Economic evaluation of Mumbai and its satellite cancer registries: Implications for expansion of data collection[☆]

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ABSTRACT

Background: The Mumbai Cancer Registry is a population-based cancer registry that has been in operation for more than five decades and has successfully initiated and integrated three satellite registries in Pune, Nagpur, and Aurangabad, each covering specific urban populations of the Indian state Maharashtra. Data collectors at the satellites perform data abstraction, but Mumbai carries out all other core registration activities such as data analysis and quality assurance. Each of the three satellite registries follows the same data collection methodology as the main Mumbai Cancer Registry. This study examines the cost of operating the Mumbai and its satellite cancer registries.
Methods: We modified and used the Centers for Disease Control and Prevention's (CDC's) International Registry Costing Tool (*IntRegCosting Tool*) to collect cost and resource use data for the Mumbai Cancer Registry and three satellites.
Results: Almost 60% of the registration expenditure was borne by the Indian Cancer Society, which hosts the Mumbai Cancer Registry, and more than half of the registry expenditure was related to data collection activities. Across the combined registries, 93% of the expenditure was spent on labor. Overall, registration activities had a low cost per case of 226.10 Indian rupees (or a little less than 4.00 US dollars in 2014 [used average exchange rate in 2014: 1 US $ = 60 Indian rupees]).
Conclusion: The centralization of fixed-cost activities in Mumbai likely resulted in economies of scale in operating the Mumbai and satellite registries, which, together, report on almost 20,000 cancer cases annually. In middle-income countries like India, where financial resources are limited, the operational framework provided by the Mumbai and satellite registries can serve as a model for other registries looking to expand data collection.

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1.0. Introduction

1.1. Need for cancer registration

The Mumbai region has been a host to key advancements in cancer treatment and studies in India. The country's first cancer treatment center, Tata Memorial Center, was initiated in Mumbai in 1941; since then, it has played a leading role in improving cancer outcomes. The Indian Cancer Society, founded in Mumbai in 1951, is the oldest and largest cancer organization in the country. Its objective is to reduce the suffering of cancer patients and support cancer interventions to reduce the overall burden. The Tata Memorial Center and other Regional Cancer Centers highlight the magnitude of the cancer burden in India and the need for early

detection and comprehensive treatment [1–7]. India, with around 1.2 billion people, has over 1 million new cancer cases per year, and, in 2012, had just under 700,000 cancer-related deaths [8]. To improve cancer care and outcomes, it is essential to understand the magnitude and pattern of the disease as it manifests in communities, and to identify modifiable and non-modifiable risk factors [9,10]. Such observations help to organize cancer care and treatment facilities and control of the disease, as well as research into its causation for prevention and control.

1.2. Establishment of the Mumbai cancer registry

Mumbai, formally called Bombay, is located on India's west coast. It is the country's most populous city and the capital of the Indian state Maharashtra [11]. India's first cancer registry covering the population of greater Mumbai was established in 1963 as an entity within the Indian Cancer Society. The aim of the population-based cancer registry was to obtain reliable cancer-related morbidity and mortality data from a defined urban population. Data collection and compilation began in 1964; before then, no continuous registration of cancer cases at the population level had been undertaken anywhere in India.

From its inception until 1975, the Mumbai Cancer Registry operated with continuous financial support from the United States' National Cancer Institute. The Government of India's Department of Science and Technology supported the registry from 1976 to 1980. Since 1982, the registry has been part of the National Center for Disease Informatics and Research-National Cancer Registry Program (NCDIR-NCRP), which is the national effort organized by the Indian Council of Medical Research (ICMR). The Mumbai Cancer Registry receives partial financial support from ICMR [12]. Although the Mumbai Cancer Registry does not receive financial support directly from the Tata Memorial Center, the registry collaborates with the center on cancer data analysis and dissemination.

There is no nationwide collection of cancer data in India. There are a total of 29 population-based and 7 hospital-based cancer registries functioning under the aegis of the NCDIR-NCRP and state or central governments [13]. National, projected cancer incidence information is based on data from regional registries.

1.3. Expansion through satellite registries

Due to the Mumbai Cancer Registry's success, the Indian Cancer Society decided to expand cancer registration to provide more comprehensive coverage in Maharashtra. As policy makers became more aware of the cancer burden at the local level among the urban population in Mumbai, they saw the need to study patterns of cancer incidence and cancer site patterns in geographically disperse areas of the state, among communities that exist in disparate climate and ecological zones, and that have differing dietary habits and social customs. Therefore, between 1972 and 1980, three satellite registries were established across the state: one in Pune in 1972, one in Aurangabad in 1978, and one in Nagpur in 1980 [12,14–16].

1.4. Goal of the economics evaluation study

The Mumbai Cancer Registry has been in operation for more than five decades and has successfully initiated and integrated satellite registries. The purpose of this economic evaluation is to provide feedback to the Mumbai and satellite registries to further improve operational efficiency and optimize resource allocation. Examining the registry's cost of operations also can provide important lessons for other registries looking to expand operations. Economic evaluation is the best methodology to assess the optimal use of labor and non-labor registry resources. Developing countries like

India have limited resources for cancer control, so it is critical to identify efficient approaches that can maximize the impact of available funding. We hypothesize that the establishment of satellite registries can be a promising model for expanding cancer registration coverage area in resource-constrained settings since economies of scale can arise from sharing fixed costs of registry operations.

2. Materials and methods

2.1. Mumbai cancer registry operations

Cancer is not a notifiable disease in India, which means that hospitals and other data sources are not required by legislation to report cancer cases to cancer registries. The Mumbai Cancer Registry has adopted an active data collection methodology, including active case finding and abstraction, to collect information on cancer incidence and mortality in the predefined geographic area of the registry. The registry collects data from two major sources:

- all hospitals, nursing homes, hospices, and consultants in private practice in the coverage area,
- the Municipal Corporation of Greater Mumbai's Department of Public Health's Vital Statistics Division.

Staff members regularly visit the wards of cooperating hospitals to examine the records of reported cancer cases. Staff examine the records maintained by the pathology, hematology, and radiology departments at the hospitals, as well as the various registers in specialized surgical and medical wards. Standard data elements that are endorsed by the International Association of Cancer Registries (IACR) are collected and reported annually. Data elements collected include stage and extent of disease, TNM classification of malignant tumors, treatment, date of last contact, status at last contact. The registry also collects cases on melanoma and non-melanoma skin cancers.

The base population of India is estimated for each year from the decennial National Census Data. The population covered by the registry operations increased from 4.6 million in 1964 to approximately 12.0 million in 2012. There were a total of 3057 cancer cases recorded in 1964, compared to 13,383 cases in 2012—an increase of more than 400%. At present, the registry covers over 60 hospitals and private nursing homes in metropolitan Mumbai. The majority of hospitals in the city are maintained by the Municipal Corporation of Greater Mumbai and the state government, which are responsible for organizing medical and public health services in the city. Over the past decade, private-sector medical care services in Mumbai have grown substantially, and the number of mid-sized and large, private hospitals has increased. Cancer surgery is now provided at all major hospitals, as well as in a number of well-equipped, private nursing homes in the city.

2.2. Satellite registry operations

All three satellite registries follow the same data collection methodology as the Mumbai Cancer Registry, and each covers a specific urban population of Maharashtra. During 2012, the four cancer registries registered a total of 19,485 incidence cases [12,14–16]. As shown in Table 1, the satellite registries collect 31% (6102/19,485) of the total cases. The satellite registries cover smaller-sized populations than Mumbai. Also, although the Mumbai Cancer Registry covers about 603 square kilometers, Pune and Nagpur each cover about half that area, and Aurangabad covers only 50 square kilometers. Altogether, the Mumbai and satellite registries cover about 16% of Maharashtra's population [10]. Pune is a large city near Mumbai that has a similar health care