

Commentary

Need for Making Cancer a Notifiable Disease in India

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Despite various advocacy measures, the Indian health ministry has, not made/not directed the Indian states to make, cancer a notifiable disease. The reason given by the ministry is that cancer is not a communicable disease and does not have community spread. India faces a double burden of disease and there has been a rise in cancer cases. The notification of cancer leading to a legal mandate to report cases, will give impetus to the decades-old National Cancer Registry Program. This may enable robust recordkeeping of cancer cases and subsequent policy focus, as has been seen in many developed nations.

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Cancer, an uncontrolled growth of the cells in the body, is a non-communicable disease and can spread to other parts of the body. Close to half of the cancer deaths can be avoided by prevention and control of risk factors. These include issues like smoking, mineral dusts (like asbestos), and other exposures. To manage cancer, the government must first know its incidence, prevalence, morbidity, and mortality rates in the country. This happens through proper record-keeping, which enables proper allocation of resources, highlights the areas in the country where priority must be given to reduce cancer. It also enables the right data to reach national and international agencies and development sectors to prioritise the focus on priority areas. This data may be key to ending conjectures like '*arsenic causing cancer in Bihar or pesticides causing a cancer surge in India*' and provide real-time epidemiological evidence^[1].

Cancer record-keeping is made possible through registries, which are operated either individually by hospitals or as a collective of many hospitals (where a big hospital records cases in a common database from the other smaller hospitals in its catchment area). Since 1981, the Government of India's National Cancer Registry Program is run by the Indian Council of Medical Research's National

Centre for Disease Informatics and Research, Bengaluru, or ICMR-NCDIR. But the problem with the ICMR-NCDIR-run registry is that despite being operative since 1981, it only covers 16% of the total population of the country. This fact has even been noted by a parliamentary committee report on health set up to deal with cancer, which expressed 'it's deep displeasure' over this fact^[2]. The potential reason for this low coverage by the National Cancer Registry Program may be an absence of legal mandate for hospitals and healthcare providers to provide this data to the central government registry. The solution therefore can be making cancer a notifiable disease, which means that once done, medical practitioners will be required by law to report cases to government authorities. This has also been recommended by ICMR-NCDIR itself in its 2020 policy brief, which reads as: '*Making cancer a notifiable disease to enable increased coverage by registries and establishment of registries in areas hitherto uncovered regions.*'^[3]

In a case filed before the National Human Rights Commission of India or NHRC (59/30/3/2024) on this matter of making cancer notifiable in India, the NHRC disposed of the matter with a direction to the Secretary of the Ministry of Health and Family Welfare or MoHFW to ensure that such an action, as deemed appropriate, in the matter, is taken (See Figure 1, and supplementary files).

Action Date	01/02/2024
Authority	To:- THE SECRETARY - Health & Family Welfare MINISTRY OF HEALTH AND FAMILY WELFARE, GOVERNMENT OF INDIA NEW DELHI DELHI Email- secyhfw@nic.in
Proceeding	<p>On perusal of the complaint it is seen that the complainant, an International Post-Doctoral Fellow in the Department of Environment and Occupational Health at Dornsife School of Public Health, Drexel University, has drawn the attention of the Commission to the outbreak of the cancer in India, seeking intervention by the Commission, to get the cancer notified as notifiable disease at the pan India level and making cancer cases record keeping robust at the pan India level to control the disease.</p> <p>2. Let the complaint be transmitted to the Secretary, Ministry of Health and Family Welfare, Government of India, New Delhi. He is directed to ensure that such an action, as deemed appropriate, in the matter, is taken within eight weeks and the complainant is informed of the action taken.</p>

Figure 1. Snapshot of the judgment of the National Human Rights Commission disposed of in the matter related to making cancer a notifiable disease. Source: NHRC

The Ministry replied that 'Cancer is a type of non-communicable disease' and that it is not an infectious disease that '*does not spread from one person to another or does not have any community spread.*' The MoHFW further stated that 'In the present circumstances, it may not be declared as a notifiable disease.' This was later also reaffirmed by the same Parliamentary Committee, which took back its recommendations in the face of a response from the MoHFW^[4].

I am directed to refer to National Human Rights Commission (NHRC) Case No.- 59/30/3/2024, dated 01.02.2024 and to say that the comments of this Ministry are given as under :

"A notifiable disease is any disease that is required by law to be reported to government authorities. The collation of information allows the authorities to monitor the disease and provides early warning of possible outbreaks.

The World Health Organization's International Health Regulations require disease reporting to the WHO in order to help with its global surveillance and advisory role. Making a disease legally notifiable by doctors and health professionals allows intervention to control the spread of highly infectious diseases.

Cancer is a type of non-communicable disease. It is not an infectious disease. It does not spread from one person to another or also does not have any community spread. In present circumstances, it may not be declared as notifiable disease.

Figure 2. Snapshot of the reply of the Indian Ministry of Health and Family Welfare on its position for making cancer notifiable. Source: MoHFW

There may be a lack of uniformity in approach as despite the MoHFW position, 17 states in India have already made cancer notifiable at the state level. Some of these states took out of the way measures, even in the absence of public health legislation, by using administrative orders to notify cancer. Some states, like Tamil Nadu, operate a comprehensive state-level registry program.

The other issue can be around communicable vs non-communicable diseases, and whether only communicable diseases be made notifiable? Tata Memorial Centre Mumbai or TMC came up with an innovative semantic solution and recommended to the parliamentary committee to declare that cancer be made a "documentable disease" so that it can still be compulsorily reported and rigorous recordkeeping can still take place, even as it is non-communicable^[2]. It may be noted that cervical cancer caused by skin to skin contact (and the human papillomavirus) may not entirely keep cancer out of the domain of communicable diseases. We also have a recent exception where another non-communicable disease, i.e., snakebite, was directed by the MoHFW to be made a notifiable disease^[5]. A direction by the MoHFW to the states to make cancer notifiable or the MoHFW itself making cancer notifiable is all the more relevant when India is facing a double burden of disease from communicable

as well as non-communicable diseases. There may well be very common exposure factors in communities leading to many cases, which must be monitored, recorded and acted upon. Cancer, among other non-communicable diseases must be focussed upon as a latest report now calls India the 'cancer capital of the world' as cancer cases are on a sharp rise^[6]. But even calculations as such of the rise in cases may show an incomplete picture. This is because the data available may represent a small percentage of actual cases. That is characterised by the fact that in a study where hospitals were actually keeping records of cases and having numbers of cancers in their books, 75% of these were not part of the population-based cancer registry programme run by ICMR-NCDIR^[7]. Data collected by ICMR-NCDIR is reported to international agencies like the International Agency for Research on Cancer or IARC which may be used for policy decisions, and must be comprehensive^{[8][9]}.

A large number of cases recorded due to the notification of cancer, and the subsequent more robust and accurate recordkeeping may temporarily overwhelm government agencies in terms of large numbers of cancer incidence/prevalence coming on record. But in the long run, having registries will pave the way for proper management of cancer prevention, as has been accomplished in Nordic countries where registries have been operating since 1942 (Denmark). Around the time when India's cancer registry program's predecessor started in 1964, a study reports that 'there were several well-established cancer registries in Europe (Finland, Scotland, and Denmark), North America, and South America (Brazil), Asia (China and Singapore), and Oceania (Australia and New Zealand) ^[10].' Notification of cancer at the national level as a 'magic bullet' may provide the impetus needed to make the 4-decade-old Indian cancer registry programme work better and impact the future prevention of this dreadful disease.

Statements and Declarations

No conflict of interest reported (The first author, a citizen of India, was the petitioner before the NHRC in India to make cancer notifiable in India). No funding was received for this work. Ethics approval not required as it is a commentary, involves no human participants, tissues or animals.

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