Intervention Strategies for Adherence to the Treatment of Childhood Cancer: Case Report

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Estratégias de Intervenção para Adesão ao Tratamento do Câncer Infantojuvenil: Relato de Caso

Estrategias de Intervención para la Adhesión al Tratamiento del Cancer Infanto Juvenil: Relato de Caso

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Abstract

Introduction: Childhood cancer is considered as public health problem because of the impact on mortality. The abandonment of treatment is indicated as one of the main causes of failure in therapy; because of this, strategies to avoid abandonment are fundamental for the improvement of treatment outcomes in low-and middle-income countries. **Case report:** Patient 4 years 11 months, admitted in the institution with abdominal mass on the right of rapid growth. Biopsy confirmed malignant disease. The treatment included chemotherapy and radiation therapy. The patient had irregular follow-up with multiple faults in appointments, scheduled exams and treatment due to the socioeconomic context in which he was inserted. The multiprofessional team advised the family about the importance of treatment, seeking to safeguard the child's health, as well as ensuring continuity of treatment. The implemented strategies were: institutional, articulation with the network and social support. **Conclusion:** After several interventions by INCA's multiprofessional team, it was possible to contribute to the child's adherence to the proposed treatment.

Key words: Case Reports; Child; Neoplasms; Treatment Adherence and Compliance.

Resumo

Introdução: O câncer infantil é considerado um problema de saúde pública em razão do seu impacto na mortalidade. O abandono de tratamento é apontado como uma das principais causas de insucesso da terapêutica; dessa forma, estratégias para evitar o abandono são fundamentais para a melhora dos resultados de tratamento em países de baixa e média rendas. **Relato do caso:** Paciente com 4 anos e 11 meses de idade, admitido na instituição com massa abdominal à direita de crescimento rápido. A biópsia da tumoração confirmou se tratar de neoplasia maligna. O plano de tratamento incluiu quimioterapia e radioterapia. O paciente teve acompanhamento irregular com múltiplas faltas às consultas, aos exames agendados e ao tratamento devido ao contexto socioeconômico em que estava inserido. A equipe multiprofissional orientou à família sobre a importância do tratamento, buscando salvaguardar a saúde da criança, assim como garantir a continuidade do tratamento. As estratégias implementadas foram: institucionais, articulação com a rede e suporte social. **Conclusão:** Após diversas intervenções da equipe multiprofissional do INCA, foi possível contribuir para aderência da criança ao tratamento proposto.

Palavras-chave: Estudos de Casos; Criança; Neoplasias; Cooperação e Adesão ao Tratamento.

Resumen

Introducción: El cancer infantil es considerado un problema de salud pública, devido a su impacto en la mortalidad. El abandono del tratamiento es apuntado como una de las principales causas del fracaso de la terapeutica; de esta forma, estratégias para evitar el abandono son fundamentales para la mejoría de los resultados del tratamiento en países de baja y média renta. **Relato del caso:** Paciente con 4 anos y 11 meses de edad, admitido en la institución con masa abdominal a la derecha con crescimento rápido. La biopsia de la tumoración confirmó tratarse de neoplasia maligna. El plano de tratamiento incluye quimioterapia y radioterapia. El paciente tuvo acompañamiento irregular con múltiplas faltas a las consultas, a los exámenes agendados y al tratamento, debido al contexto socioeconómico en el que estaba insertado. El equipo multiprofissional orientó a la familia sobre la importancia del tratamiento, buscando salvaguardar la salud del niño, así como garantizar la continuidad del tratamiento. Las estrategias implementadas fueron: institucionales, articulación con la red de la salud y soporte social. **Conclusión:** Después de diversas intervenciones del equipo multiprofisional del INCA, fue posible contribuir para la adherencia del niño al tratamiento propuesto.

Palabras clave: Informes de Casos; Niño; Neoplasias; Cumplimiento y Adherencia al Tratamiento.

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INTRODUCTION

Survival rates in pediatric cancer have improved significantly in recent decades in high-income countries, reaching an overall cure rate greater than 80%[1]. However, more than 80% of pediatric cancer cases in the world are in low and middle-income countries, where considerable improvement is needed to achieve similar results[2,3].

The Brazilian National Cancer Institute José Alencar Gomes da Silva (INCA) estimates that in 2018-2019 there will be 12,500 new cases of cancer in children and adolescents (0 to 19 years of age). Although cancer is rare in childhood, it is considered a public health problem, as the second leading cause of death in this age group in most regions of Brazil, exceeded only by accidents and other violent deaths[4].

In low and middle-income countries, treatment dropout has been identified as one of the main causes of treatment failure[2,5], besides increasing the likelihood of unnecessary suffering, mutilating surgeries, the need for more intense treatments, and waste of health resources.

Treatment dropout is defined as failure to start or complete therapy for a potentially curable or definitively controlled disease and/or interruption of treatment for four or more consecutive weeks without an identifiable clinical cause[5,6].

Strategies to avoid treatment dropout are essential to improve treatment outcomes in low and middle-income countries.

The study was approved by the Institutional Review Board of INCA, under protocol number CAAE: 82799618.9.0000.5274, as a case report of a child with diagnosis of a potentially curable cancer, with irregular treatment, highlighting the strategies adopted by the interdisciplinary team that enabled avoiding treatment dropout.

CASE REPORT

Male patient 4 years and 11 months old was admitted to hospital with a rapidly growing abdominal mass on the right, vomiting, and abdominal pain that was difficult to locate. Biopsy confirmed a malignant neoplasm. The treatment plan included chemotherapy and radiotherapy. The patient presented irregular follow-up, missing multiple appointments, tests, and treatment sessions due to the family's socioeconomic difficulties.

On the date the patient was signed into the service, the mother was in the sixth month of pregnancy with her current partner and had no identification papers in her possession. The patient had a birth certificate with his parents' names, but he had no contact with his biological father, who was incarcerated at the time. During care at INCA, the attending team observed the bond between the patient and his stepfather. The mother reported a limited family support network, with conflicts and weaknesses in the ties between members of the mother's extended family.

The patient lived with his mother, age 24, and stepfather, age 55, in a low-income neighborhood on the outskirts of the city of Rio de Janeiro, 35 km from the cancer treatment center. The patient was one of three siblings constituting a nuclear family and was the only one who remained in the mother's company, since the other two were living with maternal uncles, who were in charge of their care. The patient lived in a substandard rented dwelling with precarious coverage of essential services such as water, sewerage, and garbage collection. The dwelling was hard to reach and had a negligible supply of nearby public health services.

The family income was below the poverty line as defined by the World Bank and the Brazilian government, based on the cutoff used to determine eligibility for the "Brazil without Poverty" plan and the *Bolsa Família* program as of June 29, 2016. The stepfather was the sole family provider, performing unskilled odds jobs no labor rights or social security benefits.

Starting when the patient was enrolled for treatment, the mother reported difficulties reaching INCA, due to lack of financial support for commuting to continue the treatment. Based on the patient's cancer treatment, the family was eligible for benefits from nonprofit organizations and associations. The mother's lack of identification papers hindered the patient's access to some social rights. In addition to failing to appear for the scheduled appointments, the mother failed to have the tests done as ordered, which was jeopardizing the patient's treatment.

Since the patient was considered high risk for treatment dropout, an intervention strategy was implemented by the team from the "Project to Control Treatment Adherence", under the Department of Clinical Research in Pediatric Oncology at INCA.

The initial strategy was a situational diagnosis to identify the family's needs, limits, possibilities, social support network (consisting of family members, community, and public goods and services), and life history.

The interdisciplinary team oriented the family on the treatment's importance, aiming to safeguard the child's health and guarantee the treatment's continuity. The strategies were: 1) Institutional: scheduling appointments with different members of the healthcare team all on the same day to decrease the need for trips to the hospital; a telephone call with a reminder from the attending professional in clinical research at INCA, 24 hours before

the scheduled appointment; monitoring attendance at the medical appointments; joint care by members of the interdisciplinary team; encouragement for contact with other patients (during treatment and follow-up) and their families. 2) Linkage with the Network: Contacts were made with the healthcare teams providing support and care at the family's home, such as the Family Health Strategy and other Basic Health Units. 3) Social Support: Information was provided on social benefits, projects, and programs in which the patient and family could enroll, such as a food and housing stipends and transportation vouchers from the "INCA Volunteers" project and the Ronald McDonald House. Counseling was provided to apply for government benefits such as exemption from the requirement of a second copy of identification papers.

DISCUSSION

Childhood cancer is a potentially curable disease. More than 80% of patients in high-income countries experience excellent outcomes, with treatment in specialized centers by interdisciplinary teams[3]. To achieve cure, it is necessary for the treatment to be performed in its entirety, without gaps or delays[2]. However, the results are not as favorable in low and middle-income countries, and treatment dropout appears as one of the main causes of treatment failure[2].

Given the complexity of factors that can impact treatment adherence, the initial step for the case management was a situational diagnosis by the interdisciplinary team. This stage allowed the identification of the main factors that were impacting treatment adherence and the best strategies for this specific case.

The organization and configuration of our patient's family and the actual living conditions were placing the patient at risk of treatment dropout. The family had a limited personal social network, translated as the unavailability of family members for emotional and material support during the boy's treatment.

Gerhardt *et al.*, in order to facilitate treatment adherence, found it necessary to consider the context to which the individual belongs, especially for the low-income population[7]. The effective implementation of treatment assumes satisfactorily meeting a set of social demands emerging in the family's daily routine: housing, transportation, food, income, and access to social goods and services. Some studies have signaled that dropout from treatment of pediatric cancer is closely related to individual and family socioeconomic factors. This reiterates the importance of intervention by government agencies and nonprofit institutions in situations that involve basic resources to ensure the treatment[8,9].

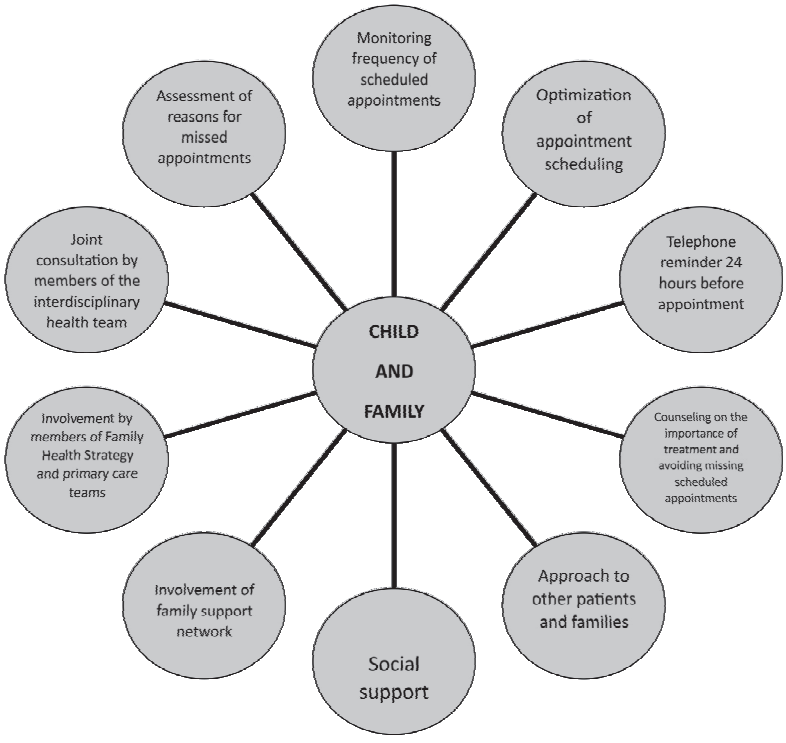

Figure 1. Strategies implemented to increase treatment adherence

The difficulties mentioned above were exacerbated by the mother's and stepfather's socioeconomic and educational limitations and the time spent to reach the cancer center. Similar difficulties have also been identified by other researchers[5,9].

In the case described here, the family was living in a socially vulnerable slum community, marked by lack of social policies, social and spatial inequalities expressed in the precarious housing conditions, lack of urban sites and services such as basic sanitation, transportation, and mobility, unemployment, low schooling, and lack of leisure-time opportunities, in addition to heavy violence[10]. The entire situation, identified in the diagnosis, fueled the number of missed appointments and tests.

According to Alvarez, interventions by a interdisciplinary team contribute to reducing the risk of treatment dropout[8].

The intervention by the interdisciplinary team focused on the child and family and aimed to safeguard his health and guarantee the continuity of his treatment. Three lines of intervention were adopted: at the institutional level, linkage with the healthcare network, and social support. These interventions have been used by Pediatric Oncology at INCA and can be adopted by other institutions.

Treatment at specialized centers with multidisciplinary teams specialized in care for children and their families, as well as governmental and nongovernmental support, are some of the strategies that can help reduce treatment dropout rates[8]. Strategies to encourage training and the incorporation of research in epidemiology concerning health services, adherence, and treatment outcomes are essential in this process[3].

CONCLUSION

The strategies adopted here were highly relevant for understanding the social demands generated in the process of cancer treatment that particularly impacted the collective existence of the child and his family. Various interventions by the interdisciplinary team at INCA enabled improving the child's adherence to the proposed treatment.

CONTRIBUTIONS

Fernanda Ferreira da Silva Lima, Senir Santos da Hora, and Carollyne Rodrigues Souza Lage participated in the study's conception, data interpretation, and writing and critical revision of the intellectual content. Ana Raquel de Mello Chaves, Ana Maria Rodrigues and Bianca Amorim Santana contributed to the data interpretation. Sima Ferman contributed to the writing, critical analysis with intellectual contributions, and approval of the final version for publication.

CONFLICT OF INTEREST

None.

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