

Child and Adolescent Cancer in Public Policies in the State of Rio de Janeiro, 2013-2021

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O Câncer Infantojuvenil nas Políticas Públicas no Estado do Rio de Janeiro, 2013-2021

El Cáncer Infantojuvenil en las Políticas en el Estado de Río de Janeiro, 2013-2021

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INTRODUCTION

Chronic noncommunicable diseases (NCDs) are a global public health problem. NCDs, including diseases of the circulatory system, cancer, diabetes, and chronic respiratory diseases, account for more than 63% of all premature deaths in the world¹.

The scenario is no different in Brazil, where NCDs represent 72% of deaths. The most vulnerable group consists of the poorest segments of the population. Among the diseases comprising this group, mortality rates from diabetes and cancer increased in 2007². However, from 2000 to 2011 there was a mean drop of 2.5% in overall mortality in adults 30 to 69 years of age. During this period, cancer (0.9%) and diabetes (1.7%) showed the lowest decreases³.

Estimates by the Brazilian National Cancer Institute José Alencar Gomes da Silva (INCA) for the two-year period 2018-2019 point to 600 thousand new cases of cancer, 12,500 of which in children and adolescents 0 to 19 years of age⁴. Although rare when compared to cancer in adults, pediatric cancer accounts for approximately 3% of all cancer cases in the population. Pediatric cancer has become a global concern, with an estimated 175 thousand new diagnoses of the disease in this age bracket⁵.

In a scenario of increasing international alliances to control NCDs in the world, the Sustainable Development Goals increase the pressure on world leaders to define and implement policies and programs to deal with inequalities in access to healthcare. According to Galindo *et al.*, the most important prognostic factor for a child with cancer is the place where he or she was born⁵.

Although pediatric oncology has undergone major progress in the control and treatment of the disease in recent decades⁶, the world still lacks greater attention to national and global policies and plans, considering the specificity of cancer care in this age bracket. Specialists in the area have produced evidence on the measures needed

to organize quality treatment. Such evidence can be used to orient the elaboration of public policies targeted to children and adolescents with cancer.

WHICH CHALLENGES NEED TO BE OVERCOME TO INCREASE SURVIVAL IN CHILDREN AND ADOLESCENTS WITH CANCER?

Gupta *et al.*⁷ list the following important strategies in low and middle-income countries: i) financial coverage of cancer treatment; ii) accreditation of pediatric cancer centers; iii) mandatory reporting and recording of pediatric cancer; iv) development of national standards of care, considering local capacities and realities; and v) the creation of a national pediatric cancer control agency.

Magalhães *et al.*⁷ warn that although pediatric cancer has undergone major progress in Brazil in the last 50 years, there have still been few strides when compared to developed countries and other developing nations like Chile, Argentina, and Mexico. The main challenges, according to the authors, are: i) timely access to diagnostic tests and treatment; ii) integration of clinical care and research groups; and iii) availability of data and evaluation of results.

According to Gabriele Calaminus⁸, global advocacy leader of the International Society of Pediatric Oncology (SIOP), the differences between rich and poor countries in relation to quality access, essential drugs, early diagnosis and timely treatment and care are the main reasons that children with cancer in developing countries fail to survive more often (90%) than children in developed countries (20%).

Although it is not an organization focused specifically on pediatric cancer, the Union for International Cancer Control (UICC)⁹ recommends that measures in the fight against pediatric cancer should be incorporated into national cancer control plans and viewed as an important platform for convening stakeholders around common objectives.

Based on the authors' observations, nine actions were identified that need to be incorporated by health

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administrators for greater effectiveness in pediatric cancer care: 1) access to early diagnosis, quality tests, and timely treatment; 2) essential drugs; 3) integration of clinical care and research and development groups and national standards of care; 4) availability of data and evaluation of results; 5) financial coverage; 6) accreditation of treatment centers; 7) cancer control plans; 8) palliative care; and 9) the creation of a national pediatric cancer control agency.

DEVELOPMENT

This study focused on an analysis of the National Policy for Cancer Prevention and Control in the Healthcare Network for Persons with Chronic Diseases in the scope of the Unified National Health System (SUS)¹⁰, the Rio de Janeiro State Cancer Care Plan¹¹, and Ruling no. 140 of February 27, 2014,¹² showing that the central themes raised by specialists are covered in these documents for pediatric oncology.

The implementation of effective policies, plans, and activities in pediatric oncology requires considering the specific characteristics of the disease: a short latency period with rapid growth, increased aggressiveness, and better response to chemotherapy. Cancer in children and adolescents usually affects the blood system and supporting tissues, thus differing from cancer in adults¹³.

Local challenges for progress in the treatment of pediatric cancer

Cancer treatment in children and adolescents requires: i) early diagnosis with proper training of health professionals and rapid access to diagnostic tests; ii) precise diagnosis to guarantee treatment allowing the best likelihood of cure; iii) speedy referral of pediatric cancer

patients from any point in the network to the specialized oncology center; iv) quality treatment with rapid access to tests within the treatment centers, access to hospital beds, medications, specialized multidisciplinary team in supplying specific care in pediatric oncology, a pediatric palliative care team (from the start of treatment), cancer registries, assessment of information on treatment; patient monitoring after hospital discharge; v) integrated actions between the primary, secondary, and tertiary care network and civil society (individuals and organizations) as part of the network of care (e.g., support houses, etc.), among others. These activities are important for structuring the line of care for pediatric cancer patients, aimed at comprehensive care and increasing the likelihood of cure.

Thus, the implementation of public policies and plans with specific contents for pediatric oncology (whether in specific documents for this group or specifying care for this group in overall documents on oncology) is essential for ensuring a line of care based on this age group's needs.

As a strategy to guarantee effective policies, plans, and rulings, it is essential for the budget and funding sources to be ensured, and that the results are communicated to the population transparently, as required in a democratic society. The National Policy for Cancer Prevention and Control in the Healthcare Network for Persons with Chronic Diseases in the scope of the Unified National Health System (SUS) specifies the sources of funds for the proposed actions. The Rio de Janeiro State Cancer Care Plan does not specify the amount of funding that will be necessary to meet the goals and targets that the plan is committed to, leaving doubt as to the feasibility of executing the plan within the specified time frame. Ruling no. 140 provides the calculation of the transfers

Chart 1. Summary of pediatric cancer provisions in the National Policy, Rio de Janeiro State Plan, and Ruling no. 140

Summary of pediatric cancer provisions in the National Policy, Rio de Janeiro State Plan, and Ruling no. 140	National Policy	Rio de Janeiro State Plan	Ruling no. 140
1. access to early diagnosis, quality tests, and timely treatment	*	Yes	Yes
2. essential drugs	*	*	*
3. integration of clinical care and research and development groups and national standards of care	*	*	No information
4. availability of data and evaluation of results	*	*	*
5. financial coverage	*	No information	*
6. accreditation of treatment centers	*	*	Yes
7. cancer control plan	*	*	*
8. palliative care	*	*	Yes
9. creation of a national pediatric cancer control agency	No information	No information	No information

There is information related to the theme, but not specific to pediatric oncology. *Yes*: specific action in pediatric oncology. *No information*: does not address the topic.

from the federal government to the states, according to the hospitals' level of accreditation.

Although in a context of underfunding of the Unified National Health System with budget cuts, such as Constitutional Amendment Bill 241/16 and the removal of BRL 13.5 million (US\$ 3.5 million) from the national health budget to cover the cost of reducing diesel prices as a result of a national truckers' strike¹⁴, it is necessary to ensure (on the political and economic agendas of the federal, state, and municipal governments) the sufficient resources for oncology, and specifically for pediatric oncology.

Given the growing concern over NCDs in the global scenario, and featuring cancer in this group, a public and universal health system is necessary to achieve the best likelihood of cure. Health workers, individuals, government agencies, and nongovernmental organizations committed to strengthening the Unified National Health System and the Health Councils are key stakeholders for monitoring and defending the rights enshrined in Brazil's 1988 Constitution.

CONCLUSION

In order to increase the likelihood of cure for children and adolescents with cancer, public policies need to include specific guidelines for care and monitoring in pediatric oncology.

The concentration of treatment in specialized centers is important for generating clinical expertise. This requires a minimum number of new cases per year; the involvement of a multidisciplinary team with specific training in this care; undergraduate and on-the-job training¹⁵; the regulation of patient flows in pediatric oncology, oriented to agile care and referral and counter-referral in the system; and the definition of a specific flow to streamline tests at diagnosis and during treatment.

CONFLICT OF INTEREST

None.

FUNDING SOURCES

None.

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