

First Pakistan National Eye Cancer Survey

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Abstract

Background: This is the report of first eye national eye cancer survey in Pakistan under the auspices of National Committee of Eye Health. Eye care institutions involved in eye cancer control were approached to provide the annual data on tumors of the eye. **Methods:** All major stakeholders involved in prevention and control of eye cancer were requested to provide information related to situation analysis of eye cancer services in the country through a questionnaire. Overall, 1705 eye tumors were reported annually. 51% were malignant and 49% were benign eye tumors. From each province of the country, where data was available, benign and malignant tumors were separately identified. **Results:** The data showed that about 877 cases of eye cancers were diagnosed in a year. 38% of these were eyelid cancers, 31% were intraocular tumors, 16% were ocular surface tumors, while 15% were cancers of the orbit. KpK region had highest percentage of eyelid cancers (72%) followed by 14% of ocular surface tumors, 10% of intraocular tumors and 4% were cancers of the orbit. Sindh province had highest percentage of intraocular cancers (40%) followed by 31% of eyelid cancers, 19% of cancers of the orbit and 10% of ocular surface tumors. Like KpK, Punjab had highest proportion of eyelid malignancies (37%) followed by 29% intraocular cancers, 20% of ocular surface tumors and 14% of orbital malignancies. **Conclusion:** In terms of population, it is estimated that there are 4 cases of eye cancer per million population of Pakistan and an almost similar number of benign eye tumors. Thus, an estimated 8 cases of eye tumors per million population are examined annually.

Keywords: Eye malignancies- Eye Surveys- Pakistan- Ophthalmology- Tumors of eye

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Introduction

There is limited data about orbito-ocular tumors in Pakistan. Apart from the paucity of epidemiological data, very little is known about the challenges, both from the perspective of the service provider and the users, and the cost implications.

Cancers of the eye and orbit often present as challenging clinical presentations for ophthalmologists. The patients affected by orbito-ocular tumors often present late when treatment options are minimal. The cancers of the eye and orbit are lost in the shadows of major blinding and vision impairing conditions like cataract, refractive errors, corneal opacities, glaucoma and diabetic retinopathy. The skilled human resources required for management of eye cancer are also limited in the country. Focus of subspecialty training in the discipline of ophthalmology is more on anterior segment

and vitreo-retina. There are few training centers and even fewer subspecialist posts for oculoplastics and ocular oncology in tertiary hospitals in the public sector.

According to the International Agency for Research on Cancer, Pakistan has an age standardized incidence rate of cancer of 110.4 per 100,000 population [1]. Based on cancer data available, it is estimated that the number of new cases with cancer (all types) in 2020 were 178,000. This number is expected to rise to 319,000 by 2040. According to data available from the WHO Cancer Country profile, the annual cancer cases (0 – 14 years) in Pakistan in 2020 were 8213 [2]. Retinoblastoma accounted for 265 cases out of 8213 cases indicating a frequency of 3.2% of childhood cancers reported.

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Scope and Purpose

The National Committee for Eye Health (NCEH), Ministry of National Health Services, Regulations and Coordination, developed the National Integrated People-Centered Eye Care Plan (IPCEC) 2020 – 2025. One of the objectives of the IPCEC Plan was to develop an interim strategy for prevention and control of eye cancers. As a first step, it was decided to determine the situational status of services and data for cancers of the eye and orbit in Pakistan by conducting a national survey through mapping service delivery centres providing subspecialty services for orbit, oculoplasty and ocular oncology. Consequently, we approached all these centers and requested them to provide us their annual data for eye tumors, both benign and malignant.

Methodology

A multi-pronged strategy was adopted for the situation analysis.

The first phase involved a situational survey from various centers in the country. A structured questionnaire was used for this purpose. The centers covered in this phase included the following:

(Pakistan has four provinces: Khyber Pakhtunkhwa (KpK) in north west, Punjab in north east, Baluchistan in south west and Sindh in southeast. Major referral centers for eye cancers in these provinces were considered for this data collection.)

- Khyber Pakhtunkhwa
- Khyber Teaching Hospital, Peshawar
- Punjab
- Armed Forces Institute of Ophthalmology, Rawalpindi
- Al-Shifa Trust Eye Hospital, Rawalpindi
- College of Ophthalmology and Allied Vision Sciences, Mayo Hospital, Lahore
- Sindh
- Al-Ibrahim Eye Hospital, Malir
- Chandka Medical College and Hospital, Larkana
- Jinnah Postgraduate Medical Centre, Karachi
- Khairpur Teaching Hospital, Khairpur
- LRBT Hospital, Karachi
- Sindh Institute of Ophthalmology and Visual Sciences, Hyderabad

In the second phase, the following categories of key informants were interviewed using a semi-structured questionnaire adapted for their specific area of expertise.

- Ophthalmologists
- Medical Oncologists
- Radiation Oncologists
- Public Health Professionals
- Cancer Genetics Researcher
- Social Support Group Professional

The coverage of the situational review included the following institutions:

Institutional perspectives:

- Pakistan Institute of Medical Sciences, Islamabad
 - Combined Military Hospital, Rawalpindi
 - Al-Shifa Trust Eye Hospital, Rawalpindi
 - Aga Khan University Hospital, Karachi
- Organizational perspectives were obtained from the following national

and international NGOs:

- CBM (Christoffel Blindenmission)
- Brien Holden Foundation
- Prevention of Blindness Programme, Baluchistan
- Quaid-i-Azam University Islamabad

Results

A) Magnitude of Eye Cancers

The information about the magnitude of eye cancer in Pakistan was gathered from major tertiary eye care centers of the country through written requests. In addition, stakeholders were also requested to share this information through the questionnaire as described under methodology. We obtained some information from three major provinces of Khyber Pakhtunkhwa, Punjab and Sindh which comprise over 90% of the country population. Annual frequency and type of eye cancers in Pakistan: Table 1 presents the annual frequency and types of eye cancers. The data shows about 877 cases of eye cancers were diagnosed in a year. 38% of these are eyelid cancers, 31% were intraocular tumors, 16 % were ocular surface tumors, while 15% of were cancers of the orbit.

KpK region had highest percentage of eyelid cancers (72%) followed by 14% of ocular surface tumors, 10% of intraocular tumors and 4% were cancers of the orbit. Sindh province had highest percentage of intraocular cancers (40%) followed by 31% of eyelid cancers, 19% of cancers of the orbit and 10% of ocular surface tumors. Like KpK, Punjab had highest proportion of eyelid malignancies (37%) followed by 29% intraocular cancers, 20% of ocular surface tumors and 14% of orbital malignancies.

Benign versus Malignant

In Sindh, the average frequency of eye tumors based on stakeholders' answers indicates that benign tumors comprise about 60%, while malignant tumors comprise about 40%. It is however the reverse in Punjab and Khyber Pakhtunkhwa, where malignant tumors comprise 60% of the cancer workload and benign tumors comprise 40%.

Based on the information reported in Table 2, the annual estimated frequency of benign tumors is calculated and extrapolated along with the overall frequency of eye tumors in Pakistan. It is presented in Table 3.

It is estimated that over 1700 eye tumors occur per year out of which around 51% are likely to be malignant and 49% benign. In terms of population, it is estimated that there are 4 cases of eye cancer per million population of Pakistan and an almost similar number of benign eye tumors. Overall, there are an estimated 8 cases of eye tumors (both benign and malignant) per million population that are examined annually. The WHO Pakistan Cancer Country Profile 2020 indicates that there are about 800+ General Cancers per million population in Pakistan. This suggests that eye tumors (benign and malignant) comprise about one percent of the total examined annually in the country, while 0.5% of malignancies in Pakistan are eye cancers.

Table 1. Annual Frequency and Types of Eye Cancer

Province	Institute	Tumors				Total
		Eyelid Tumors	Ocular surface tumors	Intraocular tumors	Orbital tumors	
Sindh	Al-Ibrahim (Based on 10 years data)	15	30	151	5	
		2 per year	3 per year	15 per year	01 per year	21
	Civil Hosp Karachi	0	0	15	0	15
	Chandka Medical College	6	4	6	2	18
	JPMC	31	7	13	11	62
	Khairpur	25		12		37
	LRBT Karachi	16	9	50	30	105
	SIOVS Hyderabad	10	6	6	12	34
	Total	90 (31%)	29 (10%)	117 (40%)	56 (19%)	292
KpK	Based on Khyber Teaching Hospital 3.5 years data	65 (72%)	13 (14%)	9 (10%)	3 (4%)	90
Punjab	ASTEH Rawalpindi	60	40	55	25	180
	AFIO Rawalpindi	30	20	25	10	85
	Mayo Hospital Lahore	90	40	65	35	230
	Total	180 (37%)	100 (20%)	145 (29%)	70 (14%)	495
Grand Total		335 (38%)	142 (16%)	271 (31%)	129 (15%)	877

B) Medical Products and Technology

The major medical products and technology involved in the management of eye cancer include resources for diagnosis like imaging, surgical treatment resources, drugs for adjuvant chemotherapy, provision of radiation followed by psychosocial and aesthetic rehabilitation and a long-term follow-up.

The stakeholders' analysis revealed that there are definite gaps in the provision of drugs and technology. The ophthalmologists' indicated the need of surgical equipment, especially for orbital surgery like suction machine, diathermy, and bone saw. Ret Cam, an essential diagnostic/screening/monitoring unit for one of the commonest eye cancers, retinoblastoma, is not available in many tertiary eye care centers. The availability of the facility of MRI/CAT scan, is an essential requirement. Specialist eye hospitals in the country do not have this facility, but public sector eye units as a part of tertiary general hospitals do have these facilities. According to WHO country cancer profile 2020 [2], there are 17.2 CT scanners and 4.6 MRI scanners per 10,000 cancer patients. As a result, long waiting times as well as breakdowns are some of the issues that delay the start of cancer chemo/radiation.

The major issue in radiation oncology across the country is inadequate number of radiation machines.

According to the information gathered during this survey, there is an acute shortfall of experts and radiotherapy equipment in Pakistan. Pakistan needs 200 linear accelerators. However, currently there are hardly 30 units available at an average of two machines per department. The large workload on these machines also undermines the safety and efficacy of treatment, not to mention the long waiting times. According to WHO country profile, the number of radiation oncologists in the country is 1.8 per 10,000 cancer patients [2].

With regards to chemotherapy facilities in Pakistan, the survey revealed that at present the situation of medical oncology services in the major cities of the country is as follows:

- Islamabad- 3
- Rawalpindi – 4
- Lahore – 6
- Multan – 3
- Faisalabad – 1
- Karachi – 5
- Peshawar – 2

In general, the availability of chemotherapy facilities is not a major issue, but standard procedures are not being followed at times due to lack of resources and number of patients. For example, some leading oncologists informed that availability of Chemo-Cabinet (a lamellar

Table 2. Annual Workload of Eye Tumours in Pakistan

Region	Benign (%)	Malignant (%)	Total
Khyber Pakhtunkhwa	60 (40)	90 (60)	150
Punjab	330 (40)	495 (60)	825
Sindh	438 (60)	292 (40)	730
Total	828 (49)	877 (51)	1705

Table 3. Estimated Frequency of Eye Cancer Per Million Population

Region*	Population	Benign per million	Malignant per million	Total eye tumors per million
Khyber Pakhtunkhwa	40,856,097	1.5	2.25	3.75 / million
Punjab including Islamabad capital territory	130,052,785	2.53	3.8	6.3 / million
Sindh	55,696,147	8	5.3	13.30 / million
Total	226,605,029	3.66	3.88	7.54 / million

*Pakistan Bureau of Statistics -2023 Digital Census (3)

flow equipment needed to prepared chemo drugs in clean atmosphere) is also an issue and must be available. The major issue in chemotherapy however is cost of the treatment.

C) Health Financing

Pakistan has made some progress in health financing in provinces through allocating and spending an increasing amount of budget to the health sector and social health insurance programs. These subsidized programs aim to mobilize/allocate government financial resources to purchase medical services from both public and private service providers, targeting the poor and catastrophic conditions. Cancer management has been included as one of the areas for support. It includes both chemotherapy as well as radiation whether day care or through hospital admission. Although these are useful programs, yet their scale and scope are not fully determined.

Other than these initiatives, the low-income population also have access to social protection funds (Zakat and Bait-ul-Mal) to pay for health care. Bait-ul-Mal is a publicly funded social protection initiative created for the welfare of vulnerable populations such as people with disabilities, orphans and women. Zakat, on the other hand, is 2.5% tax paid by Muslims on their annual savings, which is collected (centrally) and allocated by the Ministry of Religious Affairs for each province. Health care is one of 6 programs administered under the Zakat fund. For both Zakat and Bait-ul-Mal, patients need to apply to receive payment for their treatment, which must be provided at a government hospital or selected hospitals for Zakat and NGOs for Bait-ul-Mal assistance.

There is a general trend that health financing for cancer management and other major diseases will gradually improve for the marginalized population. However, until this is widespread and available in all cities and towns, the private charity sector programs will continue to assume a very important role. Two hospitals in Lahore and Karachi are providing free treatment for all types of cancer. Al-Shifa Trust Eye Hospital in Rawalpindi is the only facility in the country so far that has set up a dedicated Centre for Eye Cancer that is providing free of cost chemotherapy and radiotherapy facilities exclusively for eye cancer patients.

Until these programs become universal, the National Plan for Prevention and Control of Eye Cancers should include measures and projects for provision of health financing for eye cancer treatment. The stakeholders' report abandonment of cancer treatment due to financial reasons as a major cause of concern. The patients/parents

cannot afford even transportation charges for repeated visits to the cancer care facilities, which in many cases is located only in a few major cities of the country. There are also costs of repeated diagnostic tests like MRI/CT scans, laboratory tests, ultrasound etc. that are not affordable for patients.

In summary, cost is a major barrier to cancer management in Pakistan. The patient and the family are already devastated by the news of the cancer and inability to generate resources for transport, diagnostic tests and cancer treatment further add to the problems and may result in discontinuing or abandoning the treatment. This also places enormous psycho-social pressures on the families affected.

Discussion

This is the first of its kind eye cancer survey in Pakistan sanctioned by National Committee of Eye Health (NCEH). Although it can be at best termed as a conservative estimate of the magnitude and type of eye cancers in Pakistan and available services, yet it serves as a first step towards planning services for prevention and control of eye cancer in Pakistan.

Eye cancer is relatively rare and makes up approximately 0.15%–0.2% of all cancer cases, and less than 0.1% of cancer-related deaths in various regions worldwide [3]. According to the current survey, eye malignancies comprise 0.5% of all types of cancers in the country. It means that eye cancer proportion in Pakistan is higher than average global estimates.

Although the survey tends to show national estimates, yet there are some limitations. Some of the areas had no data available on eye cancers. The survey does not take into account eye cancer related deaths. Globally there were approximately 8202 eye cancer-related deaths in 2020 [4].

Despite some of these limitations, the survey gives us a rough estimate for planning. It has identified certain gaps in different aspects of eye cancer control including service delivery, human resources and technology. Recommendations have been forwarded to policy makers at national level to fill these gaps.

In summary, more than 1700 eye tumors are reported in Pakistan annually with 51% being malignant. The tumors come mainly from eyelids, ocular surface, intra-ocular region and orbit. Roughly 4 cases of malignant eye tumors per million population may be reported annually in Pakistan.

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Statement of Transparency and Principals:

- Author declares no conflict of interest
- Study was approved by Research Ethic Committee of author affiliated Institute.
- Study's data is available upon a reasonable request.
- All authors have contributed to implementation of this research.

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