

Addressing the Data Gap: The Importance of National Cancer Registries

Sir,

This letter is intended to emphasise the challenges faced by countries such as Pakistan in trying to establish and maintain national cancer registries, as highlighted in the recent article, titled "Cancer Registry – What is the Need to be Attentive and Why Now?" by Arif A and Qureshi H.¹ The article mentions the significance of reliable data for guiding challenges to overcome cancer incidence and prevalence.

It is, however, also essential to highlight the obstacles that hinder the creation of these registries. Pakistan has limited infrastructure and resources. Poverty, lack of governmental funding and policy-making, shortage of professionals with the necessary training, fractured healthcare systems that struggle with diagnosis, limited access to treatment options like radiation therapy, chemotherapy, surgery, and issues surrounding palliative care are some of the obstacles that prevent the development of cancer registry programs in our country, like other most low- and middle-income countries.²

Furthermore, political unpredictability and competing public health goals can cause resources and attention to be diverted away from cancer registry initiatives. Policymakers and healthcare professionals are unable to develop evidence-based cancer prevention and screening policies due to the lack of a centralised system for data collecting and analysis.

The limits imposed by insufficient data weaken our attempts to prevent cancer. It is very difficult to spot trends, allocate resources wisely, and assess the effectiveness of treatments while lacking current, reliable data on cancer incidences.

Addressing these hurdles requires concerted efforts to digitalise healthcare, invest in training and capacity-building programs, and prioritise the establishment of national cancer registries. Collaboration among government agencies, academic institutions, and international partners is essential to surmounting funding limitations and ensuring the sustainability of registry programs.

Although establishing national cancer registries presents various challenges, it is of utmost importance for guiding cancer prevention and screening efforts and mitigating the burden of the disease. By addressing the barriers to registry development and collaborating with stakeholders, countries such as Pakistan can make significant strides in enhancing cancer data collection and, ultimately, improving cancer care delivery.

COMPETING INTEREST:

The author declared no conflict of interest.

AUTHOR'S CONTRIBUTION:

Substantially contributed to the concept, design, and drafting of the manuscript.

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AUTHOR'S REPLY

Sir,

Thank you very much for your comments. You have very rightly pointed out the factors that are or can lead to difficulties in maintaining a cancer registry. We are cognizant that all the above-mentioned issues such as limited infrastructure, limited resources, poverty, lack of government funding, shortage of trained staff etc. pose hurdles to developing and maintaining a cancer registry. All these are important factors and need to be addressed in a larger perspective but before that, we need to organise ourselves and ensure proper documentation of the correct data at all levels. For example, if you look at the death certificate, the primary cause of death is mentioned as cardiorespiratory failure. When you scan the patient file, you find out that the patient had decompensated cirrhosis due to hepatitis C and died of liver cancer. Now, if someone wants to analyse the deaths due to HCV-related cirrhosis leading to cancer, you just cannot get it unless you open the patient record. So, someone is entering some data in the death certificate but is ignorant of its importance and nobody is making an attempt to change this. You do not need resources funding or trained staff to do a correct entry.

If you look back to the period of the late 1970s to 1990s, Pakistan was the first country in the region to develop a national cancer registry. At that time, there were 10-12 large public sector hospitals all over the country and there were hardly any private

sector hospitals. Following the desire of like-minded people to collect cancer data, initially 8 and later 10 sites voluntarily collected cancer data from their large tertiary care public sector hospitals for 6-8 years and shared it with the head office in Karachi. There were no computers, so all data was filled by the respective centre on paper sheets, it was collated manually on large sheets and analysed without calculators. Multiple reports, papers, and theses were written from this data. The data quality was so good that even today when we compare the cancer trends, we refer to those as the baseline. The infrastructure, resources, government funding, numbers of trained professionals, etc. were very meagre at that time as compared to today. In this era, we have access to computers and scanners, and data analysis has come at the click of a button. So, what was there which is missing these days, is the sincerity and commitment to the task assigned to us. We do not want to work ourselves but

want someone to work for us. We cheat ourselves. We have become lazy and are always looking for excuses. We need to change the mindset and start taking challenges and completing them. We need to be loyal to ourselves. We have examples where we see that people with dedication to their jobs were able to achieve a lot and have developed large institutes and training sites where hundreds of young minds are trained daily on serving the unserved.

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