Psychological Adjustment of Children with Cancer: Relapse and Survival Perspectives

Amanda Muglia Wechsler¹ Carmen Bragado-Álvarez² María José Hernández-Lloreda² Luiz Fernando Lopes³ Elisa Maria Perina⁴

¹Pontifícia Universidade Católica de Campinas, São Paulo, Brasil

²Universidad Complutense de Madrid, Madrid, Spain

³Hospital de Câncer Infantojuvenil de Barretos, Barretos, São Paulo, Brasil

⁴Centro Infantil Boldrini, Campinas, São Paulo, Brasil

Abstract

In Brazil, few studies have investigated the psychological aspects of childhood cancer. The aim of this article was to compare the psychological adjustment of children with cancer from different survival perspectives with that of children without cancer, besides examining potential risk factors. The sample consisted of 179 participants (6-14 years-old) recruited in two Brazilian public hospitals and three schools, and divided in three groups (relapsed, survivors and control). Children answered orally the self-reported Behavior Assessment Scale for Children, the Revised Children's Manifest Anxiety Scale and Piers-Harris' Self-Concept Scale. No differences were found between groups regarding school and clinical maladjustment, personal adjustment, emotional symptoms and self-concept. Findings also showed positive associations between psychological maladjustment and gender, younger age, lower household income, single parenthood and lower levels of parental education. Conclusions indicate that children with cancer adapt well to the disease and do not present more psychological problems than controls. *Keywords:* Pediatric cancer; Adaptation; Psychological Maladjustment; Recurrence; Remission

Ajustamento Psicológico de Crianças com Câncer: Perspectivas da Recidiva e da Remissão

Resumo

No Brasil, poucos estudos investigaram os aspectos psicológicos do câncer infantil. O objetivo deste artigo foi comparar o ajustamento psicológico de crianças com câncer com diferentes perspectivas de sobrevivência com o de crianças sem câncer, além de examinar potenciais fatores de risco. A amostra consistiu em 179 participantes (6-14 anos de idade) recrutados em dois hospitais públicos e três escolas brasileiras. As crianças responderam oralmente à Escala de Avaliação Comportamental para Crianças, à Escala de Ansiedade Manifesta para Crianças Revisada e à Escala de Autoconceito Piers-Harris. Não foram constatadas diferenças entre os grupos com relação ao desajustamento clínico e escolar, ajustamento pessoal, sintomas emocionais e autoconceito. Os resultados também mostraram associações positivas entre o desajustamento psicológico e gênero, menor idade, menor renda, famílias monoparentais e menor nível educacional parental. As conclusões indicam que crianças com câncer se adaptam bem à doença e não apresentam mais problemas psicológicos que as do grupo controle. *Palavras-chave:* câncer pediátrico, adaptação, desajustamento psicológico, recorrência, remissão

Ajuste Psicológico De Niños Con Cáncer: Perspectivas De Recaída Y Supervivencia

Resumen

En Brasil, pocos estudios han investigado los aspectos psicológicos del cáncer infantil. El objetivo de este artículo fue comparar el ajuste psicológico de niños con cáncer con diferentes perspectivas de supervivencia con el de niños sin cáncer, además de examinar los posibles factores de riesgo. La muestra consistió en 179 participantes (6-14 años de edad) reclutados en dos hospitales públicos y tres escuelas brasileñas. Los niños contestaron oralmente a la Escala de Evaluación del Comportamiento del Niño, la Escala Revisada de Ansiedad Manifiesta en Niños y la Escala de Autoconcepto de Piers-Harris. No se constataron diferencias entre los grupos con respeto al desajuste clínico y escolar, el ajuste personal, los síntomas emocionales y el autoconcepto. Los resultados también mostraron asociaciones positivas entre el desajuste psicológico y el género, la menor edad, la menor renta, las familias monoparentales y el nivel educativo parental más bajo. Las conclusiones señalan que niños con cáncer se adaptan bien a la enfermedad y no presentan más problemas psicológicos que los del grupo de control. *Palabras clave*: Cáncer pediátrico; Adaptación; Desajuste Psicológico; Recurrencia; Remisión.

Cancer is the second leading cause of death in children and adolescents worldwide. In Brazil, 13,000 children between 0 and 19 years old are diagnosed with cancer each year, and 4,000 died in 2018 (National

Cancer Institute – INCA, 2020). On the other hand, the survival rates in Brazil are between 70% to 90% ten years post-diagnosis due to the implementation of more effective and less invasive therapeutic protocols



and improved support care (Cazé, Bueno, & Santos, 2010; Sousa, Ferreira, Félix, & Lopes, 2015).

Nonetheless, recurrences are relatively common in pediatric oncology and remain the leading cause of death, as long-term survival for children diagnosed with relapsed leukemia is around 40% (Cooper & Brown, 2015; National Cancer Institute – INCA, 2008). Moreover, Latin-American children, low-educated and financially deprived populations present even lower cancer survival rates, higher risk of early relapses and more adjustment problems, leaving them at greater psychosocial risk (Abrahão et al., 2015; Bona, Blonquist, Neuberg, Silverman, & Wolfe., 2016; Kunin-Batson et al., 2016; Ritt-Olson et al., 2018).

Despite the possible psychological risks to children with poor prognosis, research in this field is very limited. Relapse is usually an exclusion criterion (Jurbergs, Long, Ticona, & Phipps, 2009) and most publications have examined European and North-American populations (Arruda-Colli et al., 2015; Kazak et al., 2015). Therefore, little is known about the psychological adjustment of Latin-American children facing cancer and about potential risk groups.

In fact, data on how European and North-American pediatric patients adjust to cancer and its treatment is somewhat puzzling. Some authors have observed significant adjustment problems in children/adolescents who have suffered a cancer relapse (Kosir, Wiedemann, Wild, & Bowes, 2019; Webster & Skeen, 2012), whereas others did not find a clear association between cancer relapse and psychological maladjustment (Compas et al., 2014; Grootenhuis & Last, 2001; Okado, Tillery, Sharp, Long, & Phipps, 2015).

Furthermore, when analyzing children with better prognosis (childhood cancer survivors), the literature also presents mixed results. Some studies point out that the majority of survivors present good adjustment and exhibit considerable resilience (Brinkman et al., 2016; Castellano-Tejedor, Pérez-Campdepadrós, Capdevila, & Blasco-Blasco, 2014; Okado, Rowley, Schepers, Long, & Phipps, 2018; Schulte, Wurz, Reynolds, Strother, & Dewey, 2016), and others indicate that 10% to 40% of these patients belong to risk groups and require specialized psychological services (Kunin-Batson et al., 2016; Lown, Phillips, Schwartz, Rosenberg, & Jones, 2015).

Some demographic variables may help explain these paradoxical results. Some studies point out that younger children would present more distress and anxiety (Turner-Sack, Menna & Setchell, 2012; Vannatta & Salley, 2017). Additionally, single-parent status seem to affect children with cancer, as they tend to present poorer quality of life and more affective problems (Bemis et al., 2015; Quast et al., 2018). Lower house income is associated to anxiety, stress and psychosocial difficulties (Kazak et al., 2015; Kosir et al., 2019) and lower parental educational attainment is related to lower quality of life and more anxiety in children with cancer (Quast et al., 2018).

Medical variables are also important when considering psychological adjustment in pediatric cancer. Research in this field suggest that longer time under treatment would be related to poorer social competence and body image (Fan & Eiser, 2009; Fernández et al., 2009), whereas longer time since diagnosis is associated to less distress (Turner-Sack et al., 2012). Having suffered a cancer relapse or a greater number of relapses has also been reported to impact negatively on the adjustment of children and adolescents (Kosir et al., 2019; Okado et al., 2018).

Thus, considering the contradictory findings in the field and the lack of research with Latin-American populations, evaluating the psychological adjustment of Brazilian children in different oncological treatment stages (relapse and survivorship) is critical for the advancement of practical and theoretical knowledge in this area. Additionally, an evidence-based assessment of the psychosocial aspects of children and adolescents with cancer is an important first step to determine delivery of appropriate interventions targeted specifically to their needs (Kazak et al., 2015).

The aim of the present study was to evaluate the psychological adjustment of children who have suffered a cancer relapse by comparing them with survivors of childhood cancer and "healthy" children. To date, as far as we know, this is the first study that uses this kind of research design. Additionally, we verified contextual influences in the process of adjustment, examining possible associations of some sociodemographic and medical variables with children's psychological adjustment.

Considering previous studies, our research hypotheses were: 1) Children and adolescents in the RG (relapse group) would present worse adjustment than those in SG (survivor group) and CG (control group) (e.g., Kosir et al., 2019); 2) SG and CG would present a similar level of psychological adjustment (e.g., Brinkman et al., 2016; Okado et al., 2018); 3) The number of relapses and the time under treatment in RG would be negatively associated with children's/adolescents' adjustment (e.g., Kosir et al., 2019; Okado et al., 2018);

4) In SG, time since diagnosis would have a positive association with survivors' adjustment (e.g., Turner-Sack et al., 2012), while treatment duration would present a negative association with their psychological adjustment (e.g., Fan & Eiser, 2009); and, 5) Demographic variables (household income, gender, parental education and caregivers' marital status) would be negatively related to children's psychological adjustment, while children's age in the moment of recruitment would be positively associated with their adjustment.

Method

Participants

Forty-eight children who had suffered a cancer relapse/on treatment and eighty-four survivors/off treatment were approached by the main researcher in two Brazilian hospitals. 490 children without a history of cancer received in their schools an invitation letter. Sixteen parents of children with cancer relapse and nine parents of children in remission declined to participate, while 414 families of schoolchildren did not respond. Main reasons provided from those who declined were related to lack of interest or time in participating (64%). Therefore, the final sample consisted of 179 participants (6 to 14 years old), divided into three groups: cancer relapse/on treatment (n=31), cancer survivors/off treatment (n=78) and controls (n=70).

Children in the relapse/on treatment group (RG) met the following criteria: a) experienced a relapse (reappearance of a primary tumor), a second malignancy (at least 12 months after finishing oncological treatment) or a tumor progression (metastasis); b) were in oncological treatment when recruited; c) were not terminally ill and d) were well enough to be interviewed. The participants were contacted, on average, five months after the last diagnosis.

Children in the survivor/ off treatment group (SG) met the following criteria: a) had not received any type of oncological treatment for at least two years and b) had not suffered a relapse. These participants were assessed, on average, five years after tumor remission. In the control group (CG), children had no history of cancer, psychiatric disease, disabling disorder or lifethreatening illness.

Measures

Data collection was conducted in Brazil. Given the small number of Brazilian psychological tests with good psychometric validity and reliability in the time of the study, as well as the bi-national nature of this research (Brazil and Spain), we used the Spanish version of some tests. These instruments were translated to Portuguese following the back-translation method by two independent bilingual translators. Nonetheless, this may not be considered a methodological limitation, since a Brazilian control group was used as a comparison with the clinical groups, and not the Spanish tests' norms.

Sociodemographic and Medical Questionnaire

Sociodemographic data were obtained through an ad-hoc questionnaire to ascertain the following: children's gender and age, parental age, marital status (with/ without partner) and education (elementary, high school/college), and family income (monthly minimum wages). Children's medical data (including those who refused to participate) was obtained from participants' report and checked with medical records, including: diagnosis, time under treatment, time in current situation (number of months in which the child was in a remission or in a relapse situation), and number of relapses.

Spanish adaptation of the Behavior Assessment Scale for Children – BASC

The BASC (Reynolds & Kamphaus, 2004) is a multidimensional instrument designed to measure some adaptive and clinical dimensions. In this study, we used the general scales of level 2 (6-11 years old) and level 3 (12-18 years old) self-report questionnaires, according to participants' age.

The Level 2 (6-11 years old) self-report scale comprises 146 items, and Level 3 (12-18 years old) consists of 185 items. Both levels have a dichotomous response format (true/false) and generate five global scores: Clinical Maladjustment (anxiety, atypicality, locus of control, and somatization- the latter present only in level 3); School Maladjustment (attitude toward school, attitude toward teachers, and sensation-seekingthe last one only in level 3). Higher scores on this two dimensions indicate more maladjustment; Personal Adjustment (interpersonal relationships, parent-child relationship, self-confidence and self-esteem); higher scores show better adjustment; Emotional Symptoms Index (anxiety, interpersonal relationships, self-esteem, social stress, depression and sense of incapacity); higher scores on this index reveal emotional disturbance; and SAD Triad (Stress, Anxiety and Depression); higher scores on this dimension indicate emotional imbalance.

The reliability of the Spanish version ranges from 0.77 to 0.91 for the global dimensions. In this study with Brazilian data, total Cronbach's alpha for level 2 was 0.93, ranging from 0.41 to 0.93 for the global dimensions. For level 3, the total alpha was 0.92 and the global dimension alphas ranged from 0.39 to 0.91.

Brazilian version of the Revised Children's Manifest Anxiety Scale – RCMAS

The Brazilian version of the RCMAS was used as a complementary measure of anxiety symptoms. This instrument evaluates general, non-situational and non-specific anxiety in children between 6 and 19 years old. It comprises 37 dichotomous items (yes/no), that composes a general score of anxiety. In the Brazilian population, scores above 15 are considered clinically significant (Gorayeb & Gorayeb, 2008). The Brazilian version has shown a total alpha of 0.85 and a test-retest reliability of 0.75 over five weeks. In this work, total Cronbach's alpha was 0.85.

Spanish version of the Piers-Harris Children's Self-Concept Scale

This scale (Piers Harris, 1969; Díaz-Aguado & Martínez-Arias, 1995) evaluates the general and specific self-concept of children between 6 and 15 years old. It contains 80 dichotomous items (yes/no), that provide a general score of self-concept. Higher scores indicate better self-concept. The overall internal consistency of the Spanish version is 0.90 and in this study the total alpha was 0.93.

Procedure

The participants of RG and SG were recruited from two Brazilian public hospitals. Each hospital's research ethics committees approved this investigation (under the number 01576312.5.0000.5376 in *Plataforma Brasil*). Participants who met the inclusion criteria and their parents were approached by the main researcher during hospital routine checkups and invited to participate. In an empty hospital room, the researcher presented the study to the patient and his/her caregiver and they both signed an informed consent agreement. Children answered orally to the RCMAS and Piers-Harris scales, separated from their parents. The average time spent on administration was 30 minutes, and eventual questions were answered.

The control group was recruited from three public schools among children who were the same age and socioeconomic level and lived in the same cities as those

in the clinical groups. Children received in their schools an invitation letter addressed to their parents; they were instructed to take it to their caregivers and hand it in signed to the main researcher within the subsequent month. Parents who responded positively to the invitation letter received a sealed envelope, containing an informed consent. In the informed consent sheet the researcher's email address and telephone was provided in order to clarify possible doubts and concerns. Parents returned the envelopes through their children, and the researcher collected them at children's respective schools. The control children answered to the RCMAS and Piers-Harris scales orally to the main researcher in an empty classroom.

Data analysis

Descriptive analyses were calculated for continuous variables, and frequencies were presented for categorical variables. To test the sample's homogeneity and the differences between patients who accepted versus refused participation, ANOVAs or Student's t tests were used for continuous variables and Kruskal-Wallis tests for ordinal ones. For qualitative variables, Pearson's chi-square test was used. If the expected values were smaller than five, Fisher's exact test was applied.

To compare the group results for the BASC scales, each group was divided into two subgroups of children (6-11 years old) and adolescents (12-14), as this measure has different forms according to participant's age and is not standardized to the Brazilian population. Accordingly, scores were not normalized to the test's norms, and only raw scores were used. To compare the results obtained in the BASC with those collected with other measures (RCMAS and Pier-Harris), the same grouping between children and adolescents was applied.

To explore the differences between groups of children, ANOVAs were conducted. To analyze the adolescent groups, Kruskal-Wallis nonparametric tests were performed, due to the small sample size.

In each ANOVA, homogeneity and equality of variances were tested. If the homoscedasticity assumption was not met, Brown-Forsythe correction was applied. If both the normality and homoscedasticity assumptions were not fulfilled, we performed Kruskal-Wallis tests. In multiple comparisons, least significant difference (LSD) post hoc correction was used $(\alpha=0.05)$, and the effect size was calculated (Cohen's d).

To determine the association between medical and sociodemographic variables and children's psychological adjustment, Pearson correlations were conducted for the children's forms (binary transformation of categorical variables). For the adolescents' forms, Spearman correlations (numerical variables) and Mann-Whitney tests (categorical dummy variables) were applied.

Results

Tables 1 and 2 present the descriptive statistics of participants' and caregivers' sociodemographic and medical variables in each of the two subsamples (children and adolescents). Significant differences between groups were detected in children's age (F (2, 133)=4.193; p=0.017); specifically, CG had a higher age than RG (p=0.011; Cohen's d=0.660), and SG had a higher family income than the other groups in the children's subsample (Kruskal-Wallis (2)=21.962; p<0.001). The average family income was 3.53 times the minimum wage, corresponding to approximately € 840 at the time of the study (adjusting for Purchase Power Parity in Brazil and Spain in 2011 using OECD data, 2013).

The medical variables are described in Table 2. There were statistically significant differences between the two cancer groups in diagnosis (Fisher's exact test=18.763; p=0.001), time since diagnosis (t (107)=

-6.327; p<0.001, Cohen's d=1.336), and time under treatment (t (98.076)=-17.023; p <0.001). RG showed a greater incidence of bone tumors, while SG had a greater incidence of other tumors. The time elapsed since diagnosis was greater in SG, and time under treatment was greater in RG. These differences were all expected, considering the groups' characteristics. Eight children/adolescents from RG (26%) had suffered two relapses or more.

Additionally, significant differences between the participants and non-participants were found. Patients who refused to participate had significantly worse conditions: older ages (F(3, 200)=3.452; p=0.018), greater tendency for bone tumors (Fisher's exact test=27.231; p=0.001), lower time since diagnosis (F (2, 131; p<0.001) and in the current situation (Kruskal-Wallis (2)= 71.331; p<0.001), and greater time under treatment (Kruskal-Wallis (1)=22.085; p<0.001).

Regarding the psychological adjustment measures, no significant differences between groups were found in the BASC global scales (clinical maladjustment, school maladjustment, personal adjustment, emotional symptoms index and SAD triad). Moreover, no significant differences were found in either sample

Table 1.

Descriptive data of sociodemographic variables of children/adolescents and caregivers – valid cases

source con of source.		Children	Adolescents				
Variables	Relapse	Survivors	Control	Relapse	Survivors	Control	
	(n=22)	(n=60)	(n=55)	(n=9)	(n=18)	(n=16)	
Gender							
girls	11 (50%)	31 (52%)	30 (55%)	4 (44%)	8 (44%)	10 (63%)	
boys	11 (50%)	29 (48%)	25 (45%)	5 (56%)	10 (56%)	6 (37%)	
Age							
$\overline{\overline{X}}$	9.09	9.53	10.09	13.11	13.17	12,63	
SD	1.51	1.41	1.52	0.78	0.79	0.81	
Careg. marit. status							
with partner	17 (71%)	45 (76%)	32 (58%)	6 (75%)	10 (62%)	13 (68%)	
single	7 (29%)	14 (24%)	23 (42%)	2 (25%)	6 (38%)	6 (32%)	
Family income							
\overline{X}	2.14	5.34	2.27	2.86	4.25	2.19	
SD	1.49	5.59	1.72	2.76	5.93	1.05	
MD	2.00	3.50	2.00	3.00	2.00	2.00	
Careg. education							
elementary	8 (35%)	23 (39%)	25 (45%)	3 (43%)	6 (37%)	11 (61%)	
h. school/college	15 (65%)	36 (61%)	30 (55%)	4 (57%)	10 (63%)	7 (39%)	

Careg. marit. status= caregiver's marital status; Careg. education= caregiver education; H. school/ college= high school or college. Family's income (monthly minimum wages)

Table 2.

Descriptive data of medical variables of children and adolescents with cancer

	Chil	dren	Adolescents			
Variables	Relapse	Survivors	Relapse	Survivors		
	(n=22)	(n=60)	(n=9)	(n=18)		
Diagnosis						
leukemia	10 (45%)	18 (30%)	3 (33%)	4 (22%)		
sarcomas	0 (0%)	4 (7%)	0 (0%)	1 (6%)		
lymphomas	1 (5%)	7 (12%)	0 (0%)	3 (17%)		
brain tumors	4 (18%)	5 (8%)	1 (11%)	2 (11%)		
bone tumors	1 (5%)	1 (1%)	5 (56%)	0 (0%)		
other tumors	6 (27%)	25 (42%)	0 (0%)	8(44%)		
Time since diagnosis						
\overline{X}	3.44	5.98	2.97	7.29		
SD	2.46	1.83	2.09	3.13		
Time under treatment						
\overline{X}	39.59	12.20	31.78	21.67		
SD	31.03	10.85	22.94	20.82		
Number of relapses						
1 relapse	16 (73%)		7 (78%)			
2 relapses	6 (27%)		2 (22%)			

Leukemias = Acute Lymphoid Leukemia and Acute Myeloid Leukemia; Sarcomas = Synovial sarcoma, Rhabdomyosarcoma, Dermatofibrosarcoma; Lymphomas = Hodgkin's lymphoma, non-Hodgkin's lymphoma, Burkitt's lymphoma; Brain tumors = Medulloblastoma, Brain Stem tumor, Astrocytoma, Ependymoma and Craniopharyngioma; Bone tumors = Osteosarcoma, Ewing's sarcoma; Other tumors = Wilms' tumor, Histiocytosis, Teratoma, Endodermal sinus tumor, Giant cells tumor, Retinoblastoma, Neuroblastoma and Adrenal carcinoma. Time measured in months.

(children or adolescents with cancer) in anxiety or self-concept when compared to the control group (RCMAS and Piers-Harris scales), as shown in Tables 3 and 4. Likewise, by comparing the groups' mean in RCMAS general anxiety scores with the cutoff norm (Gorayeb & Gorayeb, 2008), the results showed that all groups had anxiety scores below clinical levels.

Possible correlations between the three measures of anxiety (BASC, RCMAS and Piers-Harris) were also investigated. The results showed a positive correlation between BASC's anxiety subscale and RCMAS (r=0.799; p<0.001) and negative correlation between the RCMAS and Piers-Harris (r=-0.777; p<0.001) and Piers-Harris and BASC (r=-0.713; p<0.001), suggesting they measure the same construct.

Table 5 shows the associations between demographic and medical variables and psychological adjustment in cancer groups. No significant correlations were found in the RG between demographic variables and children's or adolescent's adjustment. Also, no associations were observed between medical variables

and measures of adjustment in both cancer groups (RG and SG) in children's or adolescents' samples.

Regarding demographic data in SG, less educated parents tended to have children with more psychological problems (Emotional Symptoms Index: r=-0.290; p=0.027; SAD Triad: r=-0.281; p=0.033). The boys also tended to show more school maladjustment than girls (r=0.266; p=0.040), and younger children tended to have more psychological problems than older ones (Clinical Maladjustment: r=-0.266; p=0.040; Emotional Symptoms Index: r=-0.316; p=0.014; SAD Triad: r=-0.309; p=0.016; Total anxiety= -0.305; p=0.018). No significant correlations were found in the children's sample of the SG with respect to children's age, caregivers' marital status or family income.

In the adolescent sample (Table 6), a positive correlation was found between anxiety and both gender and family income level, indicating that surviving girls (U=14.500; p=0.043) and those from low-income families (r=-0.590; p=0.013) tended to score higher in anxiety. Adolescents whose parents were single also

Table 3.

Differences between groups in children and adolescents in BASC self-report's general scales [means, (standard deviations) and medians]

Measures X (SD) MD		Children			Adolescents	0 (10)	
	Relapse (n=22)	Survivors (n=60)	Control (n=54)	Relapse (n=9)	Survivors (n=18)	Control (n=16)	- Statistics (d.f.)
Clinical	18.09(10.23)	17.30(9.67)	21.11(9.75)	15.44(3.47)	22.89(11.14)	20.06(9.97)	I)F(2,133)=2.252;p=0.109
maladjustment				16.00	22.00	19.00	II)K-W(2)=2.669;p=0.263
School	7.00(2,18)	7.18(2.24)	7.81(2.31)	12.00(3.35)	12.06(4.70)	10.06(4.79)	I)F(2,133)=1.535;p=0.219
maladjustment				13.00	12.00	9.50	II)K-W(2)=1.901;p=0.386
Personal	24.18(3.06)	24.20(2.95)	24.07(3.20)	25.22(3.19)	27.33(4.47)	27.63(2.58)	I)F(2,133)=0.026;p=0.975
adjustment				27.00	28.00	28.00	II)K-W(2)=3.735;p=0.154
Emotional	27.68(12.56)	24.55(12.99)	28.68(13.10)	31.22(11.37)	35.61(12.22)	33.88(14.11)	I)F(2,132)=2.047;p=0.133
Symptoms				26.00	37.50	30,50	II)K-W(2)=0.826;p=0.662
Index							
	16.73(9.55)	14.38(10.04)	17.92(10.29)	14.78(7.19)	18.28(9.67)	15.81(10.92)	I)F(2,132)=2.412;p=0.091
SAD triad				13.00	19.00	14.00	II)K-W(2)=1.104;p=0.576

I) Comparisons between children's groups (6-11 years old); II) Comparisons between adolescents' groups (12-14 years old). Parenthesis (Degrees of freedom of the effect, Degrees of freedom of error). K-W= Kruskal-Wallis.

Table 4.

Differences between groups in children and adolescents in RCMAS' and Piers-Harris' general scales [means, (standard deviations) and medians]

$\frac{\text{Measures}}{\overline{X}}$ (SD)		Children			Adolescents	0	
X (SD) MD	Relapse (n=22)	Survivors (n=60)	Control (n=54)	Relapse (n=9)	Survivors (n=18)	Control (n=16)	- Statistics (d.f.)
Total anxiety							I)F(2,132)=1.742;p=0.179
(RCMAS)	10.82(7.10)	10.20(6.89)	12.04(6.90)	9.11(7.25)	13.47(6.53)	10.38(7.43)	II)K-W(2)=2.608;p=0.271
				7.00	14.00	10.50	
Gen.							I)F(2,133)=0.101; p=0.904
self-concept	64.45(11.63)	64.43(14.88)	63.37(12.69)	58.89(15.35)	59.29(11.22)	59.94(12.95)	II)K-W(2)=0.323; p=0.851
(Piers-Harris)				55.00	60.00	58.00	

I) Comparisons between children's groups (6-11 years old); II) Comparisons between adolescents' groups (12-14 years old). Parenthesis (Degrees of freedom of the effect, Degrees of freedom of error). K-W= Kruskal-Wallis.

tended to present more school adjustment problems than those from married parents (U=13.000; p=0.020). No significant associations were observed in the adolescent sample of the SG regarding adolescents' age or their parents' education.

Discussion

The aim of this study was to investigate the psychological adjustment of Brazilian children and adolescents in cancer relapse or in survival situations.

Table 5.

Correlations between sociodemographic/ medical variables and children's psychological problems

Number
relapses
-0.098
0.000
-0.084
-0.026
-0.058
-0.033

Statistically significant analysis are in **bold** *p<0.05. Caregiver's mar. status = Caregivers' martial status. Codifications: Gender: 0= girls; 1=boys; Marital status: 0=no partner; 1=with partner; Education: 0=elementary school; 1=high school and college.

Table 6.

Correlations and Mann Whitney's tests between sociodemographic/medical variables and adolescent's psychological problems

Clinical	Groups	Gender	Age	Caregiver's	Caregiver's	Family	Time	Time	Number
				education	mar. status	income	diagnosis	treatment	relapses
Maladjustment	Relapse	7.500	0.341	4.000	8.500	-0.685	-0.034	-0.030	0.052
	Survivors	26.000	0.111	34.000	25.500	-0.358	0.415	0.146	
School Maladjustment	Relapse	8.000	0.456	7.500	7.500	-0.136	0.111	0.244	0.312
	Survivors	28.500	-0.084	34.000	13.000*	-0.260	0.139	0.049	
Emotional Symptoms	Relapse	10.000	0.347	2.000	4.000	-0.184	-0.298	-0.276	0.104
Index	Survivors	27.500	0.112	34.500	21.000	-0.290	0.318	0.032	
SAD Triad	Relapse	10.000	0.169	3.000	3.000	-0.123	-0.179	-0.134	0.207
	Survivors	30.000	0.196	33.000	24.500	-0.327	0.293	0.003	
Total anxiety	Relapse	6.500	0.085	4.000	3.500	-0.303	-0.180	-0.101	0.312
(RCMAS)	Survivors	14.500*	0.259	25.500	34.000	-0.590*	0.328	0.054	
General Self-concept	Relapse	9.000	-0.356	3.000	7.000	0.552	0.289	0.176	-0.104
(Piers-Harris)	Survivors	18.000	-0.433	29.000	34.500	0.237	-0.365	-0.126	

Statistically significant analysis are in **bold** *p<0.05. Caregiver's mar. status= Caregiver's marital status. Gender and caregiver's education and marital status analyzed with Mann Whitney's U test. Codifications: Gender: 0= girls; 1=boys; Marital status: 0=no partner; 1=with partner; Education: 0=elementary school; 1=high school and college.

Contrary to our first hypothesis that children/adolescents who had suffered a relapse would present worse psychological adjustment than survivors and controls,

data indicated that these patients did not show more psychological problems than their peers. They presented similar emotional symptoms and comparable school and clinical maladjustment as participants in the control group, suggesting that these children adapt psychologically well to the situation. This result, although somewhat counterintuitive, is consistent with those reported in previous research (Compas et al., 2014; Grootenhuis & Last, 2001; Okado et al., 2015).

Moreover, our data also showed that children who had suffered a cancer relapse presented levels of personal adjustment comparable to those of controls, suggesting that they possess adaptive skills to cope with the disease and its treatment and overcome adversity, as asserted by Grootenhuis and Last (2001) and Okado et al. (2015).

These results confront the idea that a more aggressive treatment and lower survival perception would generate significant psychopathological disorders in pediatric patients, as we supposed in our first hypothesis. Several reasons have been stated to explain such findings. Some studies (Phipps, 2007; Arruda-Colli, Perina, & Santos, 2015) argue that patients' first experience with cancer treatment could serve a learning purpose, facilitating the acquisition of new coping strategies for the relapse situation. When tumors reappear, patients' habituation to the hospital setting may help reduce uncertainty (Kohlsdorf & Costa Jr, 2012; Stewart, Mishel, Lynn, & Terhorst, 2010) increasing adaptive skills and decreasing emotional symptoms. Furthermore, other researchers suggest that social support received in the hospital facilities and the observation of other patients' coping strategies could help relapsed children develop new behaviors, expanding their adaptive repertoire (Castellano-Tejador et al., 2014; Salgueiro, Ramos, Falk, Raymundo, & Schenkel, 2007).

It is also possible that the absence of differences between the relapse group and the control group can be attributed to the sociodemographic characteristics of the samples. When considering the broader contextual system in which the participants are inserted, we can highlight healthcare, community and cultural factors to help comprehend our findings. Therefore, given the unfavorable social-economic condition of this study's sample (families monthly income around €840), it is possible that Brazilian hospitals may function as facilitators of patients' adaptation, since they provide stimuli that children in the control group could not access (e.g. toys, social events, financial support, accommodation for families) (Salgueiro et al., 2007). In this sense, we hypothesize that the stressors experienced daily by the control group (such as poverty, violence and bullying)

may be more "traumatic" and cause more emotional distress than the oncological treatment itself (Jurbergs et al., 2009).

Furthermore, cancer patients tend to be overprotected by their parents, as they perceive their child more vulnerable due his/her medical condition (Kohlsdorf & Costa Jr, 2012; Schepers, Okado, Russell, Long, & Phipps, 2018), which could mean that they may not have to face the same stressors as "healthy" children do. Consequently, medical procedures may be as aversive as other stressors in "healthy" children's routine.

As for survivors, results showed that they present a similar adjustment than children who never had cancer, confirming our second hypothesis and the findings of prior research (Maurice-Stam et al., 2009; Okado et al., 2018; Schulte et al., 2016). These results suggest that survivors do not present more psychological problems than children without a cancer history, and that they adapt specially well after the end of the treatment. Hence, the presence of emotional alterations or social dysfunctions seems more "exception than the rule", as pointed out by Noll and Kupst (2007).

The role of some demographic and medical variables was also investigated, and significant associations were found in the survivor group only. For children's gender, surviving boys (in the children's group) tended to exhibit more school maladjustment than girls, confirming findings from other countries (Robinson, Gerhardt, Vannatta, & Noll, 2009; Schepers et al., 2018).

Regarding adolescents, the results showed the opposite trend: surviving girls tended to present more anxiety than boys, endorsing findings from Kosir et al. (2019) and Maurice-Stam et al. (2009). Girls may have more anxiety than boys when simultaneously managing the physical and social consequences of cancer treatment (such as changes in the appearance, distancing from school and friends, constant hospitalizations and physical discomfort) as well as typical adolescence challenges (Von Essen, Enskär, Kreuger, Larsson, & Sjödén, 2000).

In line with Turner-Sack et al. (2012) and with Vannatta and Salley (2017), we also found negative associations between survivor's age (children's group) and a greater amount of stress, anxiety, depression, clinical maladjustment and emotional symptoms. It is possible that younger children are psychologically vulnerable because they may not have the cognitive ability to understand all the implications of their disease and the follow-up recommendations (Caires, Machado, Antunes, & Melo, 2018; Schepers et al., 2018).

Adolescent survivors from economically disadvantaged families tended to present more anxiety, in line with the findings of Kazak et al. (2015) and Kosir et al. (2019). The unfavorable socioeconomic context, which is related to more stressful events (Platt, Williams, & Ginsburg, 2015) and does not provide sufficient conditions and opportunities for emotional development or recreational and cultural activities (Hulteen et al., 2017; Pereira, 2016), combined with the effects and restrictions post-cancer treatment can be responsible for such feelings.

A significant relationship was found between lower parental education and more stress, anxiety, depression and emotional symptoms in surviving children, supporting earlier research (Quast, Phillips, Kazak, Barakat, & Hocking, 2018). Parents with less formal education may have trouble understanding the diagnosis and oncological treatment, resulting in non-adherence to medical procedures (Gage, 2010). In addition, less educated parents tend to have worse relationships with their children and to use more denial and negative coping strategies (Belsky, Bell, Bradley, Stallard, & Stewart-Brown, 2007). These trends could lead to a greater sense of uncontrollability and unpredictability and, consequently, more symptoms of anxiety and depression (Stewart et al., 2010).

The children of non-partnered parents also tended to have more school maladjustment, corroborating the results of Kazak et al. (2015) and Quast et al. (2018). This trend may occur because single parenthood can be overwhelming, as these parents have to take care of all medical and educational tasks in addition to managing the financial constraints implied in this condition, which may affect children (Bemis et al., 2015; Melo & Marin, 2016). It is also possible that these associations were not found in the relapse group due to the social support received in the hospital (potentially reducing the burden of single parenthood).

No significant relations between medical variables and psychological adjustment in children/adolescents were found (contrary to hypotheses 3 and 4). Similar results were reported by Okado et al. (2015) and Wechsler, Sartorelli, Pereira and Paro (2017), who showed that there was no significant relationship between patients' psychological adjustment and objective medical variables. Zebrack et al. (2012) suggested investigating certain subjective medical variables, such as sense of threat to life or perception of treatment intensity. Nevertheless, this was not possible in this study, as we did not have reliable standardized instruments to measure these constructs.

Some limitations of this research include the small sample size in the relapse group and the data gathered from a convenience clinical sample, limiting generalizability. Additionally, it is possible that patients who refused to participate could have had worse medical characteristics than those who accepted, given that they showed a greater tendency for bone tumors (which is related to worse prognosis), lower time since diagnosis and in the current situation and greater time under treatment, implying that there may have been a "self-selection effect", which may have generated biased results.

Avenues for future research include replicating this study's assessment in other contexts and cultures, such as in private hospitals, higher income families, as well as in other Latin-American countries, particularly, since there is a lack of research in this region. Additionally, future studies focusing on the adaptation and validation of foreign pediatric psychological instruments to the Brazilian context could also contribute to more precise measurement of this population and stimulate research in this field. In this sense, evaluation protocols and/or instruments specifically designed to evaluate pediatric oncology patients' adjustment are essential to access their needs and provide adequate psychosocial intervention, as suggested by Kazak et al. (2010).

Despite the limitations mentioned above, this research contributes to the comprehension of understudied groups in Latin-American context, highlighting the capacity of children with cancer in different stages of treatment to adapt and even thrive the demands of this disease (Phipps et al., 2014). Findings demonstrated that relapsed children/adolescents are capable of coping with new therapeutic demands showing good psychological functioning. Similarly, survivors also presented adequate psychological adjustment, comparable to children who never had cancer. This does not mean that these patients do not suffer or present some psychopathological symptoms, but that they can adjust well to treatment challenges (Bragado, 2009). On the other hand, this research contributes to identify groups who may be at psychological risk.

Overall, results reinforce the idea held by several authors (Groothenhuis & Last, 2001; Kazak et al., 2010; Zebrack et al., 2012) that the psychopathological focus of research in this field should be changed towards an adaptive approach. In this direction and under the umbrella of Positive Psychology, it is necessary to deepen investigation to the strategies used by children to cope with the disease and its consequences,

their strengths and the factors which help them manage emotional distress (Gunst, Kaatsch, & Goldbeck, 2016; Noll & Kupst, 2007).

Implications for clinical practice include humanization strategies care in Brazilian hospitals and interventions specifically targeted to risk groups (male children and female adolescent survivors, with younger ages, from monoparental or economically unprivileged families, and/or whose parents had lower education levels). Nonetheless, Brazilian patients usually present several of these conditions, maximizing potential psychological problems. Therefore, it is important to track, monitor and offer psychological care to families who might be at risk. Possible interventions encompass psychological preparation to invasive procedures, playful strategies, insertion of a playroom in the hospital facilities, support groups for adolescents and their families and problem-solving skills training (Koumarianou et al., 2020; Salgueiro et al., 2007).

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About the authors:

Amanda Muglia Wechsler – Professor of the Pontifical Catholic University of Campinas. PhD in Clinical/Health Psychology (Complutense University of Madrid) and Master in Psychology as Science and Profession (Puc-Campinas). Specialist in Therapy with contingencies of reinforcement (ITCR). Author of 16 articles and 2 book chapters. Reviewer of the Revista Sul Americana de Psicologia, the Estudos Interdisciplinares em Psicologia and Pediatric Blood & Cancer.

ORCID: https://orcid.org/0000-0001-5916-1667

E-mail: amanda_wechsler@yahoo.com.br

Carmen Bragado-Álvarez – Emerit Professor of Clinical Psychology of Infants in Complutense University of Madrid. PhD in Psychology. Specialist in Clinical Psychology. Specialist in psychological problems in infants. Author of numerous publications (articles, books and book chapters). Member of the editorial comittee of several journals: Revista de Psicología Clínica con Niños y Adolescentes, Clínica y salud, Psicooncología and Papeles del Psicólogo.

ORCID: https://orcid.org/0000-0002-8971-2025

E-mail:cbragado@psi.ucm.es

María José Hernández-Lloreda – Professor of Methodology in Behavioral Sciences of the Complutense University of Madrid. PhD in Psychology (Complutense University of Madrid). Specialist in data analysis in social sciences, co-orientation of 6 theses, participation in 13 research projects, and publication of 25 scientific articles. Member of the editorial committee of the Spanish Journal of Psychology

ORCID: https://orcid.org/0000-0001-5227-7587

E-mail: mjhernandez@psi.ucm.es

Luiz Fernando Lopes – Master and PhD in Medical Sciences (Unicamp), Emerithus Professor (USP). Medical director of the Hospital of Youth Cancer of Barretos. Scientific consultant at FAPESP. Coordinator of the Brazilian Cooperative Group of Myelodysplasia in Childhood and of the Brazilian Cooperative Group of Germ Cell Tumors in Pediatrics. Member of the executive committee of the Malignant Germ Cell International Consortium.

ORCID: https://orcid.org/0000-0001-7289-6430

E-mail: lf.lopes@yahoo.com

Elisa Maria Perina – Retired psychologist from Unicamp and Boldrini Children's Center. Coordinator of Phoenix-Center for Studies and Counseling in Health Psychology and Tanatology. Master in Clinical Psychology (USP). PhD in Child and Adolescent Health (Unicamp). Coordinator of the Pediatric Psycho-oncology Committee of the Brazilian Society of Psycho-Oncology and the Psychosocial Committee of the Latin American Society of Pediatric Oncology. ORCID: https://orcid.org/0000-0001-8453-7953

E-mail: elisaperina@gmail.com

Contact:

Amanda Muglia Wechsler Pontificia Universidade Católica de Campinas Av. John Boyd Dunlop s/n Campinas-SP, Brasil Telefone: (19) 3343-8600

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