

Survivorship to Osteosarcomas and Social Reinsertion

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Sobrevivência aos Cânceres Ósseos e Reinserção Social

Supervivencia de los Cánceres de Hueso y Reinserción Social

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ABSTRACT

Introduction: Patients with bone cancer are a unique population with poorly investigated psychosocial needs. **Objective:** To understand the process and impact of social reintegration on the daily lives of adolescents and young adults after treatment and oncological follow-up of bone cancers. **Method:** Qualitative, exploratory, hermeneutic-based investigation with data obtained from semistructured interviews with 12 bone cancer survivors. **Results:** The empirical material was organized into three categories: *Social reintegration into the family, Social reintegration at school and Insertion into social-labor life*, which are challenging and involve a complex concept of coping with the stigmas and limitations imposed by the disease and its treatment. **Conclusion:** The emotions and experiences of cancer survivors indicate social life as a place of challenges and uncertainties, losses and grief. It is extremely important to count with specialized multidisciplinary support, as well as family and social background to enable this group to face cancer treatment related challenges.

Key words: bone neoplasms; cancer survivors/psychology; adolescent; psychoanalysis; qualitative research.

RESUMO

Introdução: Pacientes com cânceres ósseos representam uma população singular com necessidades psicossociais pouco estudadas. **Objetivo:** Compreender o processo e o impacto da reinserção social para a vida cotidiana de adolescentes e adultos jovens após o tratamento e seguimento oncológico de cânceres ósseos. **Método:** Pesquisa qualitativa e exploratória, utilizando referencial metodológico da tradição hermenêutica com produção de dados por meio de entrevistas semiestruturadas com 12 sobreviventes de cânceres ósseos. **Resultados:** O material empírico foi organizado em três categorias: *Reinserção social na família, Reinserção social na escola e Inserção na vida sociolaboral*. Os desafios da reinserção social na família, escola e vida laboral de adolescentes e adultos jovens após o tratamento de câncer ósseo envolvem um complexo sentido de enfrentamento dos estigmas e limitações impostas pela doença e seu tratamento. **Conclusão:** As percepções e experiências dos sobreviventes ao câncer ósseo apontam para a vida social como um lugar de desafios e incertezas, perdas e lutos. É de extrema importância a existência de apoio multiprofissional especializado, assim como apoios familiar e social, para que esse grupo consiga suportes material e humano para enfrentar as mudanças decorrentes do tratamento oncológico. **Palavras-chave:** neoplasias ósseas; sobreviventes de câncer/psicologia; adolescente; psicanálise; pesquisa qualitativa.

RESUMEN

Introducción: Los pacientes con cáncer de huesos representan una población con necesidades psicossociales poco estudiadas. **Objetivo:** Comprender el proceso y el impacto de la reinserción social en la vida cotidiana de los adolescentes y adultos jóvenes después del tratamiento y seguimiento oncológico de los cánceres de huesos. **Método:** Investigación cualitativa y exploratoria, con referente metodológico de la tradición hermenéutica. La producción y el análisis de datos se basaron en 12 entrevistas semiestructuradas con sobrevivientes de cáncer de huesos. **Resultados:** El material empírico se organizó en tres categorías: *Reinserción social en la familia, Reinserción social en la escuela e Inserción en la vida sociolaboral*. Los desafíos de la reinserción social en la vida familiar, escolar y laboral de los adolescentes y jóvenes después del tratamiento del cáncer de huesos implican un sentido complejo de enfrentamiento de los estigmas y limitaciones que impone el cáncer y su tratamiento. **Conclusión:** Las emociones y experiencias de los sobrevivientes de cáncer apuntan a la vida social como un lugar de desafíos y choques, pérdida y duelo. Es de suma importancia contar con un apoyo multidisciplinario especializado, familiar y social, para que este grupo pueda obtener apoyo material y humano para enfrentar los cambios derivados del tratamiento del cáncer.

Palabras clave: neoplasias óseas; supervivientes de cáncer/psicología; adolescente; psicoanálisis; investigación cualitativa.

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INTRODUCTION

Child and adolescent cancer represents a challenging public health problem¹. Recent data indicate that, among the 704,000 new cases estimated in Brazil for the three-year period 2023-2025 (with the exception of non-melanoma skin cancer), 7,900 will affect children and adolescents (0 to 19 years), a population in which cancer already represents the first cause of death due to disease (8% of the total)^{2,3}.

Among cancers that affect children and adolescents, osteosarcomas are one of the groups of tumors that most affect young people in the first two decades of life^{1,2,4}. The different treatment modalities – surgery, chemotherapy and radiotherapy – require interventions that are often painful and mutilating, marking the individual in the physical, psychological and social dimensions⁵⁻¹⁰. Surgical resection of the tumor, the main treatment modality, profoundly affects the lives of these adolescents, since it tends to generate changes in body image and subjectivity, causing a rupture in the way of living. This rupture, common to cancer patients in the face of positive diagnosis and treatment¹¹⁻¹³, becomes more worrying at this stage of life, as adolescents and young adults are in a biographically, educationally and professionally sensitive stage of development. Studies indicate that this population may present physical disabilities, cognitive limitations, and psychological suffering, which can negatively affect their intellectual performance, their social relationships, and their chances of placement and success in the labor market¹⁴⁻¹⁶.

Despite the existence of literature on childhood cancer, there are still few qualitative studies focusing on the psychosocial needs of people who have lived the experience of coping with bone cancer, especially those related to the needs for social insertion and reintegration resulting from treatment. In this sense, this research aims to understand the process and impact of social reintegration for the daily life of adolescents and young adults after treatment and oncological follow-up of bone cancers.

METHOD

Exploratory, qualitative research, based on the qualitative approach, within the interpretative tradition, considering the subjective experiences of individuals diagnosed with cancer¹⁷⁻¹⁹. This study aims to assess the coping processes for the reorganization of the lives of adolescents and young adults who experienced cancer in the diagnosis, treatment, and post-treatment phases.

The research was developed at the Pediatric Oncology Service Follow-up Outpatient Clinic of the National Cancer Institute (INCA), between September and

November 2018, and complied with Resolution n°. 466/2012²⁰ of the National Health Council. Sociodemographic and clinical information was obtained through medical records, after consideration and approval by the institution's Research Ethics Committee under the consolidated opinion n°. 2880295 (CAAE: 96478418.7.0000.5274).

The interviewees were selected through convenience sampling, from the medical records of survivors of bone tumors in adolescence, distributed into three age groups – from 10 to 12 years old, from 13 to 15 years old and from 16 to 19 years old²¹ – according to their ages at the time of diagnosis. Two women and two men per group were interviewed, considering the following inclusion criteria: a) 18 years or older; b) free of neoplastic disease; c) with a positive diagnosis for bone cancer; d) at least five years after the completion of the oncological treatment of bone tumors in adolescence. People in palliative care were excluded. The age of the participants at the time of the interview ranged from 18 to 54 years.

After prior contact for clarification and collection of signatures under the terms of informed consent, the interviewees produced their narratives. The biographical interviews, based on a semi-structured script²², lasted 30 to 60 minutes and were conducted by the research psychologist in private rooms at the pediatric outpatient clinic. The topic guide was developed according to the existing literature, whose formulations emphasize the importance of the patient as a narrative subject^{23,24}. The questions were designed to stimulate participants' narratives about their adolescent experience with cancer, their relationships with family and friends, and their future prospects. Given the critical-interpretative tradition to which this research is affiliated, the closure of the sample was based on the principle of "information power"²⁵.

The theoretical-methodological approach used to analyze the empirical material was based on the hermeneutic tradition^{17,18}, observing the following steps: (a) comprehensive reading; (b) identification and articulation between meanings and meanings in the speeches; (c) problematization of ideas and meanings, articulating them with sociocultural meanings; (d) elaboration of syntheses of meanings; (e) interpretive analysis, containing the categorization, its empirical-theoretical comparisons and its syntheses of meanings^{18,26}.

All interviews were audio-recorded, transcribed in full, and subsequently verified by comparing the transcripts, the original recordings, and the interviewer's field notes. In order to preserve the confidentiality of the participants, each interview received an alphanumeric code, consisting of the letter P (participant) and a cardinal number (sequence of interviews).

Some categories were deductively generated from the guiding questions of the interview script. Other categories were derived inductively when organizing the data. After discussion among the researchers, a coherent system of categorization of meanings was consolidated, with structure in categories, subcategories and their respective definitions²⁶.

The categories chosen for presentation in this manuscript describe the social phenomena considered to have a high impact on the well-being of the studied population. The thematic analysis adopted as a theoretical reference the critical-interpretative approach, articulated to the socio-cultural, clinical and psychoanalytic contexts of the cancer survival phase^{19,27-32}.

RESULTS AND DISCUSSION

In the set of narratives, there were two types of cancer represented: 11 cases of osteosarcomas, five in the femur (four in girls), three in the tibia (all in boys) and three in the shoulder (two in boys) – and one case of primitive neuroectodermal tumor (PNET) in a girl. Cases of osteosarcoma were treated with amputation, with and without the use of prosthesis. In the case of CNTP, chemotherapy and radiotherapy were performed.

The meanings described by the participants indicate the social environment as a place of challenges and uncertainties due to the whirlwind of physical and subjective changes, losses, griefs and gains, reinvention, relearning, and internal and external limitations that adolescents face in returning to everyday life. Even with the remission of the disease, reentry into practical life is often a long and difficult path for survivors³³. The reports on survival, insertion, and social reintegration express a sense of coping with the stigmas and social limitations imposed by the new body conformation.

The social context, still riddled with prejudice, intensifies the suffering generated by the effects of illness and cancer treatment on the adolescent subject, especially regarding body changes. According to Lacan³², the “mirror stage” begins in the baby’s early life, but continues throughout life, since the subject’s relationship with his image and with the image of the other is not sustained in isolation, as it needs the symbolic, constant confirmation. Body image is always under construction and always subject to the consent of the other.

Sociocultural relationships have an intense influence on the psychic process of adolescence. Subjectivity ends up conforming to the intersubjective field from the encounter with the other³⁴. We live in a time of overvaluation of the status of the body as a greater form of sustaining presence³⁵. It is by the body that the person shows and

moves significantly in the world. This intense process of “body worship” places it as a target of concern, making it necessary to be shaped, sculpted and rebuilt³⁵, under social pressure for the search for an ideal and healthy body.

Immersed in culture and society, adolescents are captured earlier and earlier by this idealization. Adolescence erupts as a period in which, with natural body modifications, the expectation of the “perfect” body becomes manifest and is configured as a requirement. Any damage or dent in this image, therefore, has a high potential to produce psychic effects. Birman³⁶ quotes Lacan to highlight that the effect of images on biological functioning cannot be underestimated, so that “a culture centered on image, such as ours today, will certainly have significant effects on the organism and body image”³⁶. The adolescent subject who survived cancer, in addition to suffering the psychological and physical impacts generated by the alteration of body image, also suffers from distancing himself from the ideal of a socially instituted body. In this sense, the gaze of others on their bodies permeates the discourse of the interviewees when they describe their return to all their social groups.

In the process of constituting themselves and coping with body changes, adolescent patients are subjected to the intriguing confrontation between possible perspectives and uncertainties about the continuity of life. Doubts about life to come, or even if there will be life, fear about the development of new tumors, insecurity about romantic relationships, vulnerability about starting a family. Finally, the feeling of powerlessness to plan a “so-called normal life” predominates, whose threat is translated by the uncertainties about a future that manifests itself in an urgent present, in the form of questions without immediate answers, opening an existential vacuum^{7,37-41}.

In order to deepen these issues, we present below a detail of the three categories extracted from the empirical material – *Social reintegration in the family*, *Social reintegration in school*, and *Social insertion at work* – which characterize and describe the meanings related to the needs of social insertion and reintegration of subjects with new body conformation, emphasizing the difficulties and social stigmas faced after treatment.

SOCIAL REINTEGRATION INTO THE FAMILY

In this category, the reports describe the difficulties faced by the family in the face of illness and treatment, such as the need for time to prepare the mourning for the loss of the ideal body image of the child (Chart 1). In many cases, after treatment, family members practice extreme care in relation to adolescents, described as an overprotection that deprives them of situations and difficulties they would like to experience, as a way of

developing independence and autonomy. In addition, some prejudices and constraints are also manifested in the family, excluding the surviving adolescent from certain situations due to their new body conformation.

After treatment, when returning home, the participants emphasize the importance of social reintegration into the family. Although the idea of family presupposes a sense of a basic nucleus of support, in this case, this social group needs to be relearned by its members.

In addition to the challenges evidenced in home life, the role of the family in this process varies according to the type of health problem faced and the degree of affective and material involvement. In general, the family acts as a fundamental support in the patient's health-disease process, assuming part of the care required by the therapeutic process in the home and hospital spheres. According to Ortiz and Lima⁴², the increasing prominence of the family as a caregiver is the result of the change in the way it is perceived in the current context, which involves both the idea of family as a fundamental affective support for the treatment of the patient and the idea of family support as an obligation due to the subject under treatment.

During hospitalization, it is common for the mother to assume daily care with the adolescent, "hospitalizing" with him, which, in many cases, results in the loss of his job⁴³, since there is no legislation that protects the employment of parents in case of leave to follow prolonged hospital treatment of their children. This is an issue that further accentuates the socioeconomic problem of the disease, since it decreases or extinguishes household income, imposing on the family, in addition to suffering from the adolescent's illness, material rationing due to financial scarcity, including affecting the family member's stay in the hospital.

SOCIAL REINTEGRATION INTO SCHOOL

From the speeches that address social reintegration in school, a sense of school reintegration emerges, understood as a new beginning and an attempt to return to normality as opposed to exclusion and prejudice.

Most respondents discontinued the studies during treatment. Some, however, despite the difficulties, managed to keep them. Adolescents who changed schools or did not interrupt their studies after treatment described the school environment as less hostile. After

Chart 1. Reintegration into socio-family life

Empirical category	Age range	Testimonial clippings
<p>Social reintegration into the family</p> <p>Set of speeches that attribute meanings to reactions and welcoming, when the family member returns as a subject with a new body conformation to social life with the family</p>	<p>10-12</p>	<p>P1: "In the family, everyone welcomed me when I came back. It was also difficult because of prejudiced family members."</p> <p>P10: "The issue of family protection. She puts a lot as if I couldn't do anything [...]. But there is also something that exaggerates, in the sense that others want to do everything and I can't do anything."</p> <p>P6: "Indirectly there is [discrimination and prejudice], it's embedded. [...] For a moment of anyone's anger [...], you will throw this: 'You amputee!' 'You cripple'! [...] It's a hidden feeling."</p> <p>P11: "What I can tell you is that my life has completely changed. Then, I had to live with someone else that I didn't even live with. [...] With an INCA volunteer [...]. Then, [it was] this family of volunteers who took care of me, practically, after the operation, because my mother was unhealthy."</p>
	<p>13-15</p>	<p>P2: "The first time they see that you amputated your arm is a blow to them, right? Even my mother cried."</p> <p>P4: "My mother had to abandon everything, my mother's name entered the SPC. I don't know why she should, but she had to stay with me. Someone had to stay with me. My father worked. Then, my mother had to stay here inside the hospital."</p> <p>P5: "My family has always been very close and remains present to this day. [...] They feel sorry, right? And they stay in that greater care."</p>
	<p>16-19</p>	<p>P12: "There were a lot of people at the beginning, when I really came back [...]. A lot of people at home to visit me, you know? [...] My whole family with that special care for me, everyone."</p>

Chart 2. Social reintegration into school

Category empirical	Age range	Testimonial clippings
Rethreading social at school Set of speeches that point out the meanings attributed to the reintegration process, when the adolescents return as a subject with a new body conformation to school activities	10-12	P1: "From the moment I started to live this reality of having to live without a leg that, in school and also in society, I see a lot of prejudice, a lot." P1: "I came home and told my mother: 'Mom, it really won't help to change schools because the problem isn't in school, the problem is in people.'" P11: "I go back to a new school that I don't know anyone. So, it was normal because I didn't know anyone. [...] Of course there is, right? That scare, right? A different little friend."
	13-15	P2: "At school, I didn't feel the difference. Everyone at the age of 13 [...] didn't have much of a sense of things. Prejudice is ahead, right? When we start to have more awareness." P4: "School was hard to get back to. I came back in the first year, I managed to get approved [...] but I know, there it was wearing out, because you felt different in the crowd. It was very bad because of that, I was the only one in school who walked on a crutch, you know? Then I think I stopped going."
	16-19	P12: "At school, at first, people kept noticing and it was boring. So I stopped in eighth grade. I said, 'Oh, I'm old, already. I'm going to be in the middle of a bunch of young boys.'" P9: "Yes, it bothered me a lot, being looked at differently. It was hard at first. "

treatment, another school tends to be a more welcoming environment for the surviving adolescent, since they are already inserted in the school environment with their new body conformation, with no impact caused by the comparison between "before" and "after".

On the other hand, the permanence in school, without prolonged temporal interruption of studies, allows the other students to follow the processes of illness and treatment, generating less impact and questions. Information about cancer illness and the consequences of its treatment can minimize students' estrangement from the body alteration of surviving adolescents.

For those adolescents who interrupted their studies, returning to the same school, after a long time away and with a visible body change, is an experience described as embarrassing. The gaze of the other is interpreted as judgmental and prejudiced, a kind of magnifying glass over the differences in their body, causing discomfort. Jokes, jokes, imitations and incessant questioning in the reunion with other students are often pointed out as a reason for suffering and discouragement to continue their studies.

Camara⁴⁴ maps and analyzes some difficulties encountered by adolescent cancer survivors on their return to school. Among them, the author highlights the difficulties of these adolescents in dealing with the limitations imposed by the treatment, such as restrictions

on physical activities, which can deprive them of living with other students and the lack of appropriate physical and educational structure, since the absence of access ramps to the difficulties of professionals in the management of possible cognitive changes of the surviving student. For the author, the lack of information about cancer, both from employees and students, are elements that can generate embarrassing situations for adolescents.

In this context, the support of groups of friends and the actions of interdisciplinary professional groups since diagnosis can act as elements of support and motivation for young survivors to face their physical, psychological and social difficulties¹⁵.

The condition of cancer survivor, especially after undergoing invasive and mutilating treatments, inevitably imposes on the adolescent a series of physical, psychological, social and economic struggles. For Mullan¹⁹, "survival begins at the moment of diagnosis, because it is the moment when the patient is forced to confront their own finitude and begins to make the adjustments that will be part of their immediate and long-term future". For the author, the experience of survival must be understood beyond a biomedical conception, involving a journey and a process of understanding and mitigating the impacts and clinical, psychological and social effects of cancer diagnosis and treatment until the end of the individual's life.

SOCIAL INCLUSION AT WORK

The reports that constitute the category *Social insertion at work* (Chart 3), like the previous category, point to the sense of discrimination associated with the precariousness of the adaptations necessary for the insertion of young adults in the labor market.

Social inclusion at work is signified by the interviewees as a reality that, in order to achieve an ideal of compensation and social equity, requires the legal guarantees of specific public policies and government actions.

Participants understand that workplaces also reproduce the scenarios of stigmatization and prejudice described in the other categories. The speeches portray difficulties related to the lack of opportunities and social actions that promote the insertion of cancer survivors, even with their physical limitations, in the labor market, raising vulnerable concerns in the interviewees about the possibility of a promising future.

Grinyer⁴⁵ indicates that:

[...] adolescents and young adults who had a diagnosis and underwent cancer treatment reported feeling “left behind” in their career or work trajectory compared to their peers. In the same study, adolescents and young adults who had previously pursued careers involving physical skills believed they needed to adjust their goals as a result of cancer. In addition, some adolescents and

young adults have reported potential discrimination from employers due to their health problems (our translation).

Although the literature indicates that cancer often affects work and employability issues, little knowledge has been produced regarding adolescents and young adults. However, these groups represent a significant portion of the active population, with the possibility of many years of work ahead^{15,46,47}.

Studies^{16,39,45,46} indicate that issues related to the work and professional careers of adolescents and young adults, survivors of cancer, are complex due to their physical and psychosocial implications. The problem involves not only the acquisition and maintenance of a job but also financial security, access to health care, relationships, and quality of life³⁹ so that psychosocial support to these groups is essential, with a view to professional reintegration and financial independence, which ends up being a promising field of research on cognitive skills and disease management from a multiprofessional perspective¹⁶.

Since expectations and concerns about the future do not cease with the end of treatment, it is essential to create comprehensive care networks for adolescents after treatment⁴⁰. The aftermath of emotions after treatment is a particularly vulnerable step, which may require additional time or support services. It is also important in this process to consider adolescents’ interests, dreams,

Chart 3. Insertion in socio-occupational life

Categories empirical	Age range	Testimonial clippings
Insertion in socio-occupational life Set of speeches that give meaning to the insertion process, when the subject is included under a new body conformation, in addition to being vulnerable due to doubts and apprehensions of the temporal relationship between present and future, in the groups related to the world of work	10-12	P1: "There are these two sides, when we leave here from inside to society and to the world. Many people already go out to school, there are people who go out to look for a job. I have not yet gone through this experience of looking for a job, but I also imagine that sometimes there can be prejudice. [...] These company things, something like that for work." P11: "I was able to [build a career], but can everyone do it? I had someone here who helped me with this, encouraged me, paid and such. But then, like this: this is not the reality."
	13-15	P2: "For me, the most difficult was even in the initiation of the market. [...] And I see that, like this: disabled is very difficult to get a high position. [...] You don't think you're handicapped in a high position in any company." P4: "I thought no one would want to be with me [at work] because of my leg, which was, let's say, a cripple." P4: "Sometimes, I find myself lost a little, because I think I'm getting very old and I don't have anything concrete in life. [It should] have one more project anyway, to try to insert people into society."
	16-19	P8: "I had a hard time getting [a job]; it was really hard. It's very difficult to go out on the streets today. No one wants to pick you up because you're disabled or does not want to employ you because they do not like it." P9: "Job vacancy [...]. To get these things is very difficult."

and career aspirations. For this action, interdisciplinary evaluation is necessary, aiming at a specific and adequate solution for each particular problem, promoting and offering spaces and services that help patients re-signify the pain and sequelae left by the disease.

CONCLUSION

The experience with illness and the treatment of bone cancer in adolescence does not end with the remission of the disease. The completion of treatment and leaving the hospital are not open doors for the resumption of practical life, and the normalization of daily life since the complexity of becoming ill during adolescence significantly marks the subjects and may leave irreversible physical, psychological, and social sequelae.

On the other hand, despite the limitations mentioned above, most participants developed new ways of resignifying themselves and acting in the world. However, this is only some people's real experience. Faced with the dramatic and vulnerable consequences of illness and treatment, the continuity of life with inventiveness and quality cannot depend only on individual uniqueness and sparse cases of overcoming as a reference. In this case, the practical life of adolescents needs to be reinvented, and for this, it needs to be supported by objective public policies and specific social programs that conceive of treatment beyond interventions in the physical body and also promote and ensure the reintegration of these young people into society.

It is also necessary to highlight the importance of the technical-scientific support of the specialized multidisciplinary team combined with the support of the family and other social groups so that adolescents transcend the whirlwind of changes and difficulties imposed by cancer treatment.

It is extremely important that as well as the treatments with their interventions aim to obtain maximum functionality for the physical body, there is an expanded therapeutic approach whose interventions seek maximum equity for the social body as well, so that, after becoming ill as a teenager, a life in survival is promoted with more drive to exist, with more power to act and with more *practicality to produce*, since, sometimes, the treatment is not the most difficult confrontation, but the subsequent life imposed by it, because, in this context, starting again is more dramatic than starting, reviving is more painful than living.

CONTRIBUTIONS

Marina Leorne Cruz Mesquita contributed substantially to the study's design and/or planning in

the analysis and/or interpretation of the data and the writing. Rildo Pereira da Silva, Antonio Tadeu Cheriff dos Santos, and Fernando Lopes Tavares de Lima contributed substantially to the planning of the study in the analysis and/or interpretation of the data, in the writing and/or critical review. Approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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