# Childhood and Adolescent CNS Cancer: Reflections for the Brazilian Healthcare System

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*Câncer Infantojuvenil do Sistema Nervoso Central: Reflexões para o Sistema Único de Saúde*

Cáncer Infantil y Juvenil del SNC: Reflexiones para el Sistema Único de Salud Brasileño

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## INTRODUCTION

Childhood and adolescent central nervous system (CNS) tumors are a heterogeneous group of pathologies responsible for the second cause of mortality by disease for this population[1]. Due to the necessity of multidisciplinary care for treatment and rehabilitation and life-long physical, cognitive and psychosocial sequelae, these tumors are a chronic and complex health condition[2,3]. Considerable improvement of prognosis and quality of life has been achieved for this population thanks to the incorporation of new therapies and approaches in health systems which brought new challenges to health managers and the society as a whole in regard to funding and access to neurosurgical treatment and pediatric intensive and oncologic care[3] in specialized centers.

The scenario of pediatric intensive therapy and oncology in Brazil is well below the recommended level of care for these patients. Beds at intensive pediatric care units (IPCU) in Brazil are scarce and those available are concentrated on the capitals and wealthier regions[4,5]. In June 2023, 6,489 IPCU were available country-wide at the ratio of one bed for each 6,184 children according to data of the national registry of health units (CNES). These numbers are still lower for pediatric oncology specialized centers, great part of them on the South and Southeast regions[5,6].

## DEVELOPMENT

The incidence rate of childhood and adolescent cancer is 155.8 per million, accounting for 1% to 4% of all the malignant tumors of the population[7]. The estimates for the triennium 2023-2025 are 7,930 cases of cancer in younger than 19 years of age in Brazil according to the National Cancer Institute (INCA), 8% to 15% of which are CNS tumors[7-9].

Specific mortality rates vary according to age, resection grade and types of tumor with astrocytoma presenting 5-year survival mean above 80%, while subtypes of higher risk of medulloblastoma have lower survival rates of 45%, especially in children younger than three years of age[10].

Treatment of CNS tumors in children and adolescents is complex, involving surgical interventions, longer hospital length of stay and outpatient follow-up[10]. Neurosurgery with intensive pediatric follow up is usually the initial treatment and possibly followed by chemotherapy and radiotherapy[10]. Successful treatment depends on early diagnosis with thorough physical exam and imaging tests[11,12]. However, sometimes it is not possible, since symptomatology varies according to the lesion site, and very young patients have difficulties in reporting the symptoms that can be wrongly attributed to other causes and are found in common childhood pathologies[13].

It is very important that assistance teams at primary health attention and emergency levels increase their diagnostic suspicion. In 2013, Wilne et al.[14] published a guideline for health professionals caring for children who may be carriers of CNS tumors. More recently, Costa et al.[15] analyzed the adequacy and plausibility of an intervention with health workers of primary attention through a program of continuous education for early identification of pediatric cancer. The stratified analysis of the data revealed that skilled professionals referred 3.6-fold more children to reference hospitals due to suspected CNS lesions with increased number of confirmed cases in the intervention group[15].

The impact of the creation of a neurointensivist service in reducing hospital costs and improved clinical outcomes has already been proven for these patients[16]. However, there are scarce publications on pediatric neurointensivism that corroborate the creation of specialized units. In that sense, the creation of a focused service to treat and provide specific care for children with neurologic and

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neurosurgical pathologies is a progress for the treatment of children with CNS tumors[17].

The "*Instituto Estadual do Cérebro Paulo Niemeyer (IECPN)*" is a pioneer in pediatric neurointensivism at the National Health Service (SUS). Inaugurated in 2013, it offers 15 ICU beds and ten beds at the infirmary and started chemotherapy treatment of children with CNS tumors since 2022. In the last ten years, 1,760 patients have been admitted, 1,747 surgeries were performed, of which 470 neurosurgeries to treat CNS tumors, accounting for more than 90% of all children diagnosed with this type of tumor in Rio de Janeiro.

IECPN with skilled staff and adequate infrastructure proposed to offer pediatric care to the whole national health network through the National High Complexity Regulation Center (CNRAC), whose objective is to control the interstate referral flow of patients who need high complexity hospital assistance if the state of residence does not offer these services or whose offer is not sufficient. The entity affirms that there is no demand to treat children with CNS tumors. The main question to be discussed is the potential sub-notification of cases or delayed diagnosis, given the epidemiologic data and paucity of specialized services for a continental country as Brazil

Both the diagnosis and treatment of these tumors impact the life of the child, the adolescent and their families. The course of the treatment tends to be long, which implies in pulling off the patient from school and social living during a crucial phase of different dimensions of their development, in addition to their parents and legal guardians discontinuing their labor activities with important financial repercussions. In addition, the tumor and its treatment can cause neurodevelopment deficits that will require multidisciplinary care for management and rehabilitation.

Potential neurodevelopment deficits may place children and adolescents in the category of disabled individuals requiring attention for their special needs through policies that ensure the access to support therapies, customized educational plans, emotional help and guarantee of rights to his/her family to promote inclusion and well-being.

In addition to technology and infrastructure, care to children with CNS requires consistent functioning of health systems with seamless articulation across all levels. Is SUS prepared to manage these patients?

Law 14,308[18] dated March 18, 2022 established the national policy of attention to pediatric oncology (PNAOP) with guidelines for health managers, an important landmark to ensure access and rights of children and adolescents with CNS as: integrate PNAOP with the National Policy of Cancer Prevention and Control, implement state plans of pediatric oncology attention and respective lines of care, create specialized centers and teleconsulting services to facilitate early diagnosis and clinical follow-up, strengthen the processes of regulation of the services of diagnosis, treatment, rehabilitation, and family-centered care, among others and include disciplines addressing children and adolescents cancer in graduation and residency courses.

The implementation of PNAOP is quite challenging but the perspectives are encouraging. The success of these actions depends on the implementation of coordinated strategies among different management levels at SUS and involvement of health professionals and civil society.

Overall, resources have to be ensured to offer pediatric oncology services and researches in the areas of translational medicine, clinical trial, evaluation of health technology, economic assessment, epidemiology, human sciences and other fields of knowledge.

Additionally, investments in training of multidisciplinary teams of primary attention and emergency focused to the elaboration of screening and referral protocols are required and integration among health attention levels. The objective of the integration is to strengthen regional referral centers and maintenance of excellence centers of pediatric neuro-oncology with infrastructure and specialized teams to ensure treatment, improvement of the quality-of-life and overall survival of these patients.

Furthermore, it is necessary to discuss matrixes of indicators that allow professionals across different levels of management to monitor the implementation of PNAOP.

The definition of these matrixes is not trivial given the Brazilian regional diversity, since these indicators should be more comprehensive and not only for mortality rates, procedures performed or costs. It is necessary to think of indicators that consider dimensions of care for different scenarios as level of education and capacity of multiprofessional teams regarding suspicion and fast referral to screening services; implementation and use of protocols of diagnosis; incorporation of families in clinical decisions and therapeutic approaches; awareness of the population about childhood and adolescent cancer; integration and communication among several levels of health attention; functioning of reference regional and excellence centers in pediatric neuro-oncology, in addition to other markers with impact on the incorporation of new and better treatments, increase of survival and mainly, improvement of quality of life of these patients and their families.

## CONCLUSION

The development and incorporation of new technologies is revolutionizing the course of the diagnosis,

treatment and prognosis of children and adolescents with CNS tumors in the upcoming years. Next-generation sequencing created large sets of digital data with important clinical application as risk predictors, early detection, prognosis and identification of markers.

As cancer treatment is becoming increasingly complex and challenging, Artificial Intelligence (AI), Machine Learning, Deep Learning, Big Data, among others, will become critical to support and facilitate the continuity of the care. These technological solutions are able to analyze radiological imaging patterns in search of abnormalities, identify early signs of a disease, genomic triage pursuing therapies matched to the genetic profile, summarize the content of innumerous sources in search of better evidences, identify risk factors for improved prevention and help pharmacovigilance.

This scenario prompts SUS managers to utilize tools that allow the allocation of resources and services to ensure equitable access for the population and avoid the aggravation of regional differences which often prioritizes more developed and wealthier regions.

## CONTRIBUTIONS

Luís Felipe Ribeiro Soares contributed to the study design, acquisition, analysis and interpretation of the data and wording. Saint Clair Gomes Júnior contributed to the study design, acquisition, analysis and interpretation of the data, wording and critical review. Nathalia Grigorovski de Almeida Kuyven contributed to the study design, acquisition, analysis and interpretation of the data and critical review. All the authors approved the final version for publication.

## DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare

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