

# Children and Adolescents in Cancer Treatment: an Analysis of the Vision of Postponing the Beginning or Interruption of School Education

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*Crianças e Adolescentes em Tratamento Oncológico: uma Análise sobre a Visão do Adiamento do Início ou Interrupção da Educação Escolar*

*Niños y Adolescentes en Tratamiento Oncológico: un Análisis sobre la Visión del Aplazamiento del Inicio o Interrupción de la Educación Escolar*

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## Abstract

**Introduction:** The long duration of the oncological therapeutic process leads to relevant changes in the routine of the child and adolescent with social loss, making it impossible to attend formal school during the therapeutic period. **Objective:** To analyze, in the vision of children and adolescents in cancer treatment in a specialized hospital in the city of Salvador - BA, the implications and elements involved in the postponement of the beginning of school education or its interruption. **Method:** A descriptive study with a qualitative approach performed at Oncopediatria of the Aristides Maltez Hospital through interviews conducted individually with children and adolescents on cancer treatment. **Results:** Children and adolescents were interviewed, seven males and five females, aged between eight and seventeen. Out of these, two never studied while the others were able to attend formal school. **Conclusion:** Receiving the diagnosis has different repercussions among children and adolescents. Difficulties of clinical and psychological orders were verbalized, such as side effects of clinical treatment, change of routine and impossibility of attending formal school, etc. For teenagers, dealing with the need for school drop-out is difficult as they are closer to moving towards higher education or the job market.

**Key words:** Child; Adolescent; Medical Oncology; Mainstreaming (Education); Pediatric Nursing.

## Resumo

**Introdução:** A longa durabilidade do processo terapêutico oncológico leva a mudanças na rotina da criança e do adolescente com perda social relevante, impossibilitando-os de frequentar a escola formal durante o período terapêutico. **Objetivo:** Analisar, na visão de crianças e adolescentes em tratamento oncológico em um hospital especializado da cidade de Salvador - BA, as implicações e elementos envolvidos no adiamento do início da educação escolar ou na sua interrupção. **Método:** Estudo descritivo com abordagem qualitativa realizada na Oncopediatria do Hospital Aristides Maltez, por meio de entrevistas realizadas individualmente com crianças e adolescentes em tratamento oncológico. **Resultados:** Foram entrevistadas crianças e adolescentes, sete do sexo masculino e cinco do feminino, com idades entre 8 e 17 anos. Desses, dois nunca estudaram, enquanto os demais puderam frequentar a escola formal. **Conclusão:** O recebimento do diagnóstico repercute de maneiras distintas entre as crianças e adolescentes. Foram verbalizadas dificuldades de ordens clínica e psicológica, tais como efeitos colaterais do tratamento clínico, mudança de rotina e impossibilidade de frequentar a escola formal. Para os adolescentes, lidar com a necessidade do abandono escolar é difícil, uma vez que estão mais próximos de avançar para o ensino superior ou mercado de trabalho.

**Palavras-chave:** Criança; Adolescente; Oncologia; Inclusão Educacional; Enfermagem Pediátrica.

## Resumen

**Introducción:** La larga durabilidad del proceso terapéutico oncológico lleva a cambios en la rutina del niño y del adolescente con pérdida social relevantes, imposibilitándole de frecuentar la escuela formal durante el período terapéutico. **Objetivo:** analizar, en la visión de niños y adolescentes en tratamiento oncológico en un hospital especializado de la ciudad de Salvador - BA, las implicaciones y elementos involucrados en el aplazamiento del inicio de la educación escolar o interrupción de ésta. **Método:** Estudio descriptivo con abordaje cualitativo realizado en la Oncopediatria del Hospital Aristides Maltez a través de entrevistas realizadas individualmente con niños y adolescentes en tratamiento oncológico. **Resultados:** Se entrevistaron niños y adolescentes, siete del sexo masculino y cinco del femenino, con edades entre ocho y diecisiete años. De ellos, dos nunca estudiaron mientras que los demás pudieron asistir a la escuela formal. **Conclusión:** La recepción del diagnóstico repercute de maneras distintas entre los niños y adolescentes. Se han verbalizado dificultades de orden clínico y psicológico, tales como efectos colaterales del tratamiento clínico, cambio de rutina e imposibilidad de asistir a la escuela formal, etc. Para los adolescentes, tratar con la necesidad del abandono escolar es difícil, ya que están más cerca de avanzar hacia la enseñanza superior o el mercado de trabajo.

**Palabras clave:** Niño; Adolescente; Oncología Médica; Propensión (Educación); Enfermería Pediátrica.

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## INTRODUCTION

Cancer is characterized by progressive, rapid, and uncontrolled cell growth. It is currently a public health problem with an estimated 600 thousand new cases per year in Brazil. Cancer in children and adolescents accounts for 1% to 3% of all cases of malignant neoplasms, showing that pediatric cancer is relatively rare, with the likelihood of cure depending on early diagnosis and the tumor's location and aggressiveness<sup>1,2</sup>.

Radiotherapy and chemotherapy are aggressive, often leading to alopecia, lesions, and exacerbated weight gain or loss, besides the risk of a second cancer and myelosuppression, leaving the individual more susceptible to acquiring opportunistic infections and diseases, especially in patients that spend more time in crowded environments such as daycare centers and schools<sup>3,4</sup>.

The long duration of treatment leads to changes in the child's or adolescent's routine, with social losses that include difficulty or impossibility of attending school during therapy, whether due to medical orders or protection by the parents, who are emotionally vulnerable and focus more on the child's health and less on immediate

This was a descriptive study with a qualitative approach that allowed understanding the patients' reality through interaction and a participant perspective in order to elucidate the multiple dimensions of a complex phenomenon<sup>10,11</sup>.

The study was performed from December 2017 to February 2018 in the Pediatric Oncology Department of the Aristides Maltez Hospital (HAM) in Salvador, Bahia, Brazil, which is maintained by the Bahian League for the Fight Against Cancer (LBCC). The service also has a formal agreement with the Salvador Municipal Department of Education and Culture (SECULT) to provide hospital classes for children undergoing outpatient or inpatient treatment.

Classification of the participants as children or adolescents used Brazil's Statute for Children and Adolescents (ECA), which defines children as individuals from 5 years to 11 years and 364 days and adolescents as those from 12 years to 17 years and 364 days. Inclusion criteria were thus: age from 5 years to 17 years and 364 days, currently in cancer treatment, and never having attended formal school or having left school, currently hospitalized or in outpatient follow-up at the target hospital during the data collection period, and with preserved cognitive functions.

The interviews were conducted individually and lasted a maximum of 15 minutes each. The parent or guardian was allowed to attend, on condition that he or she refrain from intervening in the interview. The

interviewers and authors of the study, one male and one female, have undergraduate degrees in nursing and psychology, respectively. There was a one-month training period in which pilot interviews were held to validate the script, but these pilot interviews were not included in the final study results.

As mentioned, two basic scripts were used for the data collection, elaborated by the researchers, thus allowing the identification of contents that were considered relevant for the study. The scripts were semi-structured, and the first section in both questionnaires was related to the individual patient: age group (child versus adolescent), sex, current age, age at diagnosis, duration of treatment, whether the patient had left or had never attended school, and which family members he or she lived with. The second part of the interview had a leading question for both groups, who were urged to talk about their routines after receiving the cancer diagnosis and their visits to the hospital. The second question in the second section differed in the questionnaires, since it was targeted to those who had never attended school versus those who had been forced to leave school.

The participants were oriented on the use of the tape recorder, and in case any of them refused to use it, their interviews would be recorded manually. Accordingly, the interviews were taped, with the participants' permission.

In order to avoid identifying the interviewees, the results were labeled "C" for children and "A" for adolescents, followed by numbers. The order of the numbers was random and thus did not follow the same order as the interviews.

The data were obtained by transcribing the interviews without omitting material and without loss of the spoken meaning, and were analyzed according to the Bardin content analysis technique<sup>12</sup>. Content analysis involves a set of subtle methodological tools in a process of constant improvement that are applied to extremely diverse discourses<sup>12</sup>. The study's operational stages were completed, namely: pre-analysis, exploration of the material, processing the results, and interpretation. No software was used in this study.

The resulting contents were organized in three categories: 1. the illness and its implications and elements involved in postponing or interrupting schooling; 2. the feelings experienced by children and adolescents about never having attended formal school because of the treatment process; and 3. the experience of having to leave regular school due to the cancer treatment.

All the participants agreed to participate voluntarily, following a complete and detailed explanation of the study and its objectives, methods, expected benefits, and potential direct risks from participation. The discomfort

and any risks involved in reflecting on the topic were minimized. In addition, the participants had the support of the psychology service in the hospital where the study was performed.

The study complies with Resolution CNS 466/12 of the Brazilian National Health Council, which regulates research in human subjects, and was approved by the institutional review boards of the State University of Bahia (UNEB), case review number 2.373.271, and of the Aristides Maltez Hospital (HAM), case review number 2.444.571.

## RESULTS

Data on the study participants were organized in a table to facilitate viewing (Table 1).

Four children and eight adolescents were interviewed who were hospitalized or in outpatient follow-up, and who had left regular school or had never attended. Of the 12 participants, 11 were undergoing chemotherapy and one had a referral for a second surgical intervention. There were seven boys and five girls. Age ranged from eight to 17 years. Only two participants were from the city of Salvador, and the others were from other municipalities (counties) in the state of Bahia.

Of the 12 participants, only two had never attended school, while the others had originally been able to attend regular school.

None of the children and adolescents had a history of another disease prior to the cancer. The children had all been in outpatient treatment lasting from seven months

to five years and had their cognitive functions preserved, answering all the questions to the best of their ability.

## DISCUSSION

### THE ILLNESS AND IMPLICATIONS AND ELEMENTS INVOLVED IN POSTPONING OR INTERRUPTING SCHOOLING

#### *The meaning of the illness for the children and adolescents*

The children and adolescents told how they had received the news of their illness, the changes in their daily routines after the diagnosis, and their visits to the hospital. Receiving a diagnosis of cancer, like that of any other disease, affects not only the life of the person that receives it, but also that of their families and others like friends and other loved ones. Given their young age, some were concerned about the difficulty of coping with the illness, as illustrated by the following quotes:

It was okay for me [to receive the diagnosis]. It was a little more complicated [to change routines]. I had to wake up earlier than usual. I was already used to the school routine, getting up at six o'clock sharp. Now I have to wake up earlier to get here (A1. 12 years. Age at diagnosis 12 years).

Life turned into a knot, turned upside-down. It was a little difficult at first. I was going to school before, and since I live out in the country, I worked to help my parents, and I had a very athletic routine (A2. 16 years. Age at diagnosis 14 years).

**Table 1.** Characteristics of a sample of children and adolescents in cancer treatment in Salvador, Bahia, Brazil

		Children	%	Adolescents	%	Total	%
		4	33%	8	67%	12	100%
Sex	Male	1	8%	6	50%	7	58%
	Female	3	25%	2	17%	5	42%
City	Salvador	0	0%	2	17%	2	17%
	Other cities	4	33%	6	50%	10	83%
Treatment	Chemotherapy	3	25%	8	67%	11	92%
	Radiotherapy	0	0%	0	0%	0	0%
	Surgery	1	8%	0	0%	1	8%
Previous illness	Yes	0	0%	0	0%	0	0%
	No	4	33%	8	67%	12	100%
Time in treatment	7 months to 1 year	0	0%	2	17%	2	17%
	1 year	2	17%	3	25%	5	42%
	2 years	0	0%	2	17%	2	17%
	3 to 5 years	2	17%	1	8%	3	25%
Regular school	Never attended	2	17%	-	-	2	17%
	Previously attended	2	17%	8	67%	10	83%

My routine didn't change much, but it affected my parents' routine more. I always see them talking, and I think it's a strain... [pause]. Sometimes I wish this was the last time I have to come to the hospital (A8. 16 years. Age at diagnosis 15 years).

The prospects of change due to the diagnosis means that every youngster reacts differently, based on their accumulated experiences. Some were less concerned about the present than the future. Others were worried about the effects of the changes on their family members, such as conflicts in their parents' relationship, thus leading to psychosocial breakdown.

Dantas et al.<sup>13</sup> show that parents reorganize their daily routine as a function of the child or adolescent with the illness, which can lead to emotional strain for both the child or adolescent and the parents. The long cancer treatment process weighs heavily on the caregivers, especially for those living in rural areas, who depend exclusively on their family members to care for the home and work. The illness alters the family's dynamics, and according to Rubira<sup>14</sup> the extensive treatment weighs more on families with low schooling and living in underprivileged conditions.

In this context, living with an illness that is now an integral part of their being causes anxiety, with situations beyond their control. Chemotherapy cycles, adverse effects, and the patients' own wishes which often need to be suppressed are all part of the new being, as noted in the following remarks:

I used to go out to a lot of places, but now everything has changed, you know? Like the fact that I can fall down any minute. Like not being able to go out because my immunity is low. Like not being able to eat and drink everything like before, especially sodas (A6. 17 years. Age at diagnosis 17 years).

It was hard. But I began to get used to it. I took the chemo, took the medicine, and went to the appointments. I used to come every day, but now it's only once a week. It was bad before, because every day they had to stick my vein, you know? (C1. 8 years. Age at diagnosis 7 years).

The children and adolescents are thus forced to cope with a new world with new rules, besides experiencing the prescribed treatment and having to learn to deal with their unmet desires and wishes. The support by the entire multidisciplinary health team, the family, and society is essential, since dealing with this new reality means a break with normal childhood and adolescence. This corroborates

a study by Gomes<sup>9</sup> showing the forced early maturity for youngsters undergoing long and traumatic health treatment, the damage of which cannot be measured, since it involves numerous psychological factors.

The patients clearly understand what is going on and the entire situation. This is obvious from the way the children and adolescents voice the experience. This is explained by the time in which they experience this process, as shown in the following remarks:

I was hospitalized. I've already been in the hospital for up to 10 months (C3. 8 years. Age at diagnosis 4 years).

Well, I used to come here, but after the surgery I went two years without coming. Then I'd go to the hospital in my hometown, and they sent me back [to the referral hospital] to do an MRI. Since I wasn't feeling any pain, they had me do another MRI. When I did the new test, the doctor looked at it, and there was another tumor growing in the same place. So, I'm going to be admitted today for another operation (C4. Age 8 years, Age at diagnosis 3 years).

It's easier now, because I only come once a week, and I go back home and spend the rest of the week there. At the beginning of treatment, I used to spend months here in the hospital, and now I only stay three or four days (A3. Age 16 years. Age at diagnosis 15 years).

Relapses are another situation, involving new arrangements in the family circle, emotional stress, more expenses, and psychological strain, reliving painful moments like returning to the hospital for long stays, extensive treatment, and clinical manifestations, ranging from hair loss to nausea, vomiting, and pain. Relapses can thus be viewed as uncertainty as to cure. They trigger feelings of frustration and suffering, and according to Arruda-Colli<sup>15</sup>, new doubts emerge concerning the uncertainty of the new form of the illness and the need for further treatment. Mazer-Gonçalves, Valle, and Santos<sup>16</sup> describe the death of the children or adolescent as cancer winning out over life, using the term "battle" as a metaphor. This creates a perverse and unthinkable scenario, when the individual in treatment is his or her only companion.

For the children and adolescents participating in this study, the illness meant changes in their own routine and that of their families, the need for a painful and stressful treatment routine, and elimination or curtailment of their social contacts.

## IMPLICATIONS AND ELEMENTS INVOLVED IN POSTPONING OR INTERRUPTING SCHOOLING

### ***Feelings experienced by children and adolescents who have never enrolled in regular school due to their treatment***

Everyone has a right to an education, which is the duty of the state and the family to provide. Schooling is also known to be a determining factor for health. However, school attendance can vary due to certain circumstances, in this case a diagnosis of cancer. The child or adolescent is thus left to imagine how school must be.

Two of the children and adolescents in this study had never been unable to attend regular school because of early manifestations of their cancer. These two youngsters expressed their ideas of regular school as follows:

I've never been to school. I imagine it must be nice. I used to go by the school building every day, so I wanted to go. I'd think to myself like that, but my mother was afraid (C3. 8 years. Age at diagnosis 4 years).

I really wanted to go to school. I even asked my mother to enroll me. She didn't put me in school, though, because she was afraid of my problem (C4. 8 years. Age at diagnosis 3 years).

Special education is thus appropriate for situations that require alternative forms, such as special teaching methods, techniques, resources, and curricula that favor access and organization of classes for students with special educational needs.

Considering that cancer treatment requires continuity and time for its conclusion, difficulties arise for children and adolescents to attend regular school. The difficulties range from material problems, due to the long distances (increasing the family's expenses with commuting for the child's treatment, especially when the oncology service is located in a different city), to emotional problems resulting from the family's apprehension and fear of exposing the child to the school environment, even when authorized by the physician.

Bianca et al.<sup>1</sup> and Ferreira<sup>5</sup> have shown that the parents' vulnerability in the face of their children's illness is grounded in various stages of protection, focusing greater attention on the children's health and safeguarding them from the formal schooling process. Still, Gomes<sup>9</sup> has demonstrated the importance of including these children in the school context, since they are continuing to grow and develop. This corroborates the study by Silva<sup>17</sup>, who interviewed hospitalized children that reported the isolation and limitations due to their inability to play, attend school, or live in society. These children and

adolescents thus need to study and participate in the school community.

For these youngsters, schooling should be provided in specialized classes, schools, or services when their specific conditions prevent them from joining ordinary classes in regular school. Some hospitals that treat children and adolescents with cancer thus provide so-called "hospital classes" aimed at minimizing the losses and gaps in this group's learning process.

When the oncology service does not provide hospital classes, the parents or guardians often fulfill this role by teaching the youngster to read and write, especially the mothers, as noted in the following remarks:

My mother helped me to read and write (C3. 8 years. Age at diagnosis 4 years).

She helped me. My mother taught me how to spell my name. She was the one that taught me (C4. 8 years. Age at diagnosis 3 years).

According to Brazil's Statute for Children and Adolescents (ECA), it is the duty of the family, community, society, and government to guarantee respect for life, health, sports, leisure, vocational training, culture, and dignity, with absolute priority for schooling and family and community living<sup>8</sup>.

Children and adolescents imagine and wish for school when they have never been able to attend due to their illness and treatment. However, their remarks reveal how they can understand the reasons for not being able to go to school.

### ***Children and adolescents who have to leave school because of their cancer treatment***

The vulnerability expressed by these patients reveals the urgent need for effective measures to reduce, insofar as possible, the impacts of cancer. After all, the school environment is full of challenges, feelings, and human values as a space for contact with classmates and teachers. However, as discussed, in certain health conditions it is impossible for children and adolescents to attend regular school.

Ten participants in this study had been forced to leave regular school to begin their treatment. We thus asked them to voice their feelings about leaving school:

It was a little complicated [to leave]. I liked school a lot, especially because it was where I saw my friends and because there were other courses, but I had to stop attending. And that's how it was (A1. Age 12 years. Age at diagnosis 12 years).

It's hard, because I was really involved in my studies, plus I had all my friends there. Now I'm out of touch

with them, so... (A2. Age 16 years. Age at diagnosis 14 years).

It was hard. I liked going to school. School was great. The first day I made friends with everybody, but now I'm out of touch. I only had some contact with them on my birthday, but not since then (C1. Age 8 years. Age at diagnosis 7 years).

The interviews touch largely on life in school, missing friends, becoming just a memory, since isolation from classmates is a real and painful fact. School provides the stage for the individual's development and social role. Leaving school means entering the hospital environment, which in turn means the pursuit of treatment, sometimes overlooking the need for education for these youngsters.

Ferreira<sup>5</sup> identifies schooling as a bridge to life that is blocked by fulltime cancer treatment. Pediatric cancer patients thus need pedagogical and psychological follow-up, since isolation from school and contact with friends has negative repercussions that are scarcely verbalized, as in the study by Silva<sup>18</sup>, where children and adolescents with cancer viewed the illness as a life-and-death dichotomy. After all, the possibility of death from cancer is imminent, hovering over the youngster's head:

It was really hard, because I'd already missed a year. I really wanted to finish the year. You have plans... [pause], and you never imagine that an illness is going to happen...[pause], that something bad is going to happen, that it can be the end (A6. Age 17 years. Age at diagnosis 17 years).

Complications can occur in any stage of cancer treatment, revealing the difficulties the children and adolescents face, such as anorexia, treatment changes, nausea, vomiting, and pain. Gomes<sup>9</sup> and Lisboa<sup>19</sup> note that including youngsters with cancer in the school environment is challenging, since the illness can lead to conflicts, discouragement, feelings of inferiority, and lack of adaptation, as follows:

I was taking chemotherapy and was expecting to feel sick. I knew it gave you fever and made you lose weight (A5. Age 12 years. Age at diagnosis 11 years).

One of the main difficulties was feeling inferior, knowing that all my friends are on a different pace at school. They're going to graduate, and I'll be left behind. I used to think I was going to finish school and start working [pause] (A8. Age 16 years. Age at diagnosis 16 years).

Time away from school means failing to learn new content and isolation from one's classmates due to the

illness and treatment. Amâncio and Castro<sup>20</sup> highlight the importance of teachers being present through visits to the hospital or home classes. The children and adolescents will be returning to regular school after they finish their treatment and have expectations about rejoining the school community:

Actually, my teacher brought the schoolwork for me to see if I could pass the schoolyear (A1. 12 years. Age at diagnosis 12 years).

Brazil's Law 1.044 of October 21, 1969, provides that students with health-limiting conditions have the right to home classes<sup>21</sup>. However, there are critical situations and difficulties to deal with:

I was ashamed at first, because I got bald, but my classmates didn't mind. (A7. 12 years. Age at diagnosis 9 years).

Lisboa<sup>19</sup> proposes to use art to work one-on-one with the children and adolescents to stimulate feelings and sensations through learning-by-playing, which can foster trust and eliminate the depression and stress by letting the children and adolescents activate their imagination, reintegrating learning activities. Santos<sup>22</sup> emphasizes the use of technologies, information, and communication as tools that should be present in education. This requires an opportunity for hospital classes working in groups, where the resources (including technological ones) must be sufficient to assist the children and adolescents with their difficulties.

## CONCLUSION

Receiving a cancer diagnosis impacts the parents and children and adolescents involved in the process in different ways. Thus, elements involved in postponing or interrupting school include the long treatment, which we consider the factor with the greatest impact, given the need for changing routines, increased family expenses, the need for psychological support, and the parents' fear of exposing the child to the external environment (i.e., school), given the state of physical vulnerability, as evidenced by decreased immunity and side effects like alopecia. Although the youngsters were the ones directly experiencing the illness, they were concerned about their parents, due to the changes in the family's life.

Postponing or interrupting schooling means delaying the child's or adolescent's formal educational process and the conclusion of middle school and the start of a new phase in their formative years. For adolescents especially, talking about the experience appears to be more painful

than it is for children, since adolescence is a life phase with transformations, building one's identity, and living with one's peer group, as well as the conclusion of middle school and thus entry into higher education, technical school, or the work market. The experience of illness and the perception of possibilities that have been compromised by the disease, the treatment, and the fears and uncertainties lead to reflection not only on life itself but on the finitude of being.

For the child or adolescent in cancer treatment, entering or rejoining the school community is a slow and painstaking process that requires dedication and participation by everyone involved.

We hope that this study will contribute to reflection on the topic both in teaching institutions and health care establishments, considering its relevance for youngsters that are growing and developing and whose subjectivities have received relatively little attention in the hospital setting. We also hope that the study will contribute to reflections on public policies for both of these age groups and encourage new studies on the theme and participation by those involved.

### CONTRIBUTIONS

All the authors contributed equally to the writing, research, discussion, data collection, revision, and final version.

### CONFLICT OF INTEREST

None.

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