Luiz, his Parentes and the Oncology Treatment: a Case Study

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Luiz, seus Pais e o Tratamento Oncológico: um Estudo de Caso

Luiz, sus Padres y el Tratamiento Oncologico: un Estúdio de Caso

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Abstract

Introduction: The complexity of treatment in pediatric oncology requires multimodal therapies in specialized centers, multiprofessional interventions and also a treatment that respects the individuality of each case. **Case report:** This is the case of a 16-year-old adolescent who was referred from a general hospital where he was diagosed with osteosarcoma. At the time, in addition to the locally advanced disease, the patient also had bilateral pulmonary metastases. With the support of the multiprofessional team, he and his parents were able to built strategies to cross the oncologic sickness. **Conclusion:** The cancer produces effects not only from an organic point of view, but also has consequences for the psyche, which can be potentially traumatic. It is noted the need to elaborate the various grievances that go through the illness and oncological treatment so that some (re)inventive capacity is possible. It was evidenced that not only patients but also their caregivers and the multiprofessional team have ways of dealing with what they experience in daily routine in pediatric oncology.

Key words: Neoplasms; Hospitalization; Bereavement; Psycho-Oncology; Adolescent.

Resumo

Introdução: A complexidade do tratamento em oncologia pediátrica exige terapias multimodais em centros especializados, intervenções multiprofissionais, assim como um manejo que respeite a singularidade de cada caso. **Relato do caso:** Trata-se do caso de um adolescente de 16 anos que foi encaminhado de um hospital geral, onde foi diagnosticado com osteossarcoma. Na ocasião, além da doença localmente avançada, também apresentava metástases pulmonares bilaterais. A partir do suporte da equipe multiprofissional, o paciente e seus familiares puderam construir estratégias para atravessar o adoecimento oncológico. **Conclusão:** O câncer produz efeitos não só do ponto de vista orgânico, mas também traz consequências ao psiquismo, que podem ser potencialmente traumáticas. Nota-se a necessidade da elaboração dos diversos lutos que perpassam o adoecimento e tratamento oncológico para que alguma capacidade (re) inventiva seja possível. Evidenciou-se que não só os pacientes, mas também seus responsáveis e a equipe multiprofissional, possuem maneiras de lidar com o que experienciam no dia a dia na oncologia pediátrica.

Palavras-chave: Neoplasias; Hospitalização; Luto; Psico-Oncologia; Adolescente.

Resumen

Introducción: La complejidad del tratamiento en oncología pediátrica requiere terapias multimodales en centros especializados, intervenciones multiprofesionales así como un tratamiento que respete la individualidad de cada paciente. **Relato del caso:** Se trata del caso de un adolescente de 16 anós, que fue encaminado desde un hospital general, donde fue diagnosticado con osteosarcoma. En la ocasión, además de la enfermedad localmente avanzada también presentaba metástasis pulmonares bilaterales. A partir del soporte del equipo multiprofesional, el paciente y sus padres pudieron constuir estrategias para enfrentar la enfermedad oncológica. **Conclusión:** El cáncer produce efectos no sólo desde el punto de vista orgánico, sino que también trae consecuencias al psiquismo, que pueden ser potencialmente traumáticas. Es necesaria la elaboración de los diversos lutos que aconpañan la enfermedad y el tratamiento oncológico, para que alguna capacidad (re)inventiva sea posible. Se evidenció que no solamente los pacientes, sino también sus responsables y el equipo multiprofesional poseen estratégias de lidiar con lo que experimentan día a día en la oncología pediátrica.

Palabras clave: Neoplasias; Hospitalización; Aflicción; Psicooncología; Adolescente.

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INTRODUCTION

Pediatric cancer represents a group of diverse diseases with the common characteristic of uncontrolled proliferation of abnormal cells. Estimates for the two-year period 2018-2019 point to 420 thousand new cases of cancer, not including non-melanoma skin cancer. The proportion of pediatric tumors in Brazil is 3% of all cancer cases, or an average of 12,500 new cases of cancer in the pediatric age bracket (0 to 19 years)[1]. According to data from the Brazilian National Cancer Institute José Alencar Gomes da Silva (INCA)[2], cancer is the leading cause of death from disease in children and adolescents from 5 to 19 years of age.

This group of potentially fatal diseases requires multimodal treatment (chemotherapy, surgery, radiotherapy, bone marrow transplantation) in specialized centers with multidisciplinary teams. Care in pediatric oncology also entails specificities, not only biological, but also psychosocial, the complexity of which requires multidisciplinary interventions.

A child in cancer treatment is exposed to repeated invasive procedures, side effects from the treatment, altered diet, suspension of leisure-time activities, interruption of school and social routines, changes in self-image, feelings of uncertainty, periodic hospitalizations, and pain, all losses that affect their socialization and interfere in their daily relations[3,4].

In this context, children and adolescents with cancer not only have to assimilate their diagnosis and cope with the treatment that will follow them throughout much of their lives, but also see their daily activities, life projects, and personal relations affected. On the one hand, they are in a constant and intense relationship with the health service and multidisciplinary team, and on the other they need to make changes to the dynamics and relations in their family, school, and social context in order to guarantee the process of normalization in their chronic condition. Sometimes there may be a fine line between the management of care and life in general[5].

It is noteworthy that in the face of such a potentially traumatic situation, patients still find unique ways of coping with their experience, that is, the diagnosis, the journey, and the vicissitudes of cancer treatment. The current study aims to highlight the subjectivity of this experience, which is unique to each patient.

The article aims to report the case of a teenage patient, and based on this report, to reflect on the strategies he created to cope with his illness. His strategy emerged from the offer by a cancer hospital in the city of Rio de Janeiro to listen to patients, as part of a residency thesis, approved by the Institutional Review Board of INCA under protocol CAAE: 68870817.6.0000.5274. The names used in the article are fictitious to protect the identity of the research subjects.

CASE REPORT

LUIZ: DIFFICULT CONTINGENCIES AND POSSIBLE WORKAROUNDS

Luiz, 16 years old, was referred from a general hospital where he had been in treatment for what was believed to be osteomyelitis (a serious *Staphylococcus aureus* infection). Due to a fracture of his left hip, he underwent surgery with the placement of an external fixator. A bone biopsy was performed during the surgery, and when the histopathology report revealed osteosarcoma, he was referred to our cancer center.

During his hospitalization in the pediatric oncology ward, tests were performed to assess the extent of the disease and perform the most appropriate treatment. Besides the locally advanced disease, bilateral pulmonary metastases were detected. The adolescent came across as a studious homebody who loved to eat. When talking about his prolonged hospital stay, he displayed some shortness of breath, but he said he accepted whatever was necessary for his own good and for his health. He was accompanied during his hospitalizations by his mother, Joyce. She referred to Luiz as the "bright one" of the family, a homebody, affectionate, extremely intelligent, and dedicated to his studies.

The patient's clinical condition worsened in the following days, and he had to be transferred to the pediatric intensive care unit, where he was intubated and consequently sedated. After performing tests and discussing the adolescent's clinical status, the team indicated disarticulation surgery of his leg, which was the focus of infection. At that stage there was some concern among the team and the family that Luiz would "wake up" and realize he was missing a leg, since he had been unaware of this possibility before being sedated.

Disarticulation surgery of the left leg was authorized by the patient's parents and performed without clinical complications. As the days passed, Luiz' clinical condition allowed reducing his level of sedation, and as the sedation decreased, his parents' anxiety increased, since they did not know how to tell their son what had happened. The patient's family brought a notebook and asked Luiz to write down what he would like to do, since the tube prevented him from speaking, but not from communicating. He used the notebook to ask questions, ask for water, say he was sleepy, complain about the discomfort from the breathing tube, and even leave messages for his mother asking her to stay calm and have faith in Jesus.

While the patient was still oscillating, during his awake phase he nodded towards his amputated leg as if to ask his father, who wrote on the notebook, “Son, they had to remove your leg for you to get better.”

Antônio, Luiz’ father, was unable to express what had happened in words and used the notebook to communicate this difficult message to his son. During his psychological follow-up, Antônio recalled he did not know how to tell his son what was happening. He showed the psychologist what he had written on the notebook and asked her for help to talk about it with Luiz.

Luiz’ alternated his counseling sessions with games of UNO and various questions on the notebook. His questions were about the ICU equipment, his health, complaints about the discomfort from the breathing tube, remarks about how he wanted to eat (to taste the food), and his uncanny feeling towards his “short-circuited” body, having to “eat through my nose, pee through a tube, breath through my neck, and wear diapers”. He asked the psychologist to manage his relationship with the healthcare team and expressed interest in learning about his treatment, what chemotherapy and radiotherapy were all about, and the effects on his body. After the sessions, Luiz would tear the pages he had written out of the notebook, rip them up, and ask the psychologist to throw them away.

One day, although Luiz already knew objectively that his leg had been amputated as part of the cancer treatment and for him to survive, he asked the psychologist what had really happened to his leg. This teenager understood the importance of the surgery to save his life, but it was still not possible to work through the grief over the loss of part of his body, or in his words, “I know they took my leg for me to get better, but are they going to put it back?” The psychologist told him the surgery was necessary for him to be alive at that moment, and that his leg had been diseased, and that was why it had to be removed and could not be put back, but that she would be there to help him cope with the change in his body.

Back on the ward, Luiz began to enjoy the game room (at the invitation of the occupational therapist), where he was able to play videogames, talk about his routine at home and his favorite activities, and meet and play with other teens in treatment. When he was unable or indisposed to get out of bed, the occupational therapist went there to play games. During hospitalization, when a patient cannot choose virtually anything – procedures, medications, and even daily activities such as the time to wake up, eat, and sleep – the possibility of being able to choose to play, where to play, and with whom to play reaffirmed the adolescent’s condition as a subject.

After Luiz was discharged, over the course of his outpatient psychology sessions, Luiz raised questions about what Freud[6] called “the uncanny” (*unheimlich*). The uncanniness has to do with what is frightening, even terrifying, but simultaneously familiar. This teenager, with his body still in development and still being appropriated by it, began to feel like a stranger to himself, unable to recognize himself in the body image of the “boy without a leg”. In his attempt to build a veil for the cause of his anxiety, he wondered about what it would be like to fit a prosthetic leg and the reasons someone might prefer not to use one, since it would apparently “hide” the leg’s absence from the view of others.

But the question remains: what about Luiz’ view of his own body? Something in this case imposed a reinvention or reconstruction of his own body, which was undergoing the grieving process for his lost leg. Although at odds with this issue, the adolescent was attempting to spare his family, especially his mother, from his suffering. During his last hospital stay, with his physical and emotional weaknesses, Luiz realized his mother’s vulnerability and anguish and tried to care for her in order for her to be able to stay with him. He asked the team to offer her support, sometimes even asking that she receive psychological support before he did.

DISCUSSION

Over the course of elaborating this case, we found that not only the patient, but also the parents and we as a team, developed inventive ways to cope with the daily experiences in pediatric oncology. Luiz’ case revealed how his father struggled with a situation that left him speechless, and how he found a possibility in the notebook to tell his son something that was so hard from him to put into words. The case also showed a loving teenager who realized his mother’s vulnerability and signaled to the healthcare team that she needed support to be able to stay by his side. The parents of patients treated at this institution have to cope (or at least try to cope) with a narcissistic wound as they face issues related to losing the image of an ideal child, with their helplessness in face of illness, enduring pain and suffering and sometimes even the loss of the one they imagined would be free of all problems.

CONCLUSION

Cancer produces not only physical effects, but also psychological consequences. The disease involves various stigmas, representations, and fantasies in the sociocultural surroundings. According to Susan Sontag[7], the historical construction of cancer in Western culture links it to a death sentence, in which the patient is purportedly fated to an agonizing and painful journey of prolonged suffering.

Even today, cancer is a stigmatized and symbolically loaded illness in the social imaginary.

Thus, subjective issues may be triggered beginning with the diagnostic workup. The unexpectedness of the illness, especially in this phase of life, can be viewed as potentially traumatic for all those involved. There is a need to work through grief in pediatric oncology, from diagnostic workup through the end of treatment, since this is accompanied by limitations and is sometimes aggressive, involving constant losses and requiring great reinventive capacity on the individual's part, made possible by building and sustaining partnerships that wager on the patient's emotional resources throughout this journey.

CONTRIBUTIONS

Roberta Corrêa Lanzetta participated in the study's conception and planning, data collection, analysis, and interpretation, and writing, critical revision, and final approval of the version for publication. Ana Beatriz Rocha Bernart participated in the study's conception and planning, data analysis and interpretation, and writing, critical revision, and final approval of the version for publication. Mariana Pereira Simonato and Fernanda Ferreira da Silva Lima participated in the study's conception, data analysis and interpretation, and writing, critical revision, and final approval of the version for publication.

CONFLICT OF INTEREST

None.

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None.

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