Psychosocial and Quality-of-Life Impacts of Cancer Treatment in Children and Adolescents

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Impactos Psicossociais e na Qualidade de Vida do Tratamento Oncológico em Crianças e Adolescentes Impactos Psicosociales y en la Calidad de Vida del Tratamiento del Cáncer en Niños y Adolescentes

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ABSTRACT

Introduction: As important as the diagnosis and treatment of pediatric cancer are the care related to psychosocial, educational, and emotional impact. **Objective:** To evaluate in children and adolescents diagnosed with cancer the psychosocial and quality-of-life impacts and the presence of a companion during the procedures. **Method:** Cross-sectional descriptive study of patients aged 8 to 18 years of age diagnosed with malignant neoplasms. Patients responded the questionnaires PedsQL 4.0 Quality of Life (8 to 12 years), PedsQL 3.0 Cancer Module (8 to 12 years), PedsQL 4.0 Quality of Life (13 to 18 years), PedsQL 3.0 Cancer Module (13 to 18 years) and another about companions created by the authors. **Results:** There were 25 pediatric oncology patients included who felt happier in the presence of a companion, and less anxious during the procedures. A great impact on quality of life was perceived. In the Quality-of-Life questionnaire, no significant difference (*p*=0.627) between the groups of patients aged 8 to 12 years and 13 to 18 years were found, but the group aged 8 to 12 years had a significantly higher impact on the Cancer Module questionnaire (*p*= 0.0094). **Conclusion:** The impact on quality of life and psychosocial is fairly large in pediatric oncology patients. The youngest appear to suffer great psychosocial impact. Patients claim they are happier in the presence of a companion, and more anxious in its absence.

Key words: neoplasms/therapy; child health; psychosocial impact; quality of life.

RESIIMO

Introdução: Tão importante quanto o diagnóstico e o tratamento do câncer pediátrico são os cuidados relacionados ao impacto psicossocial, educacional e emocional. Objetivo: Avaliar em crianças e adolescentes com diagnóstico de câncer os impactos psicossociais, de qualidade de vida e da presença de acompanhante durante os procedimentos. Método: Estudo transversal, descritivo, com pacientes de 8 a 18 anos e diagnóstico de neoplasia maligna. Os pacientes responderam aos questionários: PedsQL 4.0 Qualidade de Vida (8 a 12 anos), PedsQL 3.0 Módulo de Câncer (8 a 12 anos), PedsQL 4.0 Qualidade de Vida (13 a 18 anos), PedsQL 3.0 Módulo de Câncer (13 a 18 anos) e outro sobre acompanhantes elaborado pelos autores. Resultados: Foram incluídos 25 pacientes pediátricos oncológicos que se sentiam mais felizes na presença de um acompanhante e menos ansiosos durante os procedimentos. Foi percebido grande impacto na qualidade de vida. No questionário Qualidade de Vida, não houve diferença significativa (p=0,627) entre os grupos de pacientes com 8 a 12 anos e 13 a 18 anos, porém o grupo com 8 a 12 anos teve impacto significativamente maior no questionário Módulo de Câncer (p=0,0094). Conclusão: O impacto psicossocial e na qualidade de vida é razoavelmente grande em pacientes pediátricos oncológicos. Além disso, os mais jovens parecem sofrer um impacto psicossocial maior. Os pacientes se dizem mais felizes com a presença de acompanhante, e mais ansiosos na sua ausência.

Palavras-chave: neoplasias/terapia; saúde da criança; impacto psicossocial; qualidade de vida.

RESIIMEN

Introducción: Tan importante como el diagnóstico y tratamiento del cáncer pediátrico, son los cuidados sobre el impacto psicosocial, educativo y emocional. Objetivo: Evaluar en niños y adolescentes diagnosticados de cáncer el impacto psicosocial y en la calidad de vida y la presencia de un acompañante durante los procedimientos. Método: Estudio transversal descriptivo de pacientes de 8 a 18 años con diagnóstico de neoplasia maligna. Los pacientes respondieron a los cuestionarios: PedsQL 4.0 Calidad de Vida (8 a 12 años), PedsQL 3.0 Módulo de Cáncer (8 a 12 años), PedsQL 4.0 Calidad de Vida (13 a 18 años), PedsQL 3.0 Módulo de Cáncer (13 a 18 años) y otro sobre cuidadores elaborado por los autores. Resultados: Se incluyeron 25 pacientes de oncología pediátrica que se sentían más felices con la presencia de un acompañante y menos ansiosos al realizar procedimientos. Se percibió un gran impacto en la calidad de vida. En el cuestionario de Calidad de Vida, no hubo diferencia significativa (p=0,627) entre los grupos de pacientes de 8 a 12 años y de 13 a 18 años, pero el grupo de 8 a 12 años tuvo un impacto significativamente mayor en el cuestionario del Módulo de Cáncer (p=0,0094). Conclusión: El impacto en la calidad de vida y psicosocial es razonablemente grande en los pacientes oncológicos pediátricos. Los de menor edad parecen sufrir un mayor impacto psicosocial. Los pacientes dicen sentirse más felices con la presencia de un acompañante, y más ansiosos en su ausencia.

Palabras clave: neoplasias/terapia; salud infantil; impacto psicosocial; calidad de vida.

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INTRODUCTION

Childhood cancer is defined as a group of diseases characterized by the disordered multiplication of atypical cells and occurring anywhere in the body. The spectrum of neoplasms in children and adolescents is different from adults, and the neoplasms with the highest incidence in childhood are leukemias, those of the central nervous system and lymphomas. Pediatric tumors are usually more invasive, with a shorter latency period and greater growth speed, however, they usually respond well to treatment, with a higher probability of a good prognosis. Advances in clinical and biological diagnosis in specific therapies and supportive care result in an increase in cure rates of children with cancer^{1,2}.

The patient with neoplasia undergoes many diagnostic and therapeutic procedures (surgery, chemotherapy and radiotherapy). Some studies aim to identify and understand the psychosocial impact of treatment on patients, since as important as the treatment of cancer itself is the attention given to the social aspects of the disease³. In addition, one of the most significant factors during this treatment trajectory is the distance from home, family, friends and school⁴. The neoplasm not only affects the biological dimension, but also alters family relationships, social and school routine, leisure activities and socializing with other children and family members. In addition, the socioeconomic context of the family group undergoes professional and financial changes and adaptations during treatment, due to the increase in expenses and the need for continuous monitoring⁵.

Considering the complexity and consequences, this study questions: does cancer treatment in children and adolescents have a negative impact on the patient's quality of life and psychosocial status? And does the presence of a companion positively interfere with the emotional impact? Thus, the objective of the present study is to evaluate the impacts of cancer treatment on children and adolescents diagnosed with cancer through the application of validated questionnaires.

METHOD

Cross-sectional and descriptive study carried out in children and adolescents with neoplasms, undergoing treatment at the pediatric oncology service of *Hospital Universitário Evangélico Mackenzie do Paraná*, followed from October 2021 to March 2022. After approval by the Research Ethics Committee under opinion number 4,803,527 (CAAE: 47995421.7.0000.0103), in compliance with Resolution 466/12⁶ of the National Health Council for research with human beings, and signatures of the Informed

Consent Form (ICF) and the Informed Consent Form (tale), all children and adolescents aged 8 to 18 years who met the diagnostic criteria for malignant neoplasm, with proof of biopsy, were invited to participate in the research consecutively. In order to assess the psychosocial impact and quality of life of pediatric patients undergoing treatment, the following questionnaires were applied to the patients themselves: Pediatric Quality of Life Inventory (PedsQL) 4.0 Quality of Life (8 to 12 years), PedsQL 4.0 Quality of Life (13 to 18 years), PedsQL 3.0 Cancer Module (8 to 12 years) and PedsQL 3.0 Cancer Module (13 to 18 years), validated for the Portuguese language. The first two evaluated quality of life and Cancer Modules, the psychosocial impact. The score given to each statement ranged from 0 to 4, with the following meanings: 0 – never has difficulty with it; 1 -**almost never** has difficulty with it; 2 – **sometimes** has difficulty with it; 3 – **often** has difficulty with it; 4 -**almost always** has difficulty with it. A score of 2 or more was established as a negative impact on each statement. In addition, the questionnaire on the presence of a companion was composed of three questions and created by the authors of this research.

The data were compiled on Microsoft Excel® (Microsoft Corporation, Redmond, Washington, USA). Categorical variables were presented as number and percentage, and quantitative variables as mean and standard deviation (SD). The quality of life and psychosocial impact of the group of children aged 8 to 12 years were compared with the group of adolescents aged 13 to 18 years. The comparison of the mean score of the items of the two age groups was evaluated by Student's t-test. The differences were considered significant when p<0,05. The free and public domain program BioEstat 5.3 7 was used.

RESULTS

In the nine months of data collection, 27 pediatric patients with neoplasia were invited to participate in the research. Two patients were excluded from the survey because they refused to participate. Of the 25 patients, 15 (60%) were male. The age of the 25 participants at the time of the interview ranged from 9 to 18 years, with a mean of 14.6 years (SD = 2.8 years), six patients in the group aged 8 to 12 years and 19 patients in the group aged 13 to 18 years. Chart 1 shows the list of neoplasms and the number of cases.

The types of treatment performed were chemotherapy in 18 cases (72%), surgery in ten cases (40%) and radiotherapy in six cases (24%). In three patients, chemotherapy and surgery were combined: in another three, chemotherapy and radiotherapy. Two patients underwent the three types of treatments.

Chart 1. Types of neoplasms and number of cases

Cancer type	Case number		
Schwannoma	1		
Hodgkin Lymphoma	3		
Low grade glioma	2		
Ewing sarcoma	2		
Acute T-cell lymphoid leukemia	9		
High-grade glioma	2		
Osteosarcoma	3		
Pinealoblastoma	1		
Brainstem glioma	1		
Pituitary tumor	1		

All 25 experienced performing various procedures, sometimes with a companion and sometimes without. Of these, 24 stated that they felt happier for the presence of the companion during the procedure. Regarding emotional safety during procedures performed without the presence of a companion, ten patients (40%) revealed that they experienced feelings of anxiety and/or fear. The predominant companion was the mother, who was present in 18 cases (72%). They were also companions: the father in eight cases (32%), the grandmother in three cases (12%) and the aunt in two cases (8%).

Table 1 shows the 23 items of the Quality-of-Life questionnaire, the mean score, the SD, the number, and percentage of individuals with a score of 2 or more.

An analysis of the Quality-of-Life questionnaire was also carried out, comparing the mean scores of the 23 statements of the group aged 8 to 12 years and the group aged 13 to 18 years. The first obtained a mean of 1.44 (SD=0.53) and the second, the mean of 1.36 (SD=0.50). Therefore, there was no significant difference between the mean scores of the two age groups (p=0.627).

Table 2 presents the 27 items of the Cancer Module questionnaire, the average score, the SD, the number and percentage of individuals with a score of 2 or more.

The analysis of the Cancer Module was performed by comparing the average scores of the 27 statements of the two groups. The mean score of the 27 statements evaluated was significantly higher in the 8 to 12 years group (mean=1.46 and SD=0.63) than in the 13 to 18 years group (mean=1.06 and SD=0.46) (p=0.0094).

DISCUSSION

The present study sought to evaluate qualitatively and quantitatively the impact of cancer treatment in children and adolescents with cancer on quality of life. The impact was moderate or intense (score 2 or more) in a large proportion of the individuals analyzed. As for the Cancer Module questionnaire, which assesses the psychosocial impact, the mean score was significantly higher in the group of patients aged 8 to 12 years compared to the group aged 13 to 18 years. The concern with the treatment was the one with the highest score. Pediatric patients feel happier with the presence of a companion than without one while performing procedures. The most frequent diagnoses in the studied sample were acute lymphoblastic leukemia, central nervous system tumors and bone tumors, which is in agreement with other publications³.

According to the World Health Organization (WHO)8, quality of life is: "the individual's perception of their insertion in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". Based on this, the questionnaires applied consider physical activity, independence, concerns and the emotional, coexistence and school aspects. Regarding the data related to physical exertion and independence activities, those with the highest incidence of score 2 or more were difficulties in running and playing sports. A review article9 drew attention to the difficulties of physical activity in pediatric cancer patients, due to the adverse effects of chemotherapy and various treatments, the main ones being: fatigue, pain, weakness, and nausea. In addition, lack of energy and time can also make it difficult to practice. When asked about emotional factors, pain, tiredness, fear, sadness, and anger presented high percentages of score, with the statement "I feel tired "being the most expressive. Another researcher¹⁰ commented on fatigue being one of the main oncological symptoms and that it can be divided into primary, which is due to the clinical picture and pathophysiology of the tumor, or secondary, as a result of treatment and associated syndromes. Fear, sadness, and anger are directly linked to hospitalization and withdrawal from daily life due to cancer treatment. The need for invasive and painful procedures magnifies these negative feelings¹¹.

In this study, the impact of the statements "I feel fear" and "I feel pain" was the same among the participants. When asked in the Cancer Module questionnaire about physical pain, the biggest impacts for participants were pain and injuring themselves in the "joints" and muscles. The most current definition of pain is: "a distressing experience associated with a current or potential tissue injury with sensory, emotional, cognitive and social components", which can be related to the disease itself, the procedures performed and the treatment¹². Pain and fear are constantly related, and what most causes fear in children is the fact that they feel pain¹³.

Table 1. Quality of Life Questionnaire Results (n=25)

Statements	Mean (standard deviation) n=25	Score 2 or higher n (%) n=25	Average (8-12 years) n=6	Mean (13-18 years) n=19
It's hard for me to walk more than a block	1.5 (1.5-2.0)	12 (48.0%)	1.6	1.6
It's hard for me to run	1.9 (1.6)	14 (56.0)	2.0	2.1
It's hard for me to play sports or exercise	1.9±1.7	14 (56.0)	2.0	2.1
It's hard for me to lift heavy things	1.8 (1.6)	13 (52.0%)	2.0	1.9
It's hard for me to take a bath or shower by myself	0.6 (1.1)	5 (20.0)	0.8	0.7
It's hard for me to help with household chores	1.3 ± 1.4	11 (44.0%)	1.8	1.4
I don't even feel any pain	(1,2; 1,5)	10 (40.0%)	1.6	1.3
I feel tired	1.5 (1.2)	12 (48.0%)	1.2	1.5
I feel afraid	1.3 (1.3)	10 (40.0%)	2.2	1.2
I feel sad.	-1.2 (1.1)	10 (40.0%)	1.0	1.2
I feel angry	1.2 (1.0)	10 (40.0%)	1.0	1.2
I sleep badly	0.9/1.0	8 (32.0%)	0.8	0.9
I worry about what will happen to me	2.1 ± 1.3	16 (64.0)	2.0	2.2
I have difficulty getting along with other children	0.9 - 1.1	6 (24.0%)	0.6	0.8
The other kids don't want to be my friends	0.7 (1.1)	6 (24.0%)	1.0	0.7
The other kids pick on me	0.6 (1.0)	4 (16.0)	0.8	0.6
I can't do things that other kids my age do	1.0 - 1.2	7 (28.0)	1.0	1.0
For me, it is difficult to keep up with play with other children	(0.9; 1.2)	6 (24.0%)	1.0	0.9
It's hard to pay attention in class	1.6 (1.4)	11 (44.0%)	1.6	1.6
I forget things	1.7 +/- 1.4	13 (52.0%)	1.8	1.7
I have difficulty keeping up with my class on school assignments	1.0 - 1.4	6 (24.0%)	1.4	1.0
I miss class because I'm not feeling well	1.6 (1.4)	12 (48.0%)	1.4	1.6
I skip class to go to the doctor or hospital	2.1 ± 1.3	16 (64.0)	2.4	2.1

Regarding school performance during cancer treatment, a great impact was observed regarding school and class attendance, due to the need to go to the doctor or hospital, which may justify the high impact on the statements "it is difficult to pay attention in class" and "I forget things", since academic performance does not depend only on intellect, but also on motivations and interpretations¹⁴. In addition, the loss of content and regular absences from school, added to the medications used in the treatment and the absence of cognitive challenges, result in the regression of several areas of the central nervous system responsible for memory, concentration, attention, among others, causing school delay¹⁵.

Chemotherapeutics imply different side effects that affect the quality of life of patients who use them, nausea and vomiting are examples of this. Several authors¹⁶

report that most patients suffer from these symptoms at some period of treatment and that these periods may be concomitant with food refusal. In the present study, there was a great impact of motion sickness when doing the treatment and eating something.

The main target of complaint of children are needles, even recognizing that long-stay catheters are to reduce discomfort with procedures. Punctures for CSF and blood collection, administration of injections and chemotherapy sessions are some of the procedures that become routine for children undergoing cancer treatment¹⁷. Intravenous puncture stands out for the frequency with which it is performed, however, this procedure triggers crises of anxiety, dread and fear in pediatric patients, and is aggravated by certain incidents: repeated use of the venous network, failed puncture attempts and difficult-to-access veins¹⁸. In this study, the negative impact on quality of

Table 2. Cancer Module Questionnaire Results (n=25)

Statements	Mean (standard deviation) n=25	Score 2 or higher n (%) n=25	Average (8-12 years) n=6	Média (13-18 anos) n=19
I feel pain, I hurt my "joints" and muscles	1.3 (1.1)	12 (48.0%)	1.2	1.4
I get hurt a lot	0.9 - 1.3	5 (20.0)	1.2	0.8
I feel nauseous when I do the medical treatment	1.4 (1.5)	11 (44.0%)	1.7	1.3
I feel nauseous when I think about medical treatment	0.5 (1.0)	4 (16.0)	0.2	0.6
I feel sick to eat something	-1.2 (1.3)	9 (36.0%)	1.6	1.0
Some foods and smells make me nauseous	1.3 ± 1.5	11 (44.0%)	1.7	1.2
For me, the food doesn't taste very good	0.9 - 1.3	6 (24.0%)	1.8	0.6
I think the needles hurt me	1.5 ± 1.3	10 (40.0%)	2.2	1.3
I'm afraid of needles	1.3 ± 1.5	8 (32.0%)	2.3	1.0
I feel scared when I have to do a blood test	-0.9 (-1.5, 0.0)	6 (24.0%)	1.8	0.6
I feel scared when I'm waiting for the doctor's appointment	0.7-1.0	4 (16.0)	0.7	0.7
I feel scared when I have to go to the doctor	0,6~0,8	5 (20.0)	1.0	0.4
I feel scared when I have to go to the hospital	1.0 (1.1)	10 (40.0%)	1.0	1.1
I worry about the side effects of my medical treatment	1.6 ± 1.0	15 (62.5)	2.2	1.5
I worry if my medical treatment is working	1.8 (1.2)	16 (66.7%)	1.6	1.8
I worry if my illness will come back	2.2±1.4	17 (70.8)	2.0	2.2
For me, it's hard to think what to do when something bothers me	1.5 ± 1.3	11 (44.0%)	2.0	1.4
It's hard for me to work with numbers	1.5 ± 1.3	13 (52.0%)	1.7	1.6
It's hard for me to write	0.7 - 1.2	4 (16.7)	0.3	0.8
It's hard for me to pay attention to things	1.4 - 1.4	9 (36.0%)	1.8	1.3
For me, it's hard to remember what I've already read	1.4 (1.5)	10 (40.0%)	2.5	1.0
I don't think I'm pretty	1.3 ± 1.4	10 (40.0%)	0.7	1.5
I don't like other people to see my injuries	-0.4 (0.8)	2 (8.0%)	0.8	0.3
I feel ashamed when other people look at my body	0.8 – 1.2	5 (20.0)	0.5	1.0
For me, it's hard to tell doctors and nurses how I feel	1,3 - 1,6	9 (36.0%)	1.8	1.2
It's hard for me to ask questions of doctors and nurses	1.1/1.4%	9 (36.0%)	1.7	0.5
It's hard for me to talk about my illness with other people	-0.7 (1.3)	5 (20.0)	1.5	0.5

life and psychosocial was not as high as that of statements with the needle theme, which differs from other studies. The biggest impact appeared in the statement that needles hurt.

The score was lower for the fear of going to the doctor or waiting for a doctor's appointment, and slightly higher for the fear of going to the hospital. Hospitalized children have changes in their emotional state, which may be fear, anxiety, night terrors, sleep disorders, etc. Changes in routine and invasive procedures, often painful and uncomfortable, change the behavioral pattern¹⁹.

In the Cancer Module questionnaire, the highest impact was related to concern about treatment side effects, treatment effectiveness, and disease recurrence. In the other questionnaire, a high-impact statement was "I worry about what will happen to me." The treatment phase is

important for healing, and this is perceived by children, which raises concerns related to the recovery of health and prognosis²⁰. Hospitalization in childhood is a traumatic experience because, when hospitalized, the patient is removed from their life and routine and is exposed to pain, suffering and physical limitation, which externalizes the feeling of guilt, punishment, and fear of death²¹.

Cancer is directly related to the image of the adolescent in relation to himself, realizing that the changes in his body affect his self-perception, which reflects on his self-esteem, making him feel incapable, invalid, and tired, and may increase concern about the treatment²². In the present study, there was a great impact of the participants in relation to the statement not being beautiful, which confirms the fact that the treatment reflects on the self-esteem of the child and adolescent with cancer.

Some patients reported difficulty in communicating with doctors and nurses, both in saying how they feel and in asking questions, while others expressed greater difficulty in talking about the disease with people outside the health area. It has been documented in other studies that communication difficulties with health professionals result from limitations in the language and forms of expression of young children and adolescents, perceived by the lack of willingness to interact or the lack of a relationship of trust between them²³. However, the child's relationship with the nurse seems to occur with a stronger bond based on verbal and non-verbal communication, and in the provision of care²⁰.

It is necessary to highlight some limitations of the present research, namely: limited sample size and interference of the companion during the response period of the questionnaires in some patients. The sample size restricted to only 25 patients certainly compromised the statistical tests when comparing the younger group with the older group, with an increased probability of beta error. The sample size of this research was smaller than desired because it is a new pediatric oncology service, due to the difficulty of scheduling with patients due to the COVID-19 pandemic and the limited age group. Despite being informed of the need for the patient to respond alone and without interference, many children and adolescents had some difficulty reading, writing or due to tiredness that made it difficult to read, requiring the help of the companion.

CONCLUSION

It is concluded that most pediatric cancer patients suffer a significant impact on quality of life and psychosocial. Younger pediatric patients (8 to 12 years) have a greater psychosocial impact than older ones (13 to 18 years). As for the presence of the companion, the patients said they were happier with their presence. In addition, several reported greater anxieties when performing procedures in the absence of a companion.

Based on the results of this research, the best impact on the quality of life of pediatric cancer patients is highlighted when there is a multiprofessional structure that has the constant support of doctors, nurses, psychologists, physiotherapists, and social workers.

CONTRIBUTIONS

All authors contributed substantially in the design and/or planning of the study; in the collection, analysis and interpretation of data; in the writing and critical review; and approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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