improve healthcare professionals' and the general public's awareness. Numerous studies have shown that cancer patients most frequently refer themselves to and prefer to receive information from healthcare professionals. To improve early detection and prompt referral of children with retinoblastoma, medical professionals such as physicians and nurses must get ongoing education in medicine[12-13].

Up to two-thirds of children are diagnosed with intraocular malignancy before the age of two years, and the majority (95%) are diagnosed before the age of five years, according to a World Health Organization (WHO) report. The detection of retinoblastoma in the first 28 days of life, known as neonatal retinoblastoma, is effective in developed countries when it is prompted by a history of an affected relative or coincidentally during screening for other retinal problems. During this time, 44-71% of familial retinoblastoma's and 7%–10% of all retinoblastoma's are detected. Compared to industrialized nations, the diagnosis of retinoblastoma during the newborn period is less common in poor nations and is typically made when the disease has progressed[12].

There are certain restrictions, though. Determining the causal relationship between survey variables was hampered by the cross-sectional survey research design. Our capacity to compare our results with Arabic-speaking nations with comparable healthcare systems and cultures was hampered by the paucity of research that examined the state of knowledge on retinoblastoma in the Middle East and Arab nations in particular. Our research employed a quantitative approach. with pre-programmed answers that would have hindered the gathering of respondents' opinions to produce a variety of insightful qualitative data.

Additionally, since our data collection method was an online survey, it's possible that some members of the intended group were overlooked[12-14].

CONCLUSION

Low levels of awareness and knowledge regarding retinoblastoma were shown by the general public and healthcare professionals, which causes cases to be discovered later in life. Retinoblastoma early identification is essential for effective treatment and a better prognosis. Therefore, initiatives ought to focus on raising community knowledge of the disease's early warning symptoms and individuals who are more susceptible to it.

To further enhance clinical screening abilities, all healthcare professionals especially those who work directly with children should receive thorough training.

It is recommended that policymakers aid in the raising of awareness regarding retinoblastoma by launching campaigns during a designated time each year. In addition, governments are in charge of supplying the required screening to medical professionals.

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Potential Conflicts of Interest: None

Competing Interest: None

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