EDITORIAL

Pakistan Brain Tumour Epidemiology Study (PBTES): Uncovering the Hidden Burden of Brain Tumours in the Country

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Epidemiological studies have significantly helped determine the burden, types, and geographical distribution of brain tumours in HICs (high-income countries). However, brain tumour data from low-and-middle-income countries is often sparse, focusing on a few centres[1]. The situation in Pakistan is no different. Few oncological registries exist in our region that focus on common tumours. Collecting data regarding brain tumours has been challenging, as evidenced by the underreported incidence of brain tumours by centers such as the Karachi Cancer Registry (KCR), Pakistan Atomic Energy Commission (PAEC) report, and GLOBOCAN. Brain tumours are distinct from other cancer types by having more than 200 subtypes, requiring complex analysis, grading, and personalized therapeutic strategies. Moreover, there is no current standardized system to record brain tumour patient data, making it difficult to collate data from various centers.

The Pakistan Brain Tumour Epidemiology Study (PBTES) has responded to this challenge by taking the first step in reporting national hospital registry-based data, focusing on demographic and care pathway-related factors for patients seeking brain tumour care. Whether this was investigating the impact of distance travelled on survival and analyzing this for each tumour type or seeing the factors most likely to influence patients to be lost-to-follow-up (LTFU), the focus was on understanding the complexities associated with brain tumour care in an LMIC such as Pakistan.

This need for an epidemiological base prompted the Pakistan Society of Neuro-Oncology (PASNO) to spearhead such an endeavor. PASNO is a non-profit research organization licensed by the Government of Pakistan, founded to increase awareness and improve education about neuro-oncology in Pakistan to further develop brain tumour patient care in the country. PASNO's platform was instrumental in connecting neurosurgeons and neuro-oncologists across the country as part of the Pakistan Brain Tumour Consortium.

Despite the ongoing challenges, the current state of neuro-oncological care in Pakistan is advancing incredibly. A few established centers of neurosurgical excellence across the country provide surgical facilities for complex neuro-oncological procedures. In recent decades, evidence shows that comprehensive and holistic care for brain tumour patients helps improve outcomes. This requires equally complex systems to manage every aspect of surgical, medical, and radiation-related management[2]. In line with this, multidisciplinary neuro-oncology tumour boards are developing at national and regional levels to ensure continuity of care. We are seeing the emergence of a better system to coordinate better care for brain tumour patients in Pakistan.

However, systems require evaluations to achieve the goals set out. Large datasets, often at a national scale, are needed to help identify how well our work is progressing. This is where the role of neuro-oncological epidemiology studies comes into play. The Central Brain Tumour Registry of the United States (CBTRUS) is one of the largest population-based registries, representing the entire US population[3]. Other countries have developed similar centralized brain tumour registries. These benefits are two-fold: by monitoring epidemiological distribution, changing trends in presentation and outcomes in specific populations can be tracked. Secondly, large datasets can be leveraged to analyze predictive factors for worse or better outcomes, and to home in on unique problems affecting brain tumour patients and their access to care.

The PBTES, despite data limitations, is the precursor for developing a national brain tumour registry. With prospective data collection, patient follow-ups, and registrations, we can hope to see measurable improvements in how we care for our patients. The development of data-sharing systems between centres will hopefully pave the way for referral systems in neurosurgical oncology and complex infrastructure for

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improving patient care in Pakistan. For this to happen, neuro-oncology centers in Pakistan must continue to enhance coordination, support capacity development and strengthening of other upcoming centers, and persuade the government to improve stewardship and commitment to such centers across the country.

References

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