

Access and Adhesion to Oncological Treatment of Children and Adolescents: in Addition to the Medical-Biological Aspect

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Acesso e Adesão ao Tratamento Oncológico Infantojuvenil: para além do Aspecto Médico-Biológico

Acceso y Adhesión al Tratamiento Oncológico Infantojuvenil: además del Aspecto Médico-Biológico

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INTRODUCTION

Cancer is considered a rare disease in the pediatric age bracket. Only 3% of all cases of malignant neoplasms occur in children and adolescents (0 to 19 years of age)¹. However, it is the most important cause of death in this population. Since there is no confirmed evidence that environmental factors explain the emergence of pediatric cancer, there are no primary prevention strategies. Therefore, the most effective way to control the disease in children and adolescents is early diagnosis, combined with the guarantee of adequate treatment.

Late diagnosis, difficulties in access to treatment centers, and treatment dropout can have numerous unfavorable consequences for pediatric cancer patients. These include high rates of advanced disease, disease progression, the need for intense treatments, and higher levels of toxicity, leading to worse prognoses and outcomes. An efficient public healthcare system is thus essential for identifying important signs and symptoms for early diagnosis and effective treatment²⁻⁴.

Given this problem, which is not limited to the pediatric population, strategies have been adopted to increase the odds of cure for cancer patients. Brazil's Law no. 12.732 of November 22, 2012, article 2, determines a maximum time for the start of treatment: 60 days or less starting on the date the pathology report is issued⁵. Importantly, pediatric cancers are often more aggressive and rapidly progressive than most cancers in adults, making immediate initiation of treatment all the more urgent.

The current article aims to identify the influence of socioeconomic, cultural, and emotional factors on access

and continuity of treatment for pediatric cancer. That is, the study signals the degree to which low socioeconomic levels associated with subjective factors may impact prognosis for children and adolescents with cancer, interfering in survival rates and thus contributing to a significant increase in mortality.

CHALLENGES FOR GUARANTEEING ACCESS AND ADHERENCE TO PEDIATRIC CANCER TREATMENT

The survival of children and adolescents with cancer has improved in recent years, especially in economically developed countries, where five-year survival rates have already reached 80%⁶. In peripheral countries like Brazil, despite strides in diagnosis and treatment, the survival rates have still not reached this threshold. Estimated five-year survival in pediatric cancer, calculated from incidence and mortality data published by INCA and the Brazilian Ministry of Health in 2016, point to 64%, still low compared to developed countries⁷.

According to the World Health Organization (WHO), each year more than 150 thousand children are diagnosed with cancer worldwide. The WHO has further reported that through access to qualified health services, more than 80% of children with cancer can survive and thus enjoy the right to a full and healthy life⁸. However, many children in low and middle-income countries fail to receive complete treatment, and as a result, more than 80% of deaths from childhood cancer occur in resource-limited locations⁹.

Late diagnosis and lack of access to treatment for cancer are common in low-income countries⁸. In 2017, only 26% of low-income countries reported the existence of available pathology services in the public sector, while

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more than 90% of high-income countries reported efficient treatment services. Thus, the data show that starting in 2012, cancer has been the second leading cause of death in the world with 8.2 million deaths, most of which in low and middle-income countries⁸.

Seeking to confront this disparity between countries and reduce premature mortality from cancer, in May 2017, the 70th World Health Assembly (in Geneva, Switzerland) passed a resolution on cancer prevention and control through an integrated approach⁸. Considering that certain population groups suffer inequalities in access to screening, early diagnosis, and timely and adequate treatment, and that different cancer control strategies are necessary for specific groups of cancer patients, such as children and adolescents, the resolution allowed discussing some strategies for early diagnosis and timely and adequate treatment, including pain relief and palliative care.

In the scope of reducing mortality and improving outcomes and quality of life for cancer patients, some agreements were possible, featuring: implementation of interventions in prevention, early detection, screening, treatment, palliative care, and survival, including for childhood cancer.

Considering that socioeconomic conditions associated with emotional and cultural factors have a significant impact on access and adherence to treatment and thus on recovery from the disease, it is essential to assess the cultural and emotional background and the socioeconomic resources of families of children and adolescents with cancer. With this understanding, the obstacles to the continuity of treatment become the focus of attention for the multidisciplinary healthcare team in order to guarantee this patient group's right to health and life, as recommended in Brazil's Statute for Children and Adolescents (Ecriad)¹⁰.

DEMANDS IN PEDIATRIC CANCER TREATMENT: BEYOND MEDICINE AND BIOLOGY

Cancer is still a stigmatized disease, associated with pain, suffering, and death. In childhood, the illness and confrontation with death in this phase of life are seen as a break with the natural cycle, causing intense emotional suffering in the family.

The emotional impact is further exacerbated by profound changes in family relations and in the lives of children and adolescents exposed to repeated invasive medical procedures, resulting in side effects, pain, changes in self-image, and uncertainties concerning the treatment. Thus, cancer impacts the biological dimension and other dimensions, interrupting social and school routines and leisure-time activities, as well as contact with other children and family members. All of this occurs in an

socioeconomic context that is not always favorable for the family group, often marked by adverse conditions of existence and subsistence.

The process of pediatric cancer treatment forces changes in the family's working life, requiring financial adaptations resulting from increased expenses and the need for continuous follow-up. Since the treatment is prolonged and stressful, many families experience difficulties reconciling care for the child and work, so that one of the parents or guardians has to quit his or her job to be able to stay by their child fulltime. In some families, the caregiver is also the breadwinner, meaning a decrease in income throughout treatment and greater impoverishment of the family members, interfering directly in their quality of life and health.

Even families in which the parents are working under formal labor contracts, there is no legal backing in Brazil's Consolidated Labor Legislation (CLT) for them to take leave from work to accompany their children during treatment. Law no. 13.257/2016¹¹, which included items X and XI in Article 473 of the Consolidated Labor Legislation, only guarantees paid leave for one day a year, conditioned on a physician's excuse, to take their child up to 6 years of age to a doctor's appointment.

The obvious paradox is that children and adolescents have the right to be accompanied during their hospitalization, and that it is the duty of the family, society, and state to guarantee their life and health, as provided in the Statute for Children and Adolescents (Ecriad)¹⁰, Article 4, while the Consolidated Labor Legislation fails to ensure parental leave to accompany children during cancer treatment, constituting an explicit violation of the child's or adolescent's right to health treatment in the company of their parents.

Another factor that can further exacerbate this vulnerability is the family's housing situation, related to basic infrastructure with issues such as building standards, the home's size, water supply, electricity, and sewage and garbage disposal, which are not always favorable to the child's time at home, besides conditions in access to the cancer treatment center, such as the availability of urban transportation, steep streets, and rural versus urban location, which hinders daily commuting for treatment. There may also be issues with the cultural background: low cognitive capacity in the family independently of level of schooling and families with a worldview based exclusively on religious values and beliefs that can interfere in the treatment process, raising challenges for the healthcare team.

Considering the expanded concept of health as the result of the population's living conditions, working with families of children and adolescents in cancer

treatment assumes integrated, comprehensive action such as interdisciplinary and inter-sector care. Inter-sector care requires linkage between the levels of healthcare and between the latter and other public policies, while interdisciplinarity requires exchange of knowledge and shared decisions between team members, contributing to the expansion of spaces for sharing and dialogue between the family and the healthcare team, establishing links between socioeconomic, emotional, and cultural conditions and the complexity of cancer treatment.

CONCLUSION

Continuity of treatment is related to the socioeconomic, emotional, and cultural issues of the children and adolescents and their families. Although they may often have the best treatments in specialized centers with the most advanced technologies, the patients and families may not always have the means to access them.

Experience shows that such conditions in access are related to the families' precarious socioeconomic context and the absence of effective support for the demands that emerge during cancer treatment. Institutional contributions, capable of mitigating the families' vulnerability, are associated with comprehensive, integrated action between the healthcare team members, linkage and mobilization of resources in the social protection network, and guaranteed access to the rights involved in dealing with the illness and the other social rights ensured by public policies.

CONTRIBUTIONS

All the authors contributed to all stages of the manuscript.

CONFLICT OF INTEREST

None.

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