

Impasses and Inventions in School Readmission of Children and Adolescents on Oncohematological Treatment: an Interdisciplinary and Intersectorial Intervention

doi: <https://doi.org/10.32635/2176-9745.RBC.2018v64n3.54>

Impasses e Invenções no Reingresso Escolar de Crianças e Adolescentes em Tratamento Onco-Hematológico: uma Intervenção Interdisciplinar e Intersectorial

Imposiciones e Invenções en el Reingresso Escolar de Niños y Adolescentes en Tratamiento Onco Hematológico: una Intervención Interdisciplinaria e Intersectorial

Ana Beatriz Rocha Bernat¹; Izabel Christina Machado de Oliveira²; Mariana Pereira Simonato³; Rosane Martins dos Santos⁴; Roberta Corrêa Lanzetta⁵; Luciana da Silva Alcântara⁶; Tatilla Rangel Lobo Braga⁷

Abstract

Introduction: The present paper problematizes the report of two adolescents followed in a reference hospital for child and adolescent oncological treatment by a research team on school reinsertion, composed by teachers, psychologists, occupational therapy, nurse and social assistance. The research group, active since the year of 2013, have been promoting the interdisciplinary and intersectorial mediation between areas of health and education, and through reports seeks contextualize the importance of preserving the place of wish of two patients of continuing studying during oncological treatment. **Case reports:** MP could immortalize her vote and herself and giving origin to a school innagurated with her name in the city of residence. M in turn could make the school a place less inhospitable and more welcoming for her from the resort to the device of school visitation. **Conclusion:** As discussion, we point out the relevance of interdisciplinary activities to construct bonds beyond the hospital, as well as the needed intersectorial articulation, fundamental to the success of effective school reintegration. It is highlighted that the research team could welcome adolescents, each one with their issues and, through sustaining a reference bond, viabilize a real possibility to create bridges with life beyond the hospital walls.

Key words: Adolescent; Hematologic Neoplasms; Intersectoral Collaboration; Mainstreaming (Education).

Resumo

Introdução: O presente trabalho problematiza o relato de duas adolescentes acompanhadas em um hospital de referência para o tratamento oncológico infantojuvenil, por uma equipe de pesquisa voltada à reinserção escolar, composta por professoras, psicólogas, terapeuta ocupacional, enfermeira e assistente social. O grupo de pesquisa, atuante desde o ano de 2013, vem promovendo a mediação interdisciplinar e intersectorial entre as áreas de saúde e educação, e, por intermédio dos relatos, procura contextualizar a importância da preservação do lugar do desejo de duas pacientes de prosseguir com os estudos durante o tratamento oncológico. **Relato dos casos:** MP pôde imortalizar seu voto e a si mesma e dar origem a uma escola inaugurada com seu nome em seu município de residência. M, por sua vez, pôde tornar a escola um lugar menos inhóspito e mais acolhedor para ela, a partir do recurso ao dispositivo de visitação escolar. **Conclusão:** Como discussão, aponta-se a relevância da atuação interdisciplinar para a construção dos laços para além do hospital, bem como a necessária articulação intersectorial, fundamental para o êxito da reinserção escolar efetiva. Ressalta-se que a equipe de pesquisa pôde acolher as adolescentes, cada qual com seus impasses, e, a partir da sustentação de um laço de referência, viabilizar uma real possibilidade de criar pontes com a vida, além dos muros do hospital.

Palavras-chave: Adolescente; Neoplasias Hematológicas; Colaboração Intersectorial; Inclusão Educacional.

Resumen

Introducción: El presente estudio hizo una problematización del reporte de dos adolescentes acompañadas en un hospital de referencia para el tratamiento oncológico infanto-juvenil por un equipo de investigación con la mirada a la reinserción escolar, compuesta por maestras, psicólogas, terapeuta ocupacional, enfermera y asistente social. El grupo de investigación, que actúa desde 2013, sigue promocionando la mediación interdisciplinar y intersectorial entre las áreas de salud y educación y, a través de los reportes, procura contextualizar la importancia de la preservación del lugar del deseo de dos pacientes en seguir con los estudios durante el tratamiento oncológico. **Relato de los casos:** MP puede inmortalizar su voto y a si misma y dar origen a una escuela inaugurada con su nombre en la ciudad que ella vive. M, por su vez, puede tornar la escuela en un lugar menos inhóspito y más receptivo para ella a partir del recurso al dispositivo de visitación en la escuela. **Conclusión:** Como discusión, apuntase la relevancia de la actuación interdisciplinaria para la construcción de los lazos para allá del hospital, bien como la necesaria intersectorial, fundamental para el éxito de la reinserción escolar efectiva. Enfatizase que el equipo de investigación puede oír a las adolescentes, cada cual con suyas incertidumbres, y, a partir de la sustentación de un lazo de referencia, viabilizar una real posibilidad de crear puentes con la vida para allá del espacio del hospital.

Palabras clave: Adolescente; Neoplasias Hematológicas; Colaboración Intersectorial; Pensión (Educación).

¹ Instituto Nacional do Câncer José Alencar Gomes da Silva (INCA). Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0002-9392-0599>

² INCA. Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0001-5333-9401>

³ INCA. Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0003-0788-338X>

⁴ INCA. Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0001-9550-3273>

⁵ INCA. Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0001-9549-3829>

⁶ INCA. Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0001-8957-4104>

⁷ INCA. Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0002-5956-3292>

Corresponding author: Ana Beatriz Rocha Bernat. Rua Gomes Carneiro, 124, apto. 704 - Ipanema. Rio de Janeiro (RJ), Brazil. CEP 22071-110. E-mail: abernat@inca.gov.br.



INTRODUCTION

Pediatric cancer represents a small proportion of all cancer cases in the general population, but it has a major impact, since it manifests as unexpected in this age bracket¹.

Cancer survival is part of public health policy and is a priority and complex issue in health planning, considering that the survival rate in pediatric hematological cancer is 80%² in developed countries. When addressing the pediatric population during or after cancer treatment, one must consider the changes to body image and the patient's learning capacity, which are influenced by the treatment. Such functional and psychological body changes may trigger feelings of foreignness in these children and their parents or guardians, as well as in the broader social community to which they return after treatment³.

This feeling of foreignness or uncanniness needs to be addressed by the interdisciplinary and inter-sector discourse in order to foster a unique and personalized return to social living for these children and adolescents⁴. The school plays a key role in his process, because during childhood and adolescence, besides teaching contents and concepts, it acts as an important space of socialization⁵. At school, these young individuals are introduced to social rules and identify with their peers, building and expanding their worldview.

Considering school's importance in the lives and development of children and adolescents, it is essential to reflect on the impasses these youngsters may experience when returning to their school activities after absence due to their treatment. Our research group also reflects on what we call "inventions", or case-by-case inter-sector links created between the healthcare team and schools to minimize the losses suffered by these patients during their cancer treatment.

METHOD

This case report is part of the research project "Impasses in School Readmission for Children and Adolescents After Hematological Cancer Treatment", reviewed by the Institutional Review Board of INCA, registered and authorized under protocol number CAAE 186.22013.0.0000.5274. The parents and/or guardians and the patients themselves signed the respective free and informed consent forms and the free and informed assent form in the case of the surviving adolescent.

CASE REPORTS

The cases are part of a research group⁶ in a cancer referral hospital in Southeast Brazil. The group is an

interdisciplinary resource that allows building bridges between the hospital and beyond the hospital walls. The cases submitted to discussion are accompanied on the basis of patients' spontaneous demands during the individual sessions with the health professionals in the group (teachers, psychologists, an occupational therapist, a nurse, and a social worker), as discussed below, based on clinical fragments.

CASE 1 – A BEAUTIFUL TRIBUTE

MP, an intelligent and participant teenager, diagnosed with parameningeal rhabdomyosarcoma, underwent treatment which controlled her disease (at which point she started coming less to the hospital less frequently, due to the absence of active disease). She returned to school, made friends, dated, and dreamed of visiting London. After a year of follow-up, she began to feel numbness in her face. Frightened by this symptom, she returned to the hospital on her own, since she wanted to speak with the physician with whom she had formed a bond of trust.

The team's psychologist introduced herself to the teen and said that they could talk about her plans together. MP responded that she didn't "dig" psychologists. After the psychologist had heard (and respected) several such apparent rebuffs by the patient, one fine day the girl made a request: "Will you help me travel to London?"

MP asked the psychologist to write an e-mail to a nongovernmental organization that helps children and adolescents with cancer make their dreams come true. Despite the chemotherapy, the disease progressed, and when MP realized what was happening, she redefined her wish: "Can we fix a way for me not have to stop going to school? But I want to study at my own school, in my home town!"

The multidisciplinary team set to work to make MP's dream come true. With the help of the teacher from the hospital class, they established a dialogue between the hospital and improved MP's survival and her school involvement. MP studied hard, and what she most wanted was to know her final grade in chemistry. After several attempts, the teacher managed to upload MP's chemistry grade in the system and the girl was able to download it. According to her mother, when MP learned of her grade and that she had passed the school year, she smiled for one last time before passing away.

Several months after MP died, her mother (K) sent a letter to the multidisciplinary team thanking them for their care for the family. In the letter, she thanked and pinpointed the characteristics of each professional who had become a reference for herself and for her daughter. She told the team that a school was going to be inaugurated in her town, named in her daughter's honor,

and asked for help drafting a text about the girl to be read at the ribbon-cutting ceremony.

In this case, welcoming MP's wish to study until the end of her life led to a new public school named in her honor, immortalizing her life story and a research project that endeavors to highlight the school as an indispensable element in care for children and adolescents with cancer. Both the tribute and the research were a source of comfort for her parents in their time of loss.

CASE 2 – A STRATEGIC VISIT TO SCHOOL

This case highlights the difficulty in school activities experienced by M, a teenage girl with a primitive neuroectodermic tumor in her right rib, the treatment of which consisted of chemotherapy and local surgical resection. After discharge by the medical team, M returned to her routine school activity. However, upon returning, M experienced difficult moments in adapting, and she suffered bullying⁷ without telling her family.

Based on the spontaneous demand raised by M, age 13, and reported to her pediatric oncologist, several strategies were set in motion, previously discussed in the weekly research group for regular studies, theoretically through previous experiences and a literature review^{4,5}.

The first strategy by the multidisciplinary team was to contact the school. M's teacher and psychologist spoke to the school principal, who reported the problems that had occurred and the difficulty in addressing them. Given the skittish reactions to M's arrivals and the "prejudiced" attitudes towards her alopecia, the team planned a visit to the school, conditioned on M's agreement.

The research group convened to establish strategies to approach the adolescents at the school and determine the visit's purpose. The agenda included an explanation of cancer, its treatment, and the side effects, besides discussing M's return to school. The team that visited the school consisted of a nurse, a physician, a psychologist, and a teacher.

The research group prepared some games⁸ and interactive activities to ensure the teens' attention and participation. A clip was edited from a film as a trigger for the topic of cancer. The nurse, who was in charge of the "technical" presentation on cancer, organized a brief class, accompanied by a video that addressed the issue from the perspective of hair loss. Next, a group dynamic was performed to facilitate interaction between the team and students. The dynamic was the string game⁹, which consisted of forming a circle intertwining the research team with the teachers and students. Based on a triggering question and the round of the ball of string, each participant tossed the ball and held the end of the string before tossing it to someone else, who was supposed

to tell what he or she had learned during the meeting, and to ask a question that could be answered by whoever caught the ball, forming a net with the string.

M participated in developing these strategies, mainly contributing with her choice of the film and editing the scenes to be shown as triggers for the conversation. She displayed interest and expectations concerning the visit by the "hospital" to her school. The visit unfolded as follows: 1) an awareness-raising session was held, during which the teens were able to talk about cancer cases in their own families, calling their attention to the question at hand; 2) showing scenes from a film, which ended up not happening due to technical problems; 3) the class by the nurse about cancer, diagnosis, treatment modalities, and their effects; and 4) the string dynamic.

The string dynamic sparked questions and comments by the students, allowing the discussion to cover such issues as the place where the children and adolescents go when they recover from the illness, questions about whether cancer is "contagious", and changes in the appearance of a person with cancer during or after treatment.

When the question was launched, "What changed after this afternoon?", a student answered that he had learned not to be prejudiced. His remark was met by a round of applause. A question was asked about how a person with cancer should be treated, and the students answered, "I don't know, like acting normal is the best way, and with love and affection." At the end of the visit, several students addressed questions to the hospital team, and the girls asked to take photos with M.

This experience suggests that the strategy of visiting the school can turn the initial horror into a possibility for dialogue, creating room for the students' curiosity and for them to welcome M back to school.

CONCLUSION

These selected fragments highlight the importance of interdisciplinary and inter-sector mediation between health and education to promote quality of life for children and adolescents during and after cancer treatment. The research group has been working with this interface since 2013, oriented by clinical practice and patients' spontaneous demand, aimed at building ties beyond the hospital's walls.

Surviving pediatric cancer is more than not having the active disease¹⁰. It means living a life in keeping with the children's and adolescents' wishes, an intense experience, even in the face of a difficult treatment, often with an unfavorable outcome, as MP taught us, or finding qualified support from the hospital to foster acceptance of one's presence, despite body changes, as in the case of M.

It is necessary to clarify and discuss the criteria used by the attending team in pediatric oncology to indicate or contraindicate school attendance during and after pediatric cancer treatment. These findings are elaborated on the basis of demands raised by pediatric patients and motivated the group to include this theme in the agenda of care.

Inter-sector measures should be designed to minimize the difficulties in school enrollment and retention, beyond the purely pedagogical issues, since the conflicts emerging in daily school routine are historically and socially constructed, as in the case of M, involving broader and more complex phenomena. It is thus necessary to focus on the school's routine, examine it, and analyze its proposals and the relations between its subjects and ideas¹¹ in order to customize case-by-case measures for patients that are returning to school.

This study is dedicated to these patients, who teach us every day that when genuine partnerships are discovered, it is possible to dream and live with courage and dignity, even under adverse circumstances.

CONTRIBUTIONS

All the authors contributed substantially to the study's conception and planning, data collection, analysis, and interpretation, and writing, critical revision, and approval of the version for publication.

ACKNOWLEDGMENTS

The authors wish to thank psychologist Nina Gomes Costa, who accompanied the visit to the second patient's school and contributed greatly to the research project's development.

CONFLICT OF INTEREST

None.

FUNDING SOURCES

None.

REFERENCES

1. Instituto Nacional de Câncer José Alencar Gomes da Silva. Estimativa 2018: incidência de câncer no Brasil. [Internet]. Rio de Janeiro: INCA; 2017. [accessed 2018 Aug 29]. In: <http://www1.inca.gov.br/estimativa/2018/estimativa-2018.pdf>
2. Instituto Nacional de Câncer José Alencar Gomes da Silva. Câncer infante-juvenil. [Internet]. Rio de Janeiro: INCA, 2018. [modified 2018 Nov 21; accessed 2018]. In: <http://www2.inca.gov.br/wps/wcm/connect/tiposdecancer/site/home/infantil>.
3. Freud S. O 'Estranho' ['The Uncanny'] (1919). In: Freud S. Edição standard brasileira das obras psicológicas completas de Sigmund Freud. Vol. XVII. Rio de Janeiro: Imago; 1969-1980. P. 235-271.
4. Freitas NBC, et al. As percepções das crianças e adolescentes com câncer sobre a reinserção escolar. Rev. Psicopedag [Internet]. 2016 [accessed 2018 Aug 26]; 33(101):175-183. In: <http://pepsic.bvsalud.org/pdf/psicoped/v33n101/07.pdf>
5. Silveira CR, Custodio SAM. A reinserção escolar da criança com câncer e a importância da atuação do assistente social frente a esta realidade. RIPE: Construindo o Serviço Social. 2006;10(18):01-84.
6. CAAE nº 18622013.0.0000. 5274 – parecer favorável. [accessed 2013 Nov 21]. In: Ministério da Saúde (BR). Plataforma Brasil [Internet]. Versão 3.2. Brasília: Ministério da Saúde. [date unknown]. In: <http://plataformabrasil.saude.gov.br/login.jsf>
7. Azenha MRJ, Rodrigues SMA, Galvão DMPG. Bullying e a criança com doença crônica. Rev Enf Ref [Internet]. 2012 [accessed 2018 Aug 27]; serIII(6):45-53. In: <http://www.scielo.mec.pt/pdf/ref/vserIIIIn6/serIIIIn6a05.pdf>.
8. Silva LF, Cabral IE. O resgate do prazer de brincar da criança com câncer no espaço hospitalar. Rev Bras Enferm. 2015 Maio-Jun;68(3):391-397.
9. Cardoso FA, Cordeiro VRN, Lima DB, Melo BC, Menezes, RNB, Moulaz ALS, et al. Capacitação de agentes comunitários de saúde: experiência de ensino e prática com alunos de Enfermagem. Rev Bras Enferm. 2011;64(5):968-973.
10. Anders JC, Souza AIJ. Crianças Cienc Cuid Saude e adolescentes sobreviventes ao câncer: desafios e possibilidades. 2009;8(1):131-137.
11. Jurdi APS, Brunello MIB, Honda M. Terapia Ocupacional e propostas de intervenção na rede pública de ensino. Rev Ter Ocup. 2004 Jan-Abr;15(1):26-32.

Recebido em 1/10/2018
Aprovado em 29/11/2018