

## PSYCHOSOCIAL EFFECTS OF HEMATOPOIETIC STEM CELL TRANSPLANTATION IN PEDIATRIC PATIENTS

---

Acceptance date: 04/08/2025

*Adriane Gonçalves Menezes Choinski*  
Curitiba Municipal Health Department

*Aliane Paes Brunismann*  
Curitiba Municipal Health Department

*Jaqueline Cenci*  
Pequeno Príncipe Hospital

*Gustavo Manoel Schier Dória*  
Federal University of Paraná

*Andre Marques Choinski*  
Positivo University



All content in this magazine is licensed under the Creative Commons Attribution 4.0 International License (CC BY 4.0).

**ABSTRACT: Introduction.** Hematopoietic stem cell transplantation (HSCT) is widely accepted for the treatment of various hematological and oncological diseases in childhood. The complexity of the procedure has repercussions on the psychological suffering of children, adolescents and their families. However, the characteristics of this suffering, especially in the Brazilian population, still need to be better understood. **Objective.** The main objective of this study was to assess the effects on the psychological and social aspects of pediatric patients undergoing HSCT. **Methodology.** An observational, longitudinal and descriptive study was conducted in a pediatric hospital. The sample consisted of 19 participants and their respective main caregivers, who were assessed at three points in time: fifteen days prior to hospitalization for HSCT; in the first month after HSCT; at the 100-day post-HSCT visit. The assessments consisted of analyzing data from medical records and applying structured questionnaires: *Child Behavior Checklist* (CBCL); PedsQL (Pediatric Quality of Life Questionnaire); Socioeconomic Questionnaire of the Brazilian Association of Research Companies (ABEP); Sociodemographic Questionnaire of the Main Caregiver. In addition to applying the instruments, in each of the three surveys, the researchers provided a listening space to welcome the patient and their family member. If the children or family members identified a need for mental health care, they were referred to a specialized mental health service. **Results and discussion.** Of the 19 pediatric patients interviewed, there was a balanced distribution of age groups, with 10 participants aged between 1 and 5 years and 9 participants aged between 6 and 18 years. The majority were boys (84.2%), born and raised in the South of the country (57.9%). Statistical analysis showed a significant improvement in externalizing symptoms measured by the CBCL in patients aged between 6 and 18 at the 100-day follow-up after the procedure.

There was a statistically significant association between the participants' need to change their city and the quality of life indices in the second assessment, as well as between the number of complications in pediatric patients and the education level of the main caregivers. It is understood that HSCT interferes with various aspects of a pediatric patient's life - emotional, social and behavioral. In addition, the process of dealing with the aftermath of HSCT can have consequences that impact on the quality of life of this population as a whole. It is therefore essential to approach pediatric patients in the pre-HSCT period to identify factors that predispose to psychological distress, with a view to both prophylaxis and anticipating possible interventions. **Conclusion.** Considering the particularities of the Brazilian population, as well as the scarcity of data in the area, understanding the psychosocial effects of child HSCT is fundamental for building health services that are better able to provide adequate care for this population at a time of great vulnerability.

**Keywords:** Hematopoietic stem cell transplantation. Psychosocial effects. Pediatric HSCT.

## INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) is widely accepted for the treatment of various hematological and oncological diseases in childhood and adolescence (FRAINT et al., 2020). In 2020, 477 HSCTs were performed in children and adolescents in Brazil, 65 of which were in Paraná (ASSOCIAÇÃO BRASILEIRA DE TRANSPLANTE DE ÓRGÃOS, 2021). Given the complexity of the procedure, children and adolescents experience this stressful event for a prolonged period of their lives. This results in psychological suffering related to HSCT in these individuals.

The main psychological reactions of pediatric patients to HSCT include: anxiety, depression, social isolation, behavioral changes

and post-traumatic stress. Anxiety reactions are described above all in the pre-transplant period, and depressive reactions are more related to the length of hospitalization (PACKMAN et al., 2010). Meyers et al. (1994) found significant anxiety symptoms in 40% of children in the pre-transplant period. Phipps et al. (2002a) found higher scores of child distress between admission and the first week after HSCT.

The identification of predictors presents conflicting data in the literature. In another study by Phipps et al. (2002b), it is postulated that infant suffering increases progressively from autologous to heterologous transplantation between siblings to heterologous transplantation between strangers. Meyers et al. (1994), in turn, identified autologous transplantation as a predictor of depression and anxiety. Regarding age, the data differed according to different studies - younger ages were considered a protective factor (PHIPPS et al., 2002b), while for Meyers et al. (1994) age was not considered an independent predictor. As for socioeconomic profile, low socioeconomic status was a risk factor for child suffering only in the first six months after hospitalization (PHIPPS et al., 2002b).

The evolutionary course of the symptoms observed in the post-HSCT period is not well established in the current literature. In some studies, there is a reduction in anxiety symptoms and psychological distress in the weeks and months following HSCT (MEYERS et al., 1994; PHIPPS, 2002a). On the other hand, other authors have demonstrated the permanence of symptoms of anxiety and depression, as well as behavioral changes, in the post-HSCT period (PACKMAN et al., 2010; ADANIR, 2017; TASKIRAN et al., 2016). Stuber et al. (1991) identified that post-traumatic stress symptoms can be found even one year after HSCT.

The literature corroborates the existence of HSCT-related psychological distress, but the characterization of this distress, such as the

identification of possible predictors, as well as the evolution of symptoms, still needs to be better understood. Especially when considering the Brazilian population in particular, whose data is even scarcer.

Considering the particularities and experiences of our population, understanding the psychosocial effects of child HSCT is fundamental to building health services that are better able to provide adequate care for these individuals at this time of great vulnerability.

## OBJECTIVE

The general objective was to evaluate the effects on the psychological and social aspects of pediatric patients undergoing HSCT. Specific objectives included: assessing the quality of life of pediatric patients; identifying predisposing factors for suffering in this population; comparing the psychosocial effects at different points in the evaluation; assessing the evolution of psychological symptoms over time; providing a listening space for patients and their families, with a view to welcoming them and referring them to mental health services when necessary.

## METHODOLOGY

This study is characterized by its observational, longitudinal and descriptive design and is part of a larger study that aims to assess the psychosocial effects of HSCT on the binomial that includes pediatric patients undergoing HSCT and their respective main caregivers. Pediatric patients undergoing medical follow-up in the Bone Marrow Transplant sector of a pediatric hospital in Curitiba-PR were evaluated.

The sample included 22 pediatric patients, but there were three losses during the study: two deaths due to post-HSCT complications and one patient's palliative care and return to the city of origin due to a recurrence of the condition. In all three cases, the patients were

excluded from the study because they had not completed the initial phase of filling in the questionnaires, making it unfeasible for them to take part in the study. Therefore, the sample considered was 19 patients.

The sample number was calculated based on the estimated flow of patients undergoing HSCT at the service (between 4 and 5 patients per month), the study methodology (longitudinal study, with three planned assessments, the last around 100 days post-HSCT) and the period during which the research data was collected (between September 2021 and June 2022).

All pediatric patients who underwent HSCT between September 2021 and February 2022 were included, totaling six months of data assessment from new patients. The following months (March to June 2022) were used to carry out the second and third evaluations envisaged by this study, i.e. the follow-up of patients in the first month after HSCT and at the "100-day" visit after HSCT. All pediatric patients who voluntarily agreed to take part in the study and consented by understanding and signing the Informed Consent Form - according to age group - and whose main caregiver signed the Informed Consent Form (ICF) were included in the study.

The exclusion criteria consisted of: individuals who were unable to communicate in Portuguese (who communicated in foreign languages or in Brazilian Sign Language) and their respective peers (pediatric patients/main caregivers); individuals and their respective peers who were unable to consent or participate in the study during the assessment (for example: acute psychotic state); participants who did not complete the initial phase of filling in the questionnaires, i.e. who had not completed all the questionnaires for the first assessment (Table 1). Initially, children under the age of one and a half would also be excluded, since one of the instruments to

be used in the research, the *Child Behavior Checklist* (CBCL), is only applicable from this age. However, the decision was made to include children under 1.5 years of age, given the scarcity of data on the subject, as well as the specific nature of the population studied.

The patients were assessed at three points in time, considering the routine of consultations at the service. These were: (1) in the fifteen days prior to the HSCT, a period in which they had outpatient consultations with a series of preoperative laboratory tests; (2) in the first month after the HSCT, a period in which they remained hospitalized; (3) around 100 days after the HSCT, a period in which they had outpatient consultations to check on the possibility of returning to social activities (such as attending school, for example) and returning to their city of origin in the case of families from other places.

Each assessment included the application of structured questionnaires, as well as the analysis of data from medical records (Table 1). The questionnaires used for evaluation were: Socioeconomic Questionnaire from the Brazilian Association of Research Companies (ABEP) (ABEP, 2022); Sociodemographic Questionnaire of the Main Caregiver (Source: own elaboration); PedsQL (Pediatric Quality of Life Questionnaire), including the child's report and the caregiver's report (VARNI et al., 2003); *Child Behavior Checklist* (CBCL) (ACHENBACH et al., 2001).

Assessment	Instruments
First assessment: in the 15 days prior to HSCT	- ABEP socioeconomic questionnaire - Sociodemographic Questionnaire of the Main Caregiver - PedsQL - CBCL - Medical record data
Second assessment: in the first month after HSCT	- PedsQL - CBCL - Data from medical records
Third assessment: around 100 days after HSCT	- PedsQL - CBCL - Data from medical records

Caption:

CBCL = *Child Behavior Checklist*

PedsQL = *Pediatric Quality Life* - Pediatric Quality of Life Questionnaire

ABEP Questionnaire = Brazilian Association of Research Companies Questionnaire

WHOQOL Brief = World Health Organization's Abbreviated Quality of Life Assessment Instrument

TABLE 1 - ASSESSMENT INSTRUMENTS

The ABEP socioeconomic questionnaire uses socioeconomic variables to classify people into the following economic classes: A, B1, B2, C1, C2, D-E (ABEP, 2022). The Sociodemographic Questionnaire for the Main Caregiver, elaborated by the authors of the expanded search that includes this study, aims to objectively compile relevant information to identify possible predisposing or protective sociodemographic factors for suffering related to HSCT.

The PedsQL is an instrument validated for the Brazilian population to assess the health-related quality of life of children and adolescents, which includes the assessment of four aspects (physical, emotional, social and school) by both the patient and the parents (KLA-TCHOIAN et al., 2008).

The CBCL is designed to assess socio-emotional and behavioral problems in children and adolescents and is one of the most widely

used instruments in the world for assessing mental health in this population. It has two versions according to age group. The 1.5 to 5-year-old version consists of 99 items and the 6 to 18-year-old version consists of 118 items to be answered by parents (DUARTE & BORDIN, 2000; SANTOS & CELERI, 2018). The 1.5 to 5 years version has not yet been validated in Brazil, but it has been officially translated and is used in Brazilian research. The 6 to 18 years version has already been validated in Brazil.

In addition, the following data was obtained from the medical records of the pediatric patients: place of birth; place of residence; diagnosis that prompted the HSCT; time of diagnosis; time elapsed between diagnosis and HSCT; history of previous HSCT; type of transplant (autologous or heterologous); donor relationship with the patient (family member - specify degree of kinship, friend, bone marrow bank); HSCT complications; complementary tests that contribute to understanding the diagnosis and complications.

All the questionnaires, as well as the informed consent form, were made available to the participants in printed form. After applying the instruments, in each of the three applications with the participants, the researchers provided a listening space to welcome the patient and their family, under the supervision of the head of the Child and Adolescent Psychiatry service at the hospital. When demands for mental health care were identified in the pediatric patients, they were referred to the Child and Adolescent Psychiatry service for evaluation and follow-up. The caregivers who had mental health needs were referred for treatment by the public or private health network, depending on the case.

Since this was an observational study, the participants answered questionnaires and had their medical records analyzed. As such, the participants did not face any physical risks



when taking part in the research. They were subject to some embarrassment when answering some of the questions in the questionnaire, but they had the support of the psychiatry team for reception and management. There is also the possibility of undue disclosure of data. However, the researchers undertook to follow ethical criteria, keeping the data collected confidential during all stages of the process.

Patients benefited from serial contact with the psychiatry team in the period leading up to and after HSCT, making it possible to identify possible impacts of the procedure on patients and their families at an early stage. This enables early referral to psychiatric services when necessary. As an indirect benefit, it is worth mentioning that the analysis of the research results will contribute to the planning and development of future health promotion and prevention actions for the population in question.

The data was collected and stored in a Microsoft Excel spreadsheet. Data analysis was carried out using the SPSS v.22.0 computer program. The results were expressed as means, medians, minimum values, maximum values and standard deviations (quantitative variables); frequencies and percentages (qualitative variables). The inferential analysis was carried out using statistical tests relevant to the study (e.g. Chi Square, Fisher's Exact Test, Student's T Test), with *p-values* of less than 0.05 being considered significant.

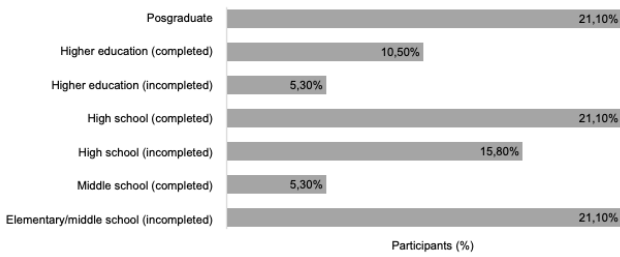
## RESULTS AND DISCUSSION

This study assessed pediatric patients being medically monitored by the Bone Marrow Transplant (BMT) department of a pediatric hospital in Curitiba-PR. The BMT service at this hospital celebrated its tenth anniversary in 2021, when 73 procedures were carried out - 11 more than in the previous year. It currently has 10 beds for the procedure and is

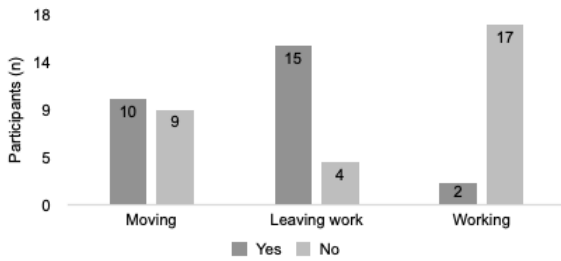
considered the main Brazilian center for pediatric HSCT via the Unified Health System (HOSPITAL PEQUENO PRÍNCIPE, 2021; HOSPITAL PEQUENO PRÍNCIPE, 2023).

This study included all pediatric patients who underwent HSCT at the hospital over a six-month period, totaling 22 participants. After three losses, two deaths due to post-HSCT complications and one palliative care and return to the city of origin due to recurrence of the condition, the N considered was 19 patients and their respective main caregivers. Among the 19 pediatric patients, one patient had only the first assessment (death due to complications after BMT), two patients had only two assessments (return to the city of origin after the second assessment), and the others had three assessments.

All 19 main caregivers interviewed declared themselves to be female, all of them mothers of pediatric patients, aged between 23 and 42 years (average 33.4 years). Regarding the ethnicity of the caregivers, there was an equal predominance of whites (47.4%) and mixed or multiple ethnic groups (47.4%), followed by blacks (5.3%). Most of them were married (42.1%) or in a stable union (31.6%). The predominant religions of the caregivers were Evangelical/Christian (42.1%) and Catholic (42.1%). The majority were from the South (47.4%), Northeast (26.3%) and Southeast (21%), with only one from the north (5.3%). Regarding origin, the majority came from the South (57.9%), followed by the Center-west (21%), Southeast (10.5%), North (5.3%) and Northeast (5.3%). The education level of the caregivers was heterogeneous, as shown in Graph 1. Most of the caregivers had to move to another city because of the participants' treatment, and only two mothers were still working (Graph 2).

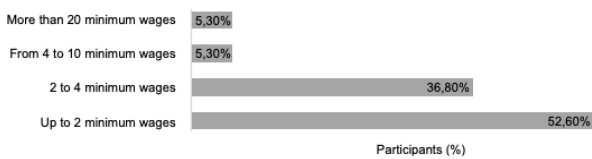


GRAPH 1 - EDUCATION LEVEL OF MAIN CAREGIVER

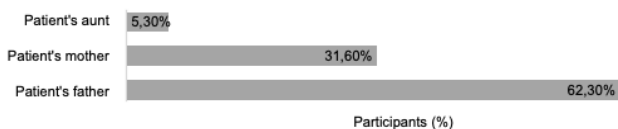


GRAPH 2 - CHANGE OF CITY AND WORK OF MAIN CAREGIVER

The family income declared by the main caregiver was predominantly up to two minimum wages (Graph 3), and the source was mainly the child's/adolescent's father (62.3%) (Graph 4). The distribution of economic class according to the ABEP questionnaire was heterogeneous (Table 2).



GRAPH 3 - FAMILY INCOME DECLARED BY THE MAIN CAREGIVER



GRAPH 4 - HEAD OF HOUSEHOLD (CONTRIBUTES MOST INCOME)

Economic class	Frequency (n)
A	1
B1	3
B2	4
C1	5
C2	1
D-E	5

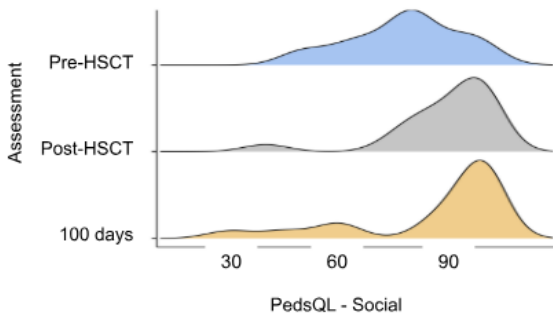
TABLE 2 - Economic class according to ABEP questionnaire

Regarding the participants' housing, the average number of people living in the house was 4 - standard deviation (SD): 1.20. Each household had an average of 6 rooms (SD: 1.63), 2.58 bedrooms (SD: 0.69), 1.53 bathrooms (SD: 0.84), 2.26 computers (SD: 1.48), 1.16 fridges (SD: 0.37) and 1 washing machine (SD: 0.33). Most families did not own their own car (average: 0.68 car/family) or motorcycle (average: 0.82 motorcycle/family), nor did they have monthly employees (average: 0.15 monthly employees/family). Most of the water used in the household came from the general distribution network (84.2%). The households were predominantly located on paved streets (78.9%).

The epidemiological survey of pediatric patients shows that the distribution of age groups was balanced, with 10 participants aged between 1 and 5 years and 9 participants aged between 6 and 18 years. The majority were boys (84.2%), born and raised in the South of the country (57.9%).

Regarding the quality of life of pediatric patients, it is known that there is an impact during all stages of HSCT: pre-transplant, during the procedure, as well as in the period following the transplant, when the chance of rejection is high (CLARKE et al., 2008). The quality of life of the pediatric patients in this study, measured by the PedsQL, showed a statistically significant improvement (paired T-test;  $p < 0.05$ ) only from the first to the second assessment, in the social area, in the

version completed by the parents (Graph 5). Considering that in the second assessment the patients were hospitalized and totally deprived of interaction with peers, both due to the post-procedure protocol and the current pandemic, it is possible that an adaptive mechanism occurred that led to this perception of improvement.



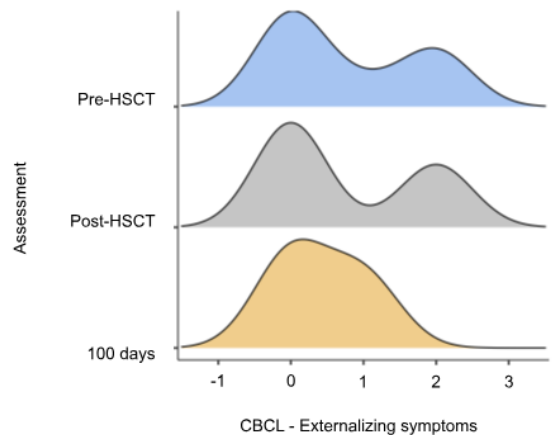
GRAPH 5 – PEDSQL - SOCIAL ASPECTS (PRE- HSCT, POST- HSCT AND 100 DAYS)

Studies suggest that specific characteristics of pediatric patients undergoing HSCT, such as optimism and resilience, have an important influence on this population's self-reported quality of life (WALLANDER & VARNI, 1998). On the other hand, pediatric patients who already had some pre-HSCT emotional disturbance, worry or communication disorders usually have worse post-HSCT quality of life indices (FELDER-PUIG et al., 2006). The literature also shows that younger children (5 to 12 years old) tend to have higher quality of life indices than older children (13 to 18 years old) (PACKMAN et al., 2010). As regards the self-reported PedsQL of the children and adolescents in this study, there was no statistically significant difference in the quality of life indices when comparing the three samples.

As regards the socio-emotional and behavioral problems of children and adolescents, Carvalho et al. (2009) state that the CBCL is one of the most effective instruments for quantifying parental responses to their children's behavior. The questionnaire assesses in

a syndromic way: emotional reactivity, anxiety/depression, somatic complaints, attention problems, aggressive behavior and sleep problems - for both age groups (1.5 to 5 years; 6 to 18 years). For the version for older children, social problems, thinking problems and rule breaking are also assessed. Based on the results obtained on these scales, the individual can be included in the clinical, borderline or normal range in terms of their overall functioning. There is also a division between internalizing profiles (isolation, somatic complaints, anxiety/depression) and externalizing profiles (violation of rules and aggressive behavior) (WIELEWICKI et al., 2011).

Analysis of the results of the CBCL in this study showed that there was a statistically significant improvement in externalizing symptoms (violation of rules and aggressive behavior) from the second to the third assessment in participants aged between 6 and 18 (pairwise comparison using the Durbin-Conover test;  $p < 0.05$ ; Graph 6). There was no statistical difference between the other parameters assessed by the CBCL when comparing the three samples.



GRAPH 6 - EXTERNALIZING SYMPTOMS IN CHILDREN AGED 6 TO 18 ACCORDING TO THE CBCL (PRE- HSCT, POST- HSCT AND 100 DAYS)



Of all the 19 hematopoietic stem cell transplants carried out in this study, 3 were autologous - from the child themselves - and the other 16 were heterologous - from a donor. Most of the patients who underwent heterologous transplantation had an intra-family donor (brother, father, uncle), and 7 patients had an unrelated donor. Two studies (PARSONS et al., 2006; BADELL et al.; 1998) showed that children who underwent heterologous HSCT from an unrelated donor had lower quality of life indices three months after the procedure, but the three-year follow-up of these same individuals showed no difference between autologous and heterologous recipients (related or not). This suggests that the impact of the HSCT donor on the quality of life of pediatric patients may be transitory.

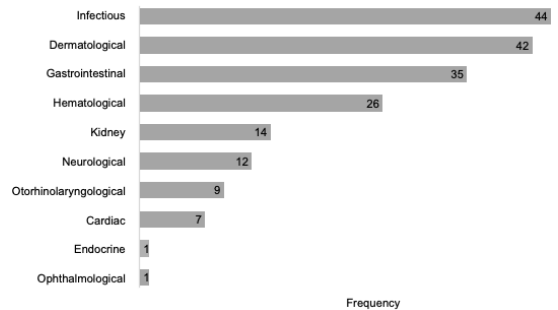
When considering the diagnosis that prompted the HSCT in the pediatric patients in this study, the most common disease was acute lymphoid leukemia (ALL), followed by sickle cell disease and stage IV neuroblastoma, i.e. metastatic (Table 3).

Diagnosis	Participants	
	(n)	(%)
Acute lymphoid leukemia	5	26.3
Sickle cell disease	3	15.8
Neuroblastoma IV	3	15.8
Chronic granulomatous disease	2	10.5
Aplastic anemia	1	5.3
Inflammatory bowel disease	1	5.3
Inborn error of immunity	1	5.3
Acute myeloid leukemia	1	5.3
Amegakaryocytic purpura	1	5.3
Congenital amegakaryocytic thrombocytopenia	1	5.3

TABLE 3 - DIAGNOSIS THAT LED TO HSCT

HSCT complications in the sample studied totaled 55 complications, with a minimum of 7 complications, a maximum of 22 complications and an average of 12.4 complications per patient. The complications were divided into large groups and summarized in Graph 7. Of

the 19 participants, 11 had complications that required further hospitalization. Five participants had serious complications and required admission to the Intensive Care Unit (ICU), 3 of whom needed vasoactive drugs.



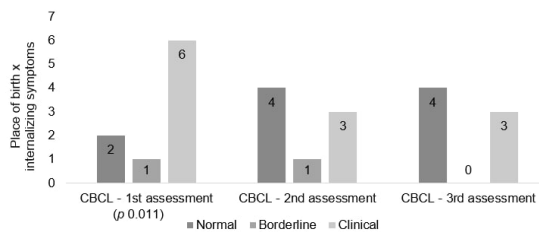
GRAPH 7 - FREQUENCY OF HSCT COMPLICATIONS IN PEDIATRIC PATIENTS

An association test was carried out between the number of complications and the education level of the main caregivers, resulting in a statistically significant association (Chi Square Test;  $p < 0.05$ ). Table 4 shows that most of the participants had between 10 and 15 complications and that the education level of the main caregivers was significantly higher in patients with fewer complications. The association between the number of complications and other epidemiological data collected from both caregivers and participants was not statistically significant.

Schooling	Complications				Total
	Between 5 e 10	Between 10 e 15	Between 15 e 20	More than 20	
Elementary/ middle school (incompleted)	2	0	2	0	4
Middle school (completed)	0	0	0	1	1
High school (incompleted)	0	2	1	0	3
High school (completed)	1	3	0	0	4
Higher education (incompleted)	0	1	0	0	1
Higher education (completed)	1	1	0	0	2
Postgraduate	0	2	2	0	4
Total	4	9	5	1	19

TABLE 4 - FREQUENCY OF COMPLICATIONS

Phipps et al. (2002a) showed that children with low socioeconomic status had worse quality of life indices between 3 and 6 months after HSCT. In this study, the outcomes of pediatric patients, measured by the PedsQL and CBCL questionnaires, were associated with sociodemographic data (Kruskal-Wallis test;  $p < 0.05$ ) and statistically significant associations were found. When comparing the different origins of pediatric patients aged between 1 and 5 years by region of the country (North, Northeast, Midwest, Southeast and South) with internalizing symptoms, there were significantly higher rates of internalizing symptoms in the first assessment of the CBCL ( $p 0.011$ ), compared to the second and third assessments (Graph 8). This may have been influenced by patients and family members who had to move to undergo HSCT.



GRAPH 8 – PLACE OF BIRTH OF PEDIATRIC PATIENTS AGED BETWEEN 1 AND 5 YEARS VERSUS INTERNALIZING SYMPTOMS MEASURED BY CBCL IN THE THREE ASSESSMENTS

When the pediatric patients' quality of life indices were compared (PedsQL - parents' report), an association was observed between the results of the second assessment and the participants' need to change city (Kruskal-Wallis test;  $p < 0.05$ ). In the physical domain, there was a worsening, while in the school domain and in the total PedsQL result of the second assessment there was an improvement compared to the first and third assessments (Table 5). It is worth noting that most of the caregivers had to move to another city due to the participants' treatment (10 individuals out of a total of 19 interviewees). It is possible that the worsening in the physical domain was influenced by the participants' need to move and the long period of hospitalization of the patients during the second assessment. As regards the improvement in the school domain, it is worth noting that hospitalization may have been a protective factor. This might be because the service where this study was carried out has a team of teachers who maintain school activities in an adapted and individualized way.

in minimizing suffering (SOUZA et al., 2021).

## CONCLUSION

HSCT interferes with various aspects of a pediatric patient's life - emotional, social and behavioral. In addition, the process of dealing with post-HSCT can have consequences that impact on the quality of life of this population. It is therefore essential to approach pediatric patients in the pre-HSCT period to identify factors that predispose to psychological distress, with a view to both prophylaxis and anticipating possible interventions.

This study contributed to knowledge about the psychosocial impact of HSCT and reinforced data from the literature, such as the improvement in externalizing symptoms in older children at the 100-day *follow-up* after the procedure. It also provided interesting data such as: the association between the need for participants to move to another city and the quality of life indices in the second assessment; the association between the number of complications and the education level of the main caregivers. It is worth noting that there were important limitations, such as the size of the sample and the restrictions imposed by the pandemic at the time, which may have had an impact on the results - for example, social isolation.

Considering the particularities of the Brazilian population, as well as the scarcity of data in the area, understanding the psychosocial effects of child HSCT is fundamental for building health services that are better able to provide adequate care for this population at a time of great vulnerability.

Assessments	PedsQL - mean (p)		
	Physical domain	School Domain	Total
1 <sup>st</sup> assessment	73,2	59,3	71,2
2 <sup>nd</sup> assessment	64,3 (p 0,034)	72,1 (p 0,026)	75,5 (p 0,034)
3 <sup>rd</sup> assessment	75,4	55,7	73,5

TABLE 5 - CHANGE OF CITY *VERSUS* QUALITY OF LIFE (PEDSQL) OF PEDIATRIC PATIENTS

In regard to the listening space provided at the end of each assessment, it is understood that it was possible for the caregivers and the children and adolescents to bond more, including moments of integration, such as the production of drawings by the younger participants (Figure 1) and playful moments with card games with the older participants. Five caregivers were referred to specialized mental health services. As to the children, there was support from the hospital's psychiatry and psychology teams, and only two referrals were made to external services (speech therapy).



FIGURE 1 - DRAWINGS MADE BY PARTICIPANTS DURING THE LISTENING SESSION (reproduction authorized by caregivers)

It is understood that the distancing of children and adolescents from the bonds inherent in the HSCT process is an important isolating factor for this population. The social interaction provided by the listening space can be beneficial in reducing isolation and improving adjustment to the adversities of HSCT. Thus, the use of playful strategies, in addition to being a form of entertainment and distraction for children and adolescents, can be a factor

## REFERENCES

ACHENBACH, T. Versão brasileira: BORDIN, I.A.S.; PAULA, C.S.; DUARTE, C.S. **Inventário de comportamentos para crianças e adolescentes de 6 a 18 anos: versão brasileira do “Child Behavior Checklist for ages 6-18” (CBCL/6-18)**. Disponível em: < <https://www.teses.usp.br/teses/disponiveis/5/5142/tde-26042006-102527/publico/anexoV.pdf> >. Acesso em: 11/01/2023.

ADANIR A.S. e cols. Psychopathology in pediatric bone marrow transplantation survivors and their mothers. **Pediatrics international**, v. 59, n. 9, p. 979-985, set. 2017.

ASSOCIAÇÃO BRASILEIRA DE EMPRESAS DE PESQUISA (ABEP). **CrITÉrio Brasil 2022**: Critério de classificação econômica Brasil. Disponível em: <<https://www.abep.org/criterio-brasil>>. Acesso em: 11/01/2023.

ASSOCIAÇÃO BRASILEIRA DE TRANSPLANTE DE ÓRGÃOS (ABTO). **Registro Brasileiro de Transplantes**: Dimensionamento dos Transplantes no Brasil e em cada estado (2014-2021). Disponível em: <<https://site.abto.org.br/publicacao/xxvii-no-4/>>. Acesso em: 11/01/2023.

BADELL, I. e cols. Quality of life in young adults having received a BMT during childhood: a GETMON study. **Bone Marrow Transplant**, v. 21, n. 2, p. S68-S71, 1998.

CARVALHO, D. M. e cols. **Avaliação do comportamento infantil: uma revisão da literatura**. Anais do III Fórum de Estudos Multidisciplinares, X Encontro de Pesquisadores e III Congresso de Iniciação Científica, v. 3, p. 164-174, 2009.

CLARKE, S.A.; EISER C.; SKINNER, R. Health-related quality of life in survivors of BMT for paediatric malignancy: a systematic review of the literature. **Bone Marrow Transplant**; v. 42, p. 73-82, 2008.

DUARTE C. S.; BORDIN, I. A. S. Instrumentos de avaliação. **Revista Brasileira de Psiquiatria**, v. 22, p. 55-58, 2000.

FELDER-PUIG, R. e cols. Health-related quality of life of pediatric patients receiving allogeneic stemcell or bone marrow transplantation: results of a longitudinal, multi-center study. **Bone Marrow Transplant**, v. 38, p. 119-126, 2006.

FRAINT, E. HOLUBA, M. J.; WRAY, L. Pediatric Hematopoietic Stem Cell Transplant. **Pediatrics in Review**, v. 41, n. 11, p. 609-611, nov. 2020.

GREEN, J. **The Fault in Our Stars**. Harlow, England: Penguin Books, 2013.

HOSPITAL PEQUENO PRÍNCIPE. **Evolução em tempos de crise: os principais avanços no atendimento do Pequeno Príncipe**. 2021. Disponível em: <<https://pequenoprincipe.org.br/relatorioweb2021/hospital-pequeno-principe/>>. Acesso em: 11/01/2023.

HOSPITAL PEQUENO PRÍNCIPE. **Especialidades clínicas: Oncologia e Hematologia**. 2023. Disponível em: <<https://pequenoprincipe.org.br/especialidades/oncologia-hematologia-e-tmo/>>. Acesso em: 11/01/2023.

KLATCHOIAN, D. A. e cols. Quality of life of children and adolescents from São Paulo: reliability and validity of the Brazilian version of the Pediatric Quality of Life Inventory™ version 4.0 Generic Core Scales. **Jornal de Pediatria**, v. 84, p. 308-315, 2008.

MEYERS, C. A. e cols. Evaluation of the Neurobehavioral Functioning of Transplantation. **Journal of Clinical Oncology**, v. 12, n. 4, p. 820-826, 1994.

PACKMAN, W. e cols. Psychological effects of hematopoietic SCT on pediatric patients, siblings and parents: a review. **Bone Marrow Transplantation**, v. 45, n. 7, p. 1134-1146, abr. 2010.

PARSONS, S. K. e cols. Maternal perspectives on children's health related quality of life during the first year after pediatric hematopoietic stem cell transplant. **Journal of Pediatric Psychology**, v. 31, p. 1100-1115, 2006.

PHIPPS, S. e cols. Acute health-related quality of life in children undergoing stem cell transplant: I. Descriptive outcomes. **Bone Marrow Transplantation**, v. 29, n. 5, p. 425–434, mar. 2002a.

PHIPPS, S. e cols. Acute health-related quality of life in children undergoing stem cell transplant: II. Medical and demographic determinants. **Bone Marrow Transplantation**, v. 29, n. 5, p. 435–442, mar. 2002b.

SANTOS, R. G. H.; CELERI, E. H. R. V. Rastreamento de Problemas de Saúde Mental em Crianças Pré-Escolares no Contexto da Atenção Básica à Saúde. **Revista Paulista de Pediatria**; v. 36, n. 1, p. 82-90, 2008.

SOUZA, R. L. A. e cols. A hospitalização na percepção de crianças e adolescentes em tratamento oncológico. **Revista Gaúcha de Enfermagem**, v. 42, e20200122, 2021.

STUBER, M. L. e cols. Stress responses after pediatric bone marrow transplantation: preliminary results of a prospective longitudinal study. **Journal of the American Academy of Child and Adolescent Psychiatry**, v. 30, n. 6, p. 952-957, nov. 1991.

TASKIRAN, G.; ADANIR, A. S.; ÖZATALAY, E. Living with the unknown: Posttraumatic stress disorder in pediatric bone marrow transplantation survivors and their mothers. **Pediatric Hematology and Oncology**, v. 33, n. 3, p. 209-218, mar. 2016.

VARNI J. W. e cols. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability and validity. **Ambulatory Pediatrics**, v. 3, p. 329-41, 2003.

WALLANDER, J.; VARNI, J. Effects of pediatric chronic physical disorders on child and family adjustment. **Journal of Child Psychology and Psychiatry**, v. 39, p. 29–46, 1998.

WIELEWICKI, A.; GALLO, A. E.; GROSSI, R. Instrumentos na prática clínica: CBCL como facilitador da análise funcional e do planejamento da intervenção. **Temas em Psicologia**, v. 19, n. 2, p. 513 – 523, 2011.