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Psychological Adjustment of Parents of Children with Different Cancer Prognoses

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Abstract: Little is known about the psychological adjustment of parents of children with cancer relapse or remission. This study investigated differences in the psychological adjustment of caregivers of children with different cancer prognosis, by comparing them with a control group. In total, 183 caregivers participated in this study: those with children in relapse/on treatment (*n* = 32), remission/off treatment (*n* = 75), and "healthy" (*n* = 76). The Beck Depression and Anxiety Inventories, the Symptom Check list-90-R, the Norbeck Social Support Questionnaire-Reviewed and the Family Environment Scale were analyzed with Variance Analysis, Student's t-test, Chi-square and Pearson correlations. The results showed that parents of children with cancer relapse presented less psychological adjustment. Furthermore, a protective effect of family cohesion and possible risk factors related to sociodemographic variables were observed. Conclusions highlight the convenience of developing specific interventions for parents of children with cancer relapse.

Keywords: emotional adjustment, cancer in children, recurrence

Ajustamento Psicológico de Pais de Crianças com Diferentes Prognósticos de Câncer

Resumo: Pouco se sabe sobre o ajustamento psicológico de pais de crianças em recidiva de câncer e em remissão. Este estudo investigou diferenças no ajustamento psicológico de cuidadores de crianças com diferentes prognósticos de câncer, comparando-os com um grupo controle. Os participantes foram 183 cuidadores de crianças em recidiva/tratamento (*n* = 32), remissão/fora de tratamento (*n* = 75) e "saudáveis" (*n* = 76). Os Inventários Beck de Depressão e Ansiedade, a Escala de Avaliação de Sintomas 90-R, o Questionário Norbeck de apoio social-revisado e a Family Environment Scale foram analisados com análises de variância, *t de Student*, Qui-quadrado e correlações de Pearson. Os resultados mostraram que os pais de crianças em recidiva apresentaram menos ajustamento psicológico. Além disto, observou-se um efeito protetor da coesão familiar e possíveis fatores de risco relacionados a variáveis sociodemográficas. Discute-se a conveniência de desenvolver intervenções psicológicas para pais de crianças em recidiva de câncer.

Palavras-chave: ajustamento emocional, câncer em crianças, recidiva

Ajuste Psicológico de Padres de Niños con Distintos Pronósticos de Cáncer

Resumen: Poco se conoce sobre el ajuste psicológico de padres de niños en recidiva de cáncer y en remisión. Este estudio investigó las diferencias en el ajuste psicológico de cuidadores de niños con distintos pronósticos de cáncer, comparándolos con un grupo control. Participaron 183 cuidadores de niños en recidiva/en tratamiento (*n* = 32), remisión/sin tratamiento (*n* = 75) y "sanos" (*n* = 76). Se analizaron los Inventarios de Depresión y Ansiedad de Beck, la Escala de Síntomas 90-R, el Cuestionario Norbeck de Apoyo Social Revisado y la Family Environment Scale mediante análisis de varianza, prueba *t de Student*, test de chi-cuadrado y correlaciones de Pearson. Los resultados mostraron que los padres de niños en recidiva presentaban menos ajuste psicológico. Además, se observó un efecto protector de la cohesión familiar y posibles factores de riesgo relacionados a variables sociodemográficas. Se discute la conveniencia de desarrollar intervenciones psicológicas para padres de niños en recidiva de cáncer.

Palabras clave: adaptación emocional, cáncer en niños, recurrencia

In Brazil, approximately 8,500 children and adolescents aged 1 to 19 years old are diagnosed with cancer annually, which makes this the leading cause of death from disease in this age group (Ministério da Saúde, 2019). Due to the stigma, treatment and mortality rate, having a child diagnosed with cancer is one of the greatest stressors that a mother or father can experience (Jurbergs, Long, Ticona, & Phipps, 2009; Schardong, Cardoso, & Mazoni, 2017).

Nevertheless, many families are forced to face an even more anxiety-provoking circumstance: cancer recurrence. Recidivism, or relapse, is understood as one or more recurrences of the tumor after it was cured or the appearance

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of a second neoplasm, within any lapse of time. Although there are no current Brazilian statistics on the recurrence rate of childhood cancer, this situation is not uncommon and affects around 20% of North American and European children treated for leukemia, resulting in an unfavorable prognosis with survival rates of around 40% (Cooper & Brown, 2015).

Since a child's physical health status is intrinsically related to parental psychological adjustment (Schepers, Okado, Russell, Long, & Phipps, 2019), cancer relapse can create feelings of stress, anger, anxiety, depression, and hopelessness in parents (Khanjari, Damghanifar, & Haqqani, 2018; Klassen et al., 2011). Such experiences are mixed with the feeling that all the effort made in the first treatment was useless, in addition to the fear about the child's future, which causes feelings associated with loss and death (Arruda-Colli & Santos, 2015).

The few studies that focused on studying parents of children in cancer recurrence emphasize significant adjustment disorders in this population, such as high levels of stress, post-traumatic stress, depression, anxiety (Arruda-Colli & Santos, 2015; Sultan, Leclair, Rondeau, Burns, & Abate, 2016), and low quality of life (Khanjari et al., 2018). In this context, uncertainty about the child's prognosis and the inability to control the contingencies involved in the treatment seem to be essential for parental psychological adjustment (Van Schoors et al., 2019; Vander Haegen & Etienne, 2018). Moreover, the first experience of parents with a child's cancer can make them more vulnerable to suffering psychological problems in a second experience, as is the case of cancer recurrence (Jurbergs et al., 2009).

Yet, national and international studies proposing to study caregivers of children with unfavorable prognoses are still rare. Cancer recurrence is hardly mentioned in psychological studies and it is usually used as an exclusion criterion (Arruda-Colli & Santos, 2015; Jurbergs et al., 2009). A possible reason for this gap in the literature may be the delicate health condition of patients, affecting parents' acceptance to participate in research and making difficult to recruit them (Gerhardt et al., 2007). Furthermore, few studies use comparison groups composed of parents of "healthy" children, which makes comparisons and generalizations difficult.

On the other hand, patients are considered to be "cured" when they present complete remission of cancer after five years of the first diagnosis without relapse, that is, without evidence of tumor cells in their organism during this period (Ministry of Health, 2018). Thus, children in cancer remission derived from a first and only treatment (called "survivors") have a better prognosis than those who are in relapse, with cure rates of up to 80% (Ministério da Saúde, 2019).

In contrast to the low number of publications on the situation of childhood cancer relapse, there are many studies on the psychological adjustment of parents of children surviving cancer (in remission). In this sense, some studies indicate that these parents present similar adjustment as the general population, although a small subgroup presents clinical levels of psychopathology (Bakker, Maertens, Van Son, & Van Loey, 2013; Ljungman et al., 2014; Vander Haegen & Etienne, 2018).

Thus, there is a pressing need to investigate risk factors associated with psychological issues of parents and caregivers of children with cancer in order to offer appropriate interventions to this population's needs (Kazak et al., 2015). Some studies show that certain sociodemographic characteristics, particularly those related to psychosocial disadvantages, could function as risk factors for the psychological adjustment of parents/caregivers. In this sense, lower family income and lower education would be related to a higher amount of psychological problems in parents/caregivers of children undergoing treatment for cancer or in remission of the disease (Kazak et al., 2015; Khanjari et al., 2018; Roser, Erdmann, Michel, Winther, & Mader, 2019). Younger age of parents and children would be related to more parental stress (Rosenberg et al., 2013; Sulkers et al., 2015) and no-partner marital status would also be related to more feelings of depression and stress (Wiener et al., 2016).

Certain medical variables may also play a risk role in the adjustment of caregivers. For example, longer duration of cancer treatment, more aggressive treatments, and active treatment status (*versus* off treatment) would be associated with more symptoms of post-traumatic stress, depression, anxiety and stress, and lower quality of life in parents and / or caregivers (Salvador, Crespo, Martins, Santos, & Canavarro, 2015; Sultan al., 2016). In turn, a shorter time period since the last treatment and a larger number of relapses would also be related to greater parental stress (Sultan et al., 2016; Wechsler &Bragado-Álvarez, 2017).

As protective factors, social support received by parents and family cohesion seem to be very relevant in the context of pediatric cancer. Thus, greater family cohesion (Bakker et al., 2013; Van Schoors et al., 2019) and wider, better quality of social support received by the parents (Kazak et al., 2015; Salvador, Crespo, & Barros, 2019; Schardong et al., 2017) would be related to better parental adjustment and fewer psychopathological symptoms.

Therefore, it is possible that the prognosis of the child would be related to the psychological adjustment of his/ her parents and to the existing protective factors, although this has not been sufficiently investigated. Furthermore, the aggressiveness of cancer relapse treatment, compared to other cancer treatments, can contribute to a continuous state of stress, which can predict behavioral problems in patients and their families (Rosenberg et al., 2013). In this sense, caregivers who are facing the relapse of a cancer may be part of psychological vulnerability groups, which would require specialized psychological attention.

Thus, this study investigated differences in the psychological adjustment of caregivers of children with different cancer prognoses, comparing them with a control group. Moreover, possible relationships were analyzed between some protective factors (social support and family functioning) and risk factors (sociodemographic and medical variables) with indicators of parental psychological adjustment.

The hypotheses of this study were: (a) parents of children with cancer relapse would have more psychological problems than parents of children in remission from cancer, and/or than parents of "healthy" children; and (b) greater family cohesion and greater social support would be negatively related to psychopathologies presented by the parents; and (c) demographic variables (younger parents, single parents, or parents with low education or income) would be positively associated with more psychological adjustment problems; (d) medical variables (longer treatment, larger number of relapses, and longer time in relapse) would be positively associated with more parental psychopathologies.

Method

Participants

Forty-eight families of children who suffered at least one relapse of cancer (and who were currently undergoing cancer treatment) and 84 families of children in remission from cancer (who were already off treatment) were invited to participate in this study. These children were receiving treatment at two public reference hospitals for pediatric oncology located in the countryside of the State of São Paulo. The families were approached by the main researcher after analyzing their medical records and checking possible inclusion characteristics. Another 490 families of children without a history of cancer (considered "healthy") were also invited to participate. These individuals attended three public schools in the same cities where the hospitals were located.

Among the approached individuals, 16 parents of children in cancer relapse and nine parents of children in remission from cancer refused to participate in this study, while 414 families of schoolchildren did not reply to the invitation. The main reasons given by those who decided not to participate were lack of interest or time (64%).

Therefore, the final sample of this study consisted of 183 parents/caregivers of children (aged 6 to 14) divided into three groups: 32 parents of children in cancer relapse/in treatment (RG), 75 parents of children in cancer remission/off treatment (RMG) and 76 parents of "healthy" children/non-clinical group (NCG). The inclusion criteria for RG participants were: (a) being the primary caregiver of the child experiencing a relapse (recurrence of the primary tumor), or a second neoplasm (at least 12 months after the end of treatment for the first tumor) or tumor progression (metastasis); (B) the child should be undergoing cancer treatment when recruited; (c) the child was not a terminal patient; (d) the child should be aged between 6 and 14 years (due to the age limit applied to children elsewhere in this research). Caregivers in this group were contacted, on average, five months after the last diagnosis.

Participants in the RMG should meet the following criteria: (a) being the primary caregiver of a child who had not received any type of cancer treatment for at least two years; (B) the child has not suffered any relapse of cancer; (c) the child should be aged between 6 and 14 years. These participants were assessed, on average, five years after the remission of the tumor. The NCG group participants were the main caregivers of children aged 6 to 14 without a history of diseases (history of cancer, psychiatric diseases, disabling diseases, or life-threatening diseases) and who lived in the same cities as the hospitals where the groups of parents of children with cancer were recruited.

Most caregivers were mothers (88%). Other caregivers were fathers (4%), uncles and aunts, grandparents, and stepparents (8%). The mean age of RG children was 10.26 (*SD* = 2.28) and 25% had suffered more than one relapse of cancer. The mean ages of children in the RMG and NCG groups was 10.37 and 10.67 (*SD* = 2.07 and 1.75, respectively). Other sociodemographic characteristics of the participants and their children are described in Table 1.

Table 1
Sociodemographic and medical characteristics of the sample (n = 183)

Characteristic	Recurrence (*n* = 32)		Remission (*n* = 75)		Non-clinical (*n* = 76)	
	n	%	*n*	%	*n*	%
Gender						
female	29	91	62	83	67	88
male	3	9	13	17	9	12
Marital Status						
with partner	23	72	55	74	46	61
no partner	9	28	20	26	30	39
Education						
primary	11	37	29	39	37	50
High school/college	19	63	46	61	37	50
Religion						
religious	27	85	70	93	69	91
no religion / not reported	5	15	5	7	7	9
Diagnosis of children						
leukemias	14	44	22	30	----	
brain tumors	5	15	7	9	----	
bone tumors	6	19	1	1	----	
other tumors	7	22	45	60	----	
	M	*DP*	*M*	*DP*	*M*	*DP*
Age	36.11	7.45	38.31	8.99	35.43	9.26
Family income	2.31	1.81	5.05	5.64	2.25	1.58
Treatment time children (months)	37.32	28.76	14.38	14.22	----	
Time current sit. children (months)	5.58	7.14	62.97	27.53	----	

Note. Family income = monthly minimum salaries; Treatment time children = how long children were in cancer treatment; Time current sit Children = how long children have been in relapse or remission status.

Instruments

Sociodemographic and medical questionnaire. The sociodemographic data were obtained through an *ad-hoc* questionnaire applied in an interview with parents/guardians. The questionnaire collected the following information: gender, child's age and caregiver's age, marital status (partner/no partner), monthly family income (number of minimum wages), education (elementary, high school/higher education), and religious practice (yes/no). The medical data of the children were collected with the participants' reports and subsequently supplemented with data from medical records, including: diagnosis, treatment length, length of current status (number of months the child was in remission or relapse), and number of relapses the child has suffered.

Beck Depression Inventory (BDI-II) (Cunha, 2001). The BDI indicates the presence and intensity of depressive symptoms measured in 21 items with a 4-point *Likert* scale, generating a total score between 0 and 63. Higher scores indicate greater severity of symptoms and scores above 12 are considered indicative of depression. The estimated application time is, on average, five minutes. The convergent validity of the instrument was measured by correlating it with the Beck Hopelessness Scale (BHS), showing correlation of 0.60 and by factor analysis, resulting in two factors: cognitive and somatic/affective. Cronbach's alpha internal consistency ranges from 0.79 to 0.91 (Cunha, 2001).

Beck Anxiety Inventory (BAI) (Cunha, 2001). This instrument contains a list of 21 items that evaluates physical, cognitive, and affective aspects of anxiety, measured on a 4-point *Likert* scale, resulting in a total score between 0 and 63. A score of 20 or more points indicates pathological anxiety. As the BDI, average application time for the BAI lasts five minutes. Factor analysis of the Brazilian version identified four factors: neurophysiological, subjective, panic, and autonomic anxiety. Internal consistency is 0.90, according to the guideline.

Symptom Assessment Scale (90-R - SCL-90-R) (Laloni, 2001). This scale contains 90 items distributed into nine dimensions (somatization, obsessiveness-compulsivity, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism). The SCL allows calculating three global indices: the Global Severity Index (GSI), a general indicator of the level of severity of psychological discomfort; the Total Positive Symptoms Index (PSI), which reports the total number of symptoms experienced by the individual (i.e. the extent and diversity of psychopathology); and the Positive Symptoms Distress Index (PSDI), which reports the average intensity of the symptoms answered affirmatively. Participants should specify the degree of psychological discomfort caused by each symptom in the previous week using a 4-point *Likert* scale. The average application time is 20 minutes. The validity of the Brazilian version by factor analysis maintained 40 items and indicated four factors: psychoticism, obsessiveness-compulsivity, somatization, and anxiety. Test-retest accuracy was 0.88 and the total internal consistency of the Brazilian scale was 0.73.

Revised Norbeck Social Support Questionnaire (NSSQ) (Andriola, Troccóli, & Dias, 1990). This questionnaire aims to assess four areas: emotional support, aid, network size, and total support. It contains eight questions in which the respondent assesses their degree of satisfaction with their relationships with other individuals by a 5-point *Likert* scale. Application time is approximately 10 minutes. The Brazilian adaptation of the scale presents Cronbach's alpha accuracy in the total scale of 0.97 and from 0.94 to 0.98 in the subscales.

Family Environment Scale (FES) (Vianna, Silva, & Souza-Formigoni, 2007). This scale assesses different areas of family (family cohesion, conflict, independence, assertiveness, cultural interests, leisure, religion, organization, and control). In this study, only the family cohesion subscale was used. It measures the connection and support between family members, as those are usually considered protective factors for the psychological adjustment of parents of children with cancer (Bakker et al., 2013; Van Schoors et al., 2019). This subscale contains 10 items arranged in a true/false format. Completion of the subscale takes around five minutes. The Brazilian adaptation of the scale shows Cronbach's alpha internal consistency of 0.87. Validity was measured by factor analysis.

Procedure

Data collection. Caregivers of children with cancer (RG and RMG) who agreed to participate in the study were invited to individually enter an empty room in the hospital, where the researcher presented the study and the participant signed the informed consent form. Then, the participant answered the instruments in a single day. Only one caregiver per eligible child participated in this study (parent or primary caregiver).

The non-clinical (control) group was recruited by invitation letter addressed to parents and handed to children in their schools. Parents/caregivers who accepted the invitation were called to the school at a scheduled time to sign the informed consent form and to respond to the instruments individually, in an empty room in the school.

The researcher answered whatever questions the participating groups may have asked. The average time spent administering the instruments was 30 to 50 minutes per individual. Data collection of all groups took approximately one year and three months and was carried out simultaneously in the three participating groups solely by the main researcher.

Data analysis. The differences between the groups were analyzed with ANOVA, Student's *t*-test, or Kruskal-Wallis test. For categorical variables, chi-square tests, Pearson correlations or Fisher's exact tests were applied. For each ANOVA, normality and equality of variances were tested by applying, if necessary, Brown-Forsyth correction or Kruskal-Wallis tests. In multiple comparisons, the post-hoc LSD correction was used and the effect size was calculated.

To determine the association between family cohesion and social support with parental psychopathology, as well as the relationships between medical and sociodemographic variables with the psychological adjustment of caregivers, Pearson correlations were used (with binary transformation for the categorical variables).

Ethical Considerations

This research was approved by the Research Ethics Committees of the Hospital de Amor (Hospital de Câncer Infanto-Juvenil De Barretos) and Centro Infantil de Investigações Hematológicas Dr. Domingos A. Boldrini (CAAE nº 01576312.5.00.5376).

Results

No statistically significant differences were found between the groups in the Beck scales of depression and anxiety. On the other hand, analysis of the results of the SCL-90 questionnaire indicated significant differences in the PSDI (Positive Symptom Distress Index). The relapse group had more intense symptoms than the RMG and NCG, and the effect size suggests that the RG might be at psychological risk. Significant differences between the groups were also detected in the depression and obsessive-compulsive disorder subscales. The RG had more depression than the RMG and more obsession-compulsion than the RMG and NCG groups (see Table 2).

Table 2

Means, Standard Deviations and Anovas on the Beck scales and the SCL-90-R Questionnaire

Characteristic	Recurrence		Remission		Non-clinical		*F*	*p*	Cohen's *d*	η^2
	M	*DP*	*M*	*DP*	*M*	*DP*				
BAI	16.61	11.03	14.08	13.82	13.28	14.24	0.31			0.00
BDI	14.54	10.28	10.47	10.44	13.27	10.72	0.75			0.01
Somatization (SCL)	11.10	9.00	11.61	10.65	11.79	10.08	0.05			0.00
Obs.- comp. (SCL)	14.61	9.16	10.85	8.43	10.16	6.94	3,11*	0.03 [a] 0.02 [b]	0.50 [a] 0.43 [b]	0.03
Interp. sens. (SCL)	11.61	8.30	8.69	7.95	9.38	7.98	0.83			0.01
Depression (SCL)	19.19	12.17	12.13	10.70	14.07	11.54	4,18*	0.00 [a]	0.62 [a]	0.05
Anxiety (SCL)	12.39	9.17	9.18	8.02	9.37	8.27	0.73			0.01
Hostility (SCL)	4.68	4.85	4.50	4.31	5.38	5.29	0.65			0.01
Phobic Anx. (SCL)	5.48	5.69	3.96	4.75	4.63	5.18	1.01			0.01
Paran. Idea. (SCL)	7.26	5.66	4.90	4.11	5.61	4.82	2.71			0.03
Psychoticism (SCL)	7.42	6.86	6.07	6.58	7.26	7.62	0.66			0.01
GSI (SCL)	1.13	0.73	0.87	0.70	0.92	0.70	1.50			0.02
PST (SCL)	45.32	21.51	36.51	21.40	38.07	26.05	1.62			0.02
PSDI (SCL)	2.21	0.74	1.85	0.80	1.78	0.73	3,65*	0.03 [a] 0.01 [b]	0.47 [a] 0.59 [b]	0.04

Note. Obs.- comp. = Obsession compulsion; Interp Sens. = interpersonal sensitivity; Phobic anx. = phobic anxiety; Paran. Idea. = paranoid ideation; GSI = Global Severity Index; PST= Total positive Symptom Index; PSDI = Positive Symptom Disorder Index; [a]Significant differences between RG and RMG; [b]Significant differences between RG and NCG; *$p < 0.05$.

Regarding the other investigated variables, negative and statistically significant correlations were detected between family cohesion and parental psychopathology in all participating groups. This suggests that parents whose families had greater cohesion tended to present fewer psychological problems (Table 3). In the relapse group, family cohesion was negatively related to GSI and PSDI, and in the RMG, cohesion was associated with all measures, except for PST. Social support was negatively associated only with depression in the RMG. No significant association was found between medical variables and parental adjustment.

Table 4 shows associations between demographic variables and parental adjustment scores. In the RG group, parents of younger children tended to present more anxiety and more intense and severe psychological problems. In the RMG group, older caregivers and those without a partner, with lower education and/or income tended to present more anxiety, depression, and more severe and intense symptoms. The same pattern was observed in the NCG among non-religious participants.

Table 3

Correlations between Psychological Adjustment, Family Cohesion, Social Support and Medical Variables

Characteristic	Group	1	2	3	4	5	6	7	8	9
1.BAI	RG	---								
	RMG	---								
	NCG	---								
2.BDI	RG	.52**	---							
	RMG	.70**	---							
	NCG	.42**	---							
3.GSI	RG	.54**	.82**	---						
	RMG	.78**	.74**	---						
	NCG	.52**	.80**	---						
4.PST	RG	.55**	.78**	.91**	---					
	RMG	.25*	.33**	.84**	---					
	NCG	−.10	.29*	.89**	---					
5.PSDI	RG	.47**	.56**	.77**	.48**	---				
		.63**	.50**	.79**	.43**	---				
	RMG	.28*	.66**	.80**	.54**	---				
6. Cohe. Family	RG	−.20	−.28	−.38*	−.25	−.39*	---			
	RMG	−.39**	−.34**	−.43**	−.14	−.37**	---			
	NCG	−.38**	−.34**	−.47**	−.13	−.20	---			
7.Social support	RG	−.01	.44	−.05	.06	.01	.45*	---		
	RMG	−.21	−.26*	−.20	.05	−.11	.06	---		
	NCG	−.06	.09	.01	.12	.08	.28*	---		
Treat. time	RG	.01	−.15	−.178	.16	−.23	.07	−.30	---	
	RMG	.01	.01	.103	.19	.02	.05	−.06	---	
9. T. current sit	RG	.11	.13	.18	−.14	.22	−.06	−.25	.26	---
	RMG	.12	.11	.12	.07	.18	−.01	−.05	−.07	---
10. N. rec	RG	.40	.04	.02	.22	−.04	−.09	−.04	.37*	−.07

Note. BAI = Beck Anxiety Scale; BDI = Beck Depression Scale; GSI = Global Severity Index; PST = Total positive Symptom Index; PSDI = Positive Symptom Disorder Index; Family. Cohe. = family cohesion; Treat. time = time in cancer treatment (Months); T.sit. current = time in the current situation (months in relapse or remission); N. rec = number of relapses suffered. **p* < .05; ***p* < .001.

Table 4

Correlations between Psychological Adjustment and Sociodemographic Variables

Characteristics	Group	1	2	3	4	5	6	7	8	9	10
1.BAI											
2. BDI											
3. GSI											
4. PST											
5.PSDI											
6. Age	GR	−.05	−.04	.03	.10	.10	---				
	RMG	.23	.23*	.14	−.02	.21	---				
	NCG	.04	-.14	−.22	−.01	−.22	---				
7. Marital status	GR	−.08	.04	−.02	.09	.11	-.03	---			
	RMG	−.22	−.41**	−.33**	.04	−.16	.06	---			
	NCG	−.14	.02	−.05	−.05	−.01	.05	---			

Continues...

Table 4
Continuation

Characteristics	Group	1	2	3	4	5	6	7	8	9	10
8. Education	GR	−.06	.09	.04	−.01	−.25	−.09	−.04	---		
	RMG	−.17	−.25*	−.11	−.01	−.02	−.20	−.05	---		
	NCG	−.10	.00	.15	.05	.17	−.24*	−.01	---		
Family income	GR	−.34	−.20	−.20	.13	−.30	.35	.41*	.33	---	
	RMG	−.24*	−.23	−.22	−.15	−.13	.07	.27*	.27*	---	
	NCG	.00	−.01	.00	.06	−.02	−.21	.19	.26*	---	
10. Religion	GR	.14	−.135	−.25	−.14	−.09	.18	.18	−.09	.18	---
	RMG	.00	.112	.08	.00	.09	.17	.05	−.04	−.03	---
	NCG	−.09	−.17	−.197	.08	−.15	.03	.15	.16	.10	---
11. Child age	GR	−.48**	−.36**	−.46**	.11	−.41**	.29	.03	−.06	.30	.11
	RMG	−.17	.04	.01	.04	.01	.12	−.11	.02	−.03	.03
	NCG	−.09	−.17	−.20	.08	−.15	.21	.16	−.21	.00	.11

Note. Correlations of psychological adjustment measures among themselves are described in Table 4; BAI = Beck Anxiety Scale; BDI = Beck Depression Scale; GSI = Global Severity Index; PST = Total Positive Symptoms Index; PSDI = Positive Symptoms Disorder Index; Education. = education; codifications: marital status: 0 = no partner; 1 = with partner; educational level: 0 = elementary; 1 = high school/high school; religion: 0 = No Religion; 1 = religious. *$p < .05$; **$p < .001$.

Discussion

This study investigated differences in the psychological adjustment of children's caregivers with different cancer prognoses, comparing them with a control group. The analyses showed that the parents of children with cancer relapse tended to present more psychological problems (more depression, more obsession-compulsion, and more intense symptoms overall) than the parents of the other two groups.

These results corroborate the hypothesis of this research that parents/caregivers of children in relapse would present lower levels of psychological adjustment, as indicated by previous studies, which found severe psychological suffering, depression and anxiety (Arruda-Colli & Santos, 2015), poor quality of life (Khanjari et al., 2018), symptoms of post-traumatic stress (Sultan et al., 2016), and higher stress level (Rosenberg et al., 2013) in these caregivers. Therefore, it is suggested that the medical condition may affect parental adjustment, as stated by Sultan et al. (2016).

It is noteworthy that the higher levels of psychological maladjustment of the parents of children in cancer relapse, compared to the parents of children in other health conditions, should be understood within a contextual approach. Cancer relapse implies a larger amount and intensity of stressors, such as uncertainty, a more tangible threat of death, more aggressive treatment and uncontrollability of results, factors that may explain the elevated levels of psychopathological symptoms found in this research (Arruda-Colli & Santos, 2015; Van Schoors et al., 2019). Furthermore, relapse can have a more traumatic and powerful effect (Rodríguez et al., 2013) due to the psychological vulnerability produced by the first experience with cancer (Jurbergs et al., 2009).

The analyses also emphasized that there were no significant differences between the parents of children in cancer remission and the non-clinical group, which confirms the results described in literature reviews (Bakker et al., 2013; Ljungman et al., 2014). This data suggests that a single cancer treatment may not be as traumatic as assumed and that caregivers adapt well to this contingency (Phipps et al., 2015).

In turn, the results of this research indicated that parents/caregivers whose families had greater cohesion tended to present fewer psychological problems, which confirms other studies´ findings (Sultan et al., 2016; Van Schoors et al., 2019). This information indicates the possible protective function of this variable in the sense of family sharing experiences, helping parents to cope with the disease and its treatment (for the clinical groups) or with daily stressors (for the non-clinical group).

However, regarding social support, the data did not show significant associations between psychological adjustment of parents and satisfaction with social support received, which has also been observed by other studies (Klassen et al., 2011; Rosenberg et al., 2013). This variable is often related to better parental adjustment and fewer psychopathological symptoms (Kazak et al., 2015; Salvador et al., 2019; Schardong et al., 2017). However, considering that social support usually declines after the (first) diagnosis due to the resignation of the social support network regarding the news of pediatric cancer (Maurice-Stam, Oort, Last, & Grootenhuis, 2008), it is possible that relationships were not found due to the long time passed since the diagnosis when the two cancer groups were recruited.

Associations between sociodemographic variables and parental adjustment were also found in this study, indicating that certain families may be at psychological risk. This identification of possible risk factors in caregivers of children with cancer is essential for offering adequate psychological interventions to the demands and needs of this population (Kazak et al., 2015). The results showed that in the cancer relapse group, parents of younger children tended to present more emotional problems, perhaps because they perceive their children as more vulnerable and in greater need of care. Thus, a younger age of patients may contribute to greater parental psychological suffering, as described in previous studies (Grootenhuis & Last, 1997; Rodríguez et al., 2013; Rosenberg et al., 2013).

In the cancer remission group, the results showed that caregivers with disadvantaged sociodemographic characteristics (i.e., lower family income, lower education and single parenthood) tended to exhibit more psychological problems, which corroborates the literature in the area (Kazak et al., 2015; Roser et al., 2019; Sulkers et al., 2015; Wiener et al., 2016). These unfavorable circumstances can lead to psychological exhaustion and can work as an additional stressor to post-treatment demands and sequelae (Bemis et al., 2015).

A higher parental age was also related to higher rates of depression in parents of children in remission, which differs from previous studies (Rosenberg et al., 2013; Sulkers et al., 2015). However, Boivin et al., (2009) found higher levels of depression in older mothers of "healthy" children. Thus, it is hypothesized that higher parental age is associated with less energy and time in the relationship between parents and children, which impacts parental practices and feelings generated by them (Wechsler & Rani, 2016).

No relationships were found between the participants' psychological adjustment and the children's medical variables, as pointed out by previous studies (Salvador et al., 2019; Sulkers et al., 2015), refuting, however, the hypothesis of this research that these medical conditions would give more aversive functions to cancer treatment. On the other hand, subjective medical variables, such as a sense of threat to life or perception of treatment intensity, were not investigated in this study and deserve attention in future research since they seem to have a greater psychological impact than objective variables (Salvador et al., 2015).

Future studies would benefit from the combination of quantitative and qualitative methodologies in order to better understand the risk factors associated with the psychological adjustment of caregivers. Larger samples and multicenter studies could also increase statistical power and improve the generalization of results and their implications. Other variables which would help understanding parental adjustment, such as self-esteem, coping strategies, relationship with the health team and use of government social benefits, were not evaluated in this article and deserve attention in future research.

In general, this study contributes to identifying factors related to psychological maladjustment in different prognostic situations, which may be useful for health teams to posit preventive and interventional actions. On the other hand, published psychological interventions aimed at risk groups are usually directed to children and rarely to their caregivers; parents usually only take the role of auxiliaries or co-therapists (Meyler, Guerin, Kiernan, & Breathnach, 2010). Therefore, it is recommended that caregivers of children in cancer relapse be given exclusive attention, since they are the ones at greatest risk and the ones who benefit most from psychological interventions (Pai, Drotar, Zebrack, Moore, & Youngstrom, 2006).

Another important contribution of this study was the use of a "healthy"/non-clinical comparison group, which adds more methodological rigor, lacking in the literature in this field. However, limitations of this study include the sample size of the relapse group, although few studies have evaluated this population. Another limitation regards the non-measurement of the number of hours the parent/caregiver dedicated to the child, which may impact on their level of psychological adjustment.

Thus, implications for clinical practice involve the development of specific and more intensive interventions both for families of children in cancer relapse and for families of children off treatment (remission) who come from disadvantaged backgrounds, given the multiple risk factors to which they are exposed and the psychopathological clinical symptoms they present. Consequently, adequate support for parents will not only contribute to better stress management and better quality of life, but will also improve the well-being of patients and their recovery (Schepers et al., 2019).

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