Obtaining Cancer Net Survival Estimates in Brazil: Potentialities and Challenges

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Obtenção de Estimativas de Sobrevivência ao Câncer no Brasil: Potencialidades e Desafios

Obtención de Estimaciones de Supervivencia al Cáncer en el Brasil: Potencial y Desafíos

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INTRODUCTION

According to the World Health Organization (WHO), the global burden of cancer continues to grow, remaining among the top ten causes of death with an estimated 9.7 million deaths in 2022. On a global level, one in five people will develop cancer during their lives and about one in ten men and one in 12 women will die from the disease. The WHO also highlights the disproportionate impact on poorer populations that depend on public health services and the coverage offered that vary widely around the world. Another impactful statistic reports that only one in five low-income countries has the necessary data to produce a cancer policy[1]. In Brazil, the National Cancer Institute (INCA) estimates, for each year of the 2023-2025 triennium, 704 thousand new cancer cases, 483 thousand if non-melanoma skin cancers are excluded[2].

In this scenario, the importance of surveillance and screening of neoplasms becomes clear, for which cancer records are considered essential sources of information for the development of epidemiological surveys that, among others, contribute to the systematization of data for planning and developing actions for cancer screening and treatment.

Cancer records are classified in the Hospital-based Cancer Registry (RHC) and Population-Based Cancer Registry (RCBP). The RHC gathers information to assess the quality of care provided by a hospital, while the RCBP must produce information that enables the description and monitoring of the cancer incidence and mortality profile in a geographically defined coverage area[3]. Based on these data, cancer statistics are estimated. The methods used for estimates are country-specific, and the quality of these estimates depends on the coverage, accuracy and timeliness of the recorded data. It is certain, however, that estimates of cancer incidence, mortality and survival are essential population-based indicators for cancer screening[4].

In Brazil, INCA uses data from RCBP to estimate cancer incidence and mortality but does not produce disease survival rates. Estimates of survival rates are essential to evaluate the improvement of patient care. To estimate these rates, data on patients' death are necessary, which is often not easy to obtain due to various obstacles, such as inconsistency and low quality, multiple data sources, limited computing, financial and human resources, complex data representation, volume of stored data, evolution of data needs, very restricted or annulled data entry rules, among others[5]. In this context, considering the irrefutable importance of survival rates for monitoring the quality of care offered to patients and the scarcity of estimates for Brazil, this article opens a discussion about the potentialities and challenges for obtaining cancer survival rates based on Brazilian data.

DEVELOPMENT

METRICS FOR CANCER SURVEILLANCE

Understanding the burden of cancer on public health requires the combined use of reliable incidence, mortality, and survival estimates[4]. Each of these estimates has their relevance and different applications in cancer surveillance. Incidence estimates the proportion of new cases in a population at risk (with no cancer) over a given period; mortality from specific causes estimates a number of deaths from the disease; and survival measures the time between cancer diagnosis and cancer-specific death, considering the possibility of censorship. Note that estimates of incidence and mortality due to specific cause in a given year are based

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on different individuals, while the cancer survival rate at a specific time is estimated using the diagnostic and death information of the same individuals.

Thus, comparing incidence with mortality requires caution. See the case of the mortality/incidence ratio (M/I), a measure created as an indicator of completeness in cancer records[5]. M/I under one indicates that fewer individuals are dying of cancer than they are being diagnosed with cancer. A decrease in M/I over time may indicate an improvement in survival, an increase in incidence or a combination of both. That is, using the complement (1-M/I) as an estimate of cancer survival is not appropriate[6]. On the other hand, comparing survival rates over time can bring robust and adequate information to evaluate the improvement in patient care and analyze the overall efficiency of cancer control by the healthcare system.

CANCER SURVIVAL ESTIMATORS

Individual follow-up data, needed to estimate cancer survival, comprise dates of diagnosis and death and the information of the cause of death (if cancer). If these data are reliable, statistical methods such as the Kaplan-Meyer estimator and the Cox regression model can be used. Note, however, that quality information about the cause of death is always a challenge. As in several parts of the world, Brazilian RCBPs bring valuable information about the dates of diagnosis and death of new cases, but the information about the cause of death is questionable, since the follow-up of many individuals is performed passively, that is, the date and cause of death are derived from death certificates, which are known to be not very accurate source of information.

This data weakness can be circumvented with the Pohar-Perme net survival estimator[7], which estimates cancer survival by comparing the overall survival estimate obtained for the cohort of patients with the estimated survival for the population of individuals who do not have the disease, thus not using cause of death information. When it comes to population data, it is a realistic assumption. Another advantage of the Pohar-Perme estimator is to adjust the estimates by the age distribution of mortality in the general population, enabling the comparison of estimates over time and between countries[8].

In Brazil, the Brazilian Institute of Geography and Statistics (IBGE) annually publishes complete tables of mortality for simple ages up to 80 years, which enable life tables softened by appropriate statistical methods to be constructed in order to allow the use of the Pohar-Perme estimator. The great challenge is the quality of the data from Brazilian RCBP.

CANCER RECORDS IN BRAZIL

The Ministry of Health Organic Law No. 8.080/1990[9] regulated the National Health System (SUS), establishing the organization, direction and management of health actions and services in Brazil. Such legislation cites INCA as the main reference institution in oncology in the country and establishes the need for RHC and RCBP in the municipalities. The role of RHC is to collect, store, process, analyze and disclose the information of patients with confirmed cancer diagnosis treated in a hospital unit, whose quality of the information produced is dependent on the performance of the clinical staff in the care provided to the patient[10]. The data are consolidated in the Hospital Cancer Registration System (SisRHC)[10], developed by INCA in 1998. Despite these records not having population coverage and, in practice, not including death data, they are fundamental to the construction of the RCBP databases, which should include all new cases of cancer of a given geographic population.

The process of identifying new cases in the RCBP is done by active search in three sources: RHC, diagnostic laboratories and the Mortality Information System (SIM). The search in laboratories and SIM aims to include patients who have not undergone care in the SUS, since these should be in the RHC. By integrating data from the three databases, it is possible to capture cases that might not be documented in other bases, such as those in which the patient died before receiving a formal diagnosis or adequate treatment. Data collection from multiple sources also facilitates cross-verification of information, improving the accuracy and reliability of records. This correlation between diagnostic, treatment and mortality data ensures that cases are recorded and classified correctly and consistently.

Finally, it should be noted that, although Brazil has cancer population data, representativeness should be viewed with caution. Currently, there are 33 active RCBPs, but only 21 (63.6%) include diagnoses from the year 2016 onwards, with the majority (n=24, 72.7%) located in the capitals (Figure 1).

SURVIVAL ESTIMATES IN BRAZIL USING RCBP DATA

Survival estimates based on Brazilian RCBP data are scarce. The first were published by the CONCORD study in 2008, with the participation of only two RCBP in Brazil. In the CONCORD-3 study, the number of Brazilian RCBP increased to six. The results highlighted an improvement in cancer survival in Brazil for some neoplasms. But one cannot forget the underrepresentation of Brazil in these results (supplementary material).

The list of studies specific to the Brazilian population began in 2021, with the study of Alves, which included colorectal cancer, and of Renna, who studied breast cancer,

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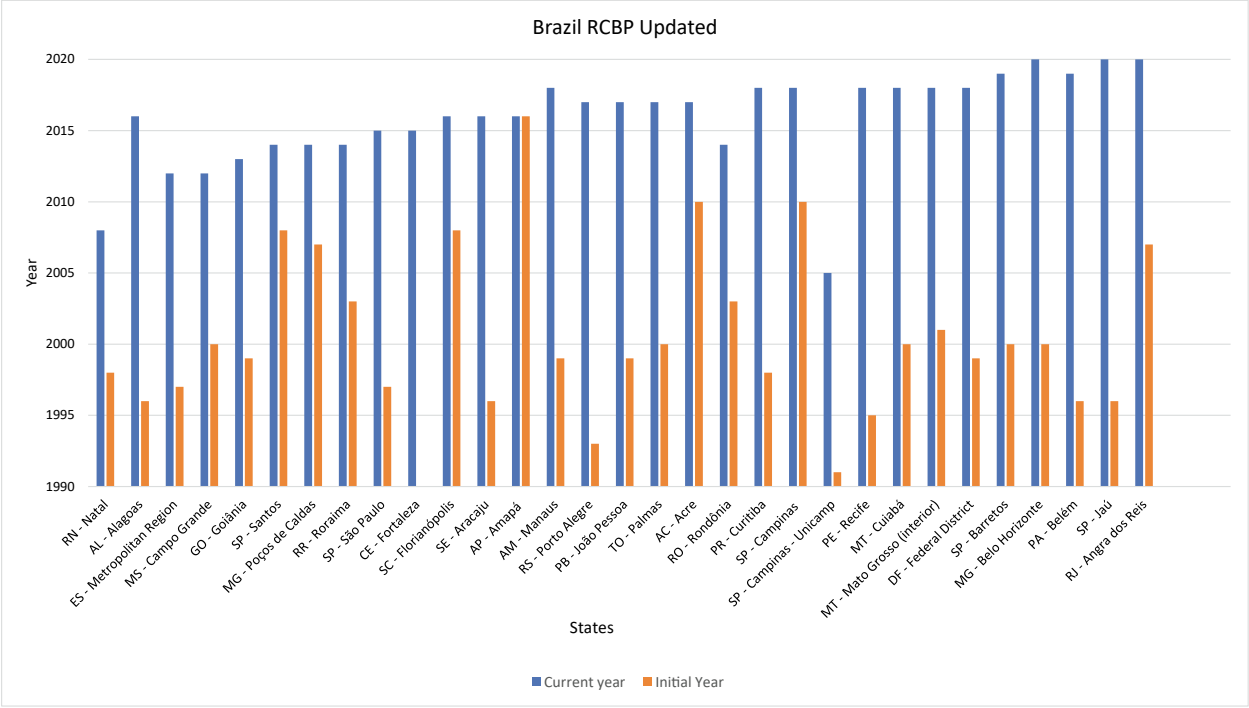

Figure 1. Updated data from Brazilian RCBP

Source: INCA[10], accessed on 16 Oct. 2024.

both estimating net survival. In 2022, it included the Evangelista study, which estimated survival for prostate cancer using the Kaplan-Meier method. Finally, in 2023, a colorectal cancer study using Kaplan-Meier; and Mafra studies for 24 types of cancer and Renna for five types of cancer, using net survival. In total, data from only ten Brazilian RCBP were used: Aracaju, Brasília, Cuiabá, Campinas, Curitiba, Goiânia, Jaú, São Paulo and Várzea Grande (Supplementary material).

POTENTIALS

The greatest potential of Brazil in the challenge of obtaining its own estimates of cancer survival is the existence of RCBP. Over the past 20 years, the role of records has expanded further to encompass planning and assessment of cancer control activities and patient care[11]. Previously existing difficulties were circumvented with the significant improvement in data collection in Brazil, given the advances in SIM and the Live Birth Information System (SINASC). These bases allow for more robust and detailed analyses of mortality in different population groups. The broader coverage of civil records and the reduction of underreporting of deaths contribute to the quality of survival estimates.

PRACTICAL CHALLENGES

Difficulties in maintaining the quality of Brazilian RCBP include the high turnover of teams and small number of employees, which shows the little support from Brazilian government institutions. RCBP lacks recognition as an essential tool to subsidize public policies. Bureaucratic and technical challenges compromise the quality of Brazilian data (Chart 1). Today, it is urgent to come up with strategies to improve the monitoring of existing records in order to ensure continuity in the collection and quality of information.

CONCLUSION

Survival rates are essential for monitoring the care provided to patients diagnosed with cancer. Brazil still lacks systematization to obtain these rates but already has active legislation and RCBP that provide the collection of necessary data that, combined with robust statistical methods existing in the literature, such as the Pohar-Perme estimator, allow to estimate comparable survival rates over time and with other countries. However, data quality challenges still limit the ability to generate accurate estimates for implementing effective public policies.

Organizing and maintaining RCBP is no easy task, especially when there is a lack of infrastructure, financing and staff turnover. It is therefore important to reflect and understand the role of survival estimates in cancer screening. Investment in improving data quality is paramount to strengthen the global capacity to tackle and

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Chart 1. Challenges in ensuring the quality of Brazilian RCBP data

• Access to laboratory data, since many of them resist providing data due to, mainly, the General Data Protection Law
• Underreporting of cases
• Data input from laboratories in the SisRHC is manually performed and in single typing, which has a high probability of human error
• Identification of case as belonging to the population: by definition the patient must reside in a said location to be considered part of its population, but address data are often misinformed
• Little education and training of technicians working in the records
• SisRHC was created in 2000 and, until the publication of this manuscript, had no updates to the system
• Government websites used to fill in demographic data of cases present incompleteness and divergences
• Difficulties in finding diagnostic data of cases included through the SIM base

control cancer safely and based on real evidence from the Brazilian population.

CONTRIBUTIONS

Patrícia Klarmann Ziegelmann and Camila Macedo Lima Nagamine have substantially contributed to the study design, planning, data acquisition, analysis and interpretation, wording, and critical review. Barbara Niegia Garcia de Goulart, Priscilla Wolff Moreira and Laura Clezar Rodrigues have substantially contributed to the study planning, data acquisition, analysis and interpretation, wording, and critical review. All the authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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