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Posttraumatic growth among childhood cancer survivors and their caregivers: associations with rumination and beliefs challenge

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Abstract. The main purpose of the study was to assess the relationship between PTG, challenge to core beliefs, intrusive and deliberate rumination in a sample of 43 dyads of childhood cancer survivors and their caregivers. **Methods:** Survivors (mean age = 17.04; *SD*=3.67) and caregivers (mean age = 46.84; *SD* = 8.32) completed the Posttraumatic Growth Inventory (PTGI), the Core Beliefs Inventory (CBI) and the Event-related Rumination Inventory (ERRI). **Results:** Results showed a positive and high correlation among PTG, CBI, and ERRI in both groups, separately. CBI was the main predictor of PTG both among survivors (β=0.826; t=9.393; R^2=0.683; $p \leq 0.001$) and caregivers (β=0.552; t=4.235; R^2=0.304; $p \leq 0.001$). Caregivers reported higher scores than survivors in PTG (t=-2.999 $p \leq 0.01$) and its dimensions Relationship with others (t=2.498; $p \leq 0.05$), Spiritual change (t=-15.823; $p \leq 0.001$), Life appreciation (t=-3.129; $<p \leq 0.01$), as well as the means for intrusive (t=-3.862; $p \leq 0.001$) and deliberate rumination (t=-3.113; $p \leq 0.01$). **Discussion:** Caregivers are more involved in cognitive processes and reported higher PTG than survivors. This can be probably related to the concomitance between the period of disease and the cognitive development process of the survivors.
Keywords: Cancer survivorship; childhood cancer; posttraumatic growth; rumination

[es] Crecimiento postraumático entre sobrevivientes de cáncer infantil y sus cuidadores: asociaciones con rumiación y desafío de creencias

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Resumen. El objetivo principal del estudio fue evaluar la relación entre el CPT, el desafío a las creencias, la rumiación intrusiva y deliberada en una muestra de 43 díadas de sobrevivientes de cáncer infantil y sus cuidadores. Métodos: Los sobrevivientes (edad media = 17,04; SD = 3,67) y los cuidadores (edad media = 46,84; SD = 8,32) completaron el Inventario de Crecimiento Postraumático (PTGI), el Inventario de Creencias Básicas (CBI) y el Inventario de Rumiación Relacionada con Eventos (ERRI). Resultados: Los resultados mostraron una correlación positiva y alta entre PTG, CBI y ERRI en ambos grupos, por separado. El CBI fue el principal predictor de CPT tanto entre los sobrevivientes (β=0,826; t=9,393; R^2=0,683; p≤0,001) como entre los cuidadores (β=0,552; t=4,235; R^2=0,304; p≤0,001). Los cuidadores reportaron puntajes más altos que los sobrevivientes en CPT (t=-2,999 p≤0,01) y sus dimensiones Relación con los demás (t=2,498; p≤0,05), Cambio espiritual (t=-15,823; p≤0,001), Valoración de la vida (t =-3,129; <p≤0,01), así como las medias para rumiación intrusiva (t=-3,862; p≤0,001) y deliberada (t=-3,113; p≤0,01). Discusión: Los cuidadores están más involucrados en los procesos cognitivos y reportaron mayor PTG que los sobrevivientes. Esto probablemente esté relacionado con la concomitancia entre el período de enfermedad y el proceso de desarrollo cognitivo de los sobrevivientes.
Palabras clave: Supervivencia al cáncer; cáncer infantil; crecimiento postraumático; rumia

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1. Introduction

Experiencing childhood cancer (CC) could be a traumatic event that may result in long-term consequences for the mental health of both the survivor and their caregivers[1–3]. However, a traumatic event may have positive consequences, and people could change their life perception from that experience, which is called Posttraumatic Growth (PTG)[4–6]. Authors[7–9] postulate that PTG embrace changes in the core beliefs as well as the individual engagement in cognitive processes of intrusive and deliberate rumination to understand what had happened and integrate the traumatic experience in life. While intrusive rumination is an immediate, negative and automatic process, deliberate rumination is a later process with positive, constructive, and intentional features[10,11].

The PTG process has been investigated among people with chronic diseases, such as CC, however studies mainly examine the survivors[12–15] and the caregivers[16–18] separately. Some studies approached CC survivors and their caregivers together, but most of them did not investigate the cognitive processes (e.g., challenge to core beliefs and rumination) involved in the PTG[3,19]. For example, based on a US sample of 150 CC survivors, 146 mothers, and 107 fathers, Barakat, Alderfer, and Kazak[19] found that PTG among adolescents and caregivers was positively associated with the past treatment/disease severity. Only survivors diagnosed under five years old did not have PTG. Wilson et al. (2016)[3] evaluated PTG among 61 children and adolescents CC survivors and other psychosocial variables (CC survivors posttraumatic stress, caregivers 'coping and resilience, and nurse trust in the patient family). The predictors of PTG in CC survivors were patient' posttraumatic stress symptoms (positive relationship), and caregivers' positive religious coping and positive relations coping.

Wilson et al. (2016) did not compare PTG levels between groups (CC survivors and caregivers) and within dyads. An exception is a recent study from South Korea[20] that included 68 adolescents who survived Leukemia and their caregivers and found that the higher the challenge to core beliefs, the higher the extent of deliberate rumination and PTG in both groups. Adolescents and caregivers who had religious beliefs also presented more PTG than those who had not. Caregivers showed higher levels of intrusive rumination, challenging core beliefs, and PTG compared to their children. Drawing on an emergent scenario of evidence, it is relevant to confirm this theoretical PTG model in Brazilian caregivers and their children who had CI.
Thereby, the present study aims: a) to assess the relationship between PTG, challenge to core beliefs, intrusive and deliberate rumination in CC survivors and their caregivers; b) to identify differences in PTG and cognitive processes among survivors and caregivers; and c) to compare caregivers and CC survivors PTG's predictive models (challenge to core beliefs, intrusive and deliberate rumination).

2. Method

Participants

To be included in the study, the survivors had to be older than 12 years old, be in remission of the disease for at least one year, and not have had further treatment for CC. The caregivers were required to have been one of their child's main caregivers during the disease period. Considering the inclusion criteria, 65 childhood cancer (CC) survivors were approached in a pediatric oncology outpatient clinic in the southern region of Brazil during survivors` routine appointments. Among them, nine individuals refused to participate in the study, and the other 13 recruited survivors were excluded because their caregivers did not answer all the measures. Of these, met the criterion 43 childhood cancer (CC) survivors and 43 caregivers. No differences were found between the final sample and the sample of participants who were excluded.

Measures

Survivors and caregivers: 1) PTG: Brazilian version of the Posttraumatic Growth Inventory (PTGI)[21]. It is a 21 item self-reported measure of PTG (range 1-5)[4]. The measure provides a total score and scores for each of the five PTG dimensions: relationship with others, personal strength, new possibilities, appreciation of life, and spiritual changes. The higher the score, higher the PTGI. 2) Challenge to Core Beliefs: Brazilian version of the Core Beliefs Inventory (CBI)[22]. CBI[23] evaluate how core beliefs are challenged by a stressful experience through nine items in which the participant should reflect and indicate how much he/she reevaluated each belief on a six-point Likert scale. The total score means the higher the score, the greater the tendency to re-examine the core beliefs[23]. 3) Deliberate and Intrusive Rumination: Brazilian version of the Event-related Rumination Inventory (ERRI)[24]. ERRI[25] assesses rumination styles associated with trauma in a 20 item self-reported scale (range 0-3). ERRI comprises two 10-item factors named deliberate rumination and

intrusive rumination. The higher the score, higher the rumination. For this study, CC survivors and caregivers answered the questionnaire considering the two weeks after the end of the cancer treatment. 4) Demographics, disease, and treatment variables were collected from the patient´s medical records.

Ethical Statements

The study was approved by the Ethics Committee of the hospital involved (CAAE 13962113.8.1001.5344). Adult participants signed an Informed Consent. CC survivors under 18 years old signed a written acceptance and their caregivers signed another Informed Consent allowing the adolescent's participation. Participants answered the measures individually and simultaneously with the survivor and their parent in separate rooms. All the ethics protocol were respect.

Data collection was performed in a hospital in southern Brazil. Initially, the hospital' system was accessed to obtain data about the participants. Those who had more than one year of remission and those older than 12 years were selected. Calls were made to invite the participants and the main person responsible/caregiver at the time of treatment was asked to come along. The researchers met the participants at the pediatric oncology outpatient clinic before or after the consultation, according to the time scheduled in the telephone contact. At that moment, they explained the research again and, if the participant accepted, they went to the hospital's clinical research center, where they signed the Informed Consent Form.

3. Data analysis

Analyzes were conducted in software *IBM SPSS Statistics* version 26. Two-sided p values < 0.05 were considered statistically significant. We used Cohen's d to assess effect size. We did descriptive analyses and assessed data normality using the Shapiro-Wilk test. Bootstrapping procedures were performed (1000 resamples; 95% CI BCa) to obtain greater reliability of the results, to correct for deviations from the normality of the sample distribution, and also to present a 95% confidence interval for the differences between means[26]. We used Paired t-test to compare differences in posttraumatic growth, core beliefs, and rumination between CC survivors and caregivers. Then, we analyzed CC survivors and the caregivers' groups separately. Pearson's correlations among PTG, challenge to core beliefs, rumination, and clinical and demographic variables (age, age at diagnosis, time in follow-up, caregiver´s age) were also performed. Furthermore, Linear Multiple Regressions was performed to investigate the predictive role of independent variables (challenge to core beliefs; intrusive and deliberate rumination) in PTG for CC survivors and their caregivers separately. Variables with significant correlations were entered into the models using the Stepwise method. We assessed Correlation matrices, tolerance, Variance Inflation Factor (VIF), and Durbin-Watson statistics (d) values. In the second stage, we performed Paired-test (with bootstrapped 95% confidence interval) to analyze dyad differences between caregivers and survivors in PTG, challenge to core beliefs, and intrusive and deliberate rumination.

4. Results

Sample characteristics

Table 1 presents the sociodemographic and clinical data of the sample of CC survivors and their caregivers. Survivors´ current age was 17.04 years old (SD = 3.674), and age at diagnosis was 9.56 years old (SD = 5.294). Most of the survivors were single (81.4%). Caregivers' mean age is 46,84 years old (SD = 8.32). Thirty-eight (88.4%) were mothers, and 36 (83.7%) were married/living with a partner. Other characteristics are in Table 1.

Table 1. Sociodemographic and Clinical Data of CC Survivors and Parents (N = 86)

Group	Variable	Categories	*n* (%) or *M* (*SD*)	Min/Max
Survivors (*N*=43)	Current age		17.04 (3.674)	12 - 29
	Age at diagnosis		9.56 (5.294)	0.48 - 18
	Time since finished treatment (years)		5.849 (4.106)	1 - 15
	Sex	Female	20 (46.5)	
		Male	23 (53.5)	
	Education	Up to elementary school	20 (46.5)	
		Up to high school	20 (46.5)	
		Up to higher education	3 (7)	
	Relationship status	Steady partner	7 (16.3)	
		Single	35 (81.4)	
	Religion	Yes	33 (76.7)	
	Cancer type	Leukemia	9 (20.9)	
		Lymphomas	7 (16.3)	
		Abdominal masses	6 (14)	
		CNS tumors	6 (14)	
		Eye tumors	4 (9.3)	
		Bone tumors	8 (18.6)	
		Soft tissue tumors	1 (2.3)	
	Treatment	Chemotherapy	37 (86)	
		Radiotherapy	14 (32.6)	
		Surgery	24 (55.8)	
		Marrow transplant	2 (4.7)	
	Relapse	Yes	5 (11.6)	
	After-effects	Yes	15 (34.9)	

Parents (*N*=43)	Kinship	Mother	38 (88.4)	
		Father	5 (11.6)	
	Current age		46.84 (8.326)	29-62
	Education	Up to elementary school	18 (42.9)	
		Up to high school	15 (35.7)	
		Up to higher education	9 (21.4)	
	Relationship status	Steady partner	36 (83.7)	
		Single	5 (11.6)	
	Religion	Yes	38 (88.4)	
	Main caregiver	Yes	37 (86)	

Differences in study variables between CC survivors and caregivers

In general, caregivers had higher scores in all variables assessed in paired analysis (Table 2). Total scores of PTG (t=-2.999, p≤0.01) and its dimensions Relationship with others (t=2.498; p≤0.05), Spiritual change (t=-15.823; p≤0.001), Life appreciation (t=-3.129; p≤0.01), as well as the means for intrusive (t=-3,862; p≤0,001) and deliberate rumination (t=-3.113; p≤0.01) were higher to caregivers when compared to survivors (Table 2).

Table 2. Comparisons between the two groups on the study variables (N=86)

	CC survivors	**Caregivers**			***p***	**Effect size (d)**
	M (DP)	**M (DP)**	**Min/ Max**	**Paired t**		
Total PTG	3.14 (1.22)	3.83 (1,019)	0 - 5	-2.999	**0.005**	0.46
Relationship with others	3.20 (1.30)	3.91 (0.99)	0 - 5	-2.498	**0.017**	0.38
New possibilities	2.96 (1.35)	3.56 (1.22)	0 - 5	-1.924	0.062	0.29
Personal change	3.45 (1.36)	3.98 (1.25)	0 - 5	-1.756	0.088	0.27
Spiritual change	3.01 (1.62)	4.08 (1.39)	0 - 5	-3.563	**0.001**	0.54
Life appreciation	3.05 (1.39)	3.94 (1.08)	0 - 5	-3.129	**0.003**	0.48
Core beliefs	3.08 (1.35)	3.85 (0.85)	1 - 5	-2.926	**0.006**	0.45
Intrusive rumination	10.84 (8.49)	18.54 (9.16)	0 - 30	-3.862	**0.000**	0.59
Deliberate rumination	16.95 (8.41)	22.41 (7.62)	0 - 30	-3.113	**0.004**	0.47

Associations among PTG, challenges to core beliefs, and intrusive and deliberate rumination

Among CC survivors and caregivers, the greater challenged core beliefs, intrusive and deliberate rumination, the higher the PTG (Table 3). Sociodemographic and clinical data were not correlated with PTG, challenged core beliefs, either with intrusive and

deliberate rumination within the groups, except among the survivors it was found that the older they were at diagnosis, the more intrusive rumination (r=0.319; p≤0.05) and deliberate rumination (r=0.337; p≤0.05), The non-relevant correlations that had the lowest p-value were between age at first surgery and intrusive rumination (r = 0.410*;* p = 0.081) and deliberate rumination (r = -0.528; p = 0.094), and between time out of treatment and intrusive rumination (r = -0.222; p = 0.162) and deliberate rumination (r = -0.226; p = 0.150), Cronbach´s alpha for all measures was adequate (> 0.70).

Table 3. Correlations among PTG, challenge to core beliefs and intrusive and deliberate rumination in CC survivors and parents (N=86)

	Categories	**1**	**2**	**3**	**4**	**Mean (SD)**	**Range**	**Cronbach´s alpha**
Survivors (n=43)	1 PTG	1	**. 805**	**.301**	**.502**	3.16 (1.97)	1-5	.948
	2 Challenge to core beliefs		1	**.604**	**.746**	3.07 (1.28)	0-5	.901
	3 Intrusive rumination			1	**.752**	11.18 (8.88)	0-30	.938
	4 Deliberate rumination				1	16.88 (8.18)	0-30	.918
Parents (n=43)	1 PTG	1	**.708**	**.337**	**.501**	3.82 (1.04)	1-5	.877
	2 Challenge to core beliefs		1	**.535**	**.580**	3.72 (.95)	0-5	.786
	3 Intrusive rumination			1	**.586**	17.64 (9.53)	0-30	.927
	4 Deliberate rumination				1	22.00 (7.67)	0-30	.908

Note. Pearson correlation with bootstrap. * Values in bold p<.01

We performed Linear Multiple Regressions analysis (Stepwise method) to check whether the challenge to core beliefs and rumination processes predict PTG in both groups. As we can see in Table 4 challenge to core beliefs after the CC experience is the unique significant predictor of PTG in survivors sample (β=0.826; t=9.393; p≤0.001); $F_{(1)}$=88.224; p≤0.001; R^2=0.683). For the caregivers, the analysis resulted in one significant model ($F_{(1)}$=17.932; p≤0.001; R^2=0.304), in which the reassessment in core beliefs (β=0.552; t=4.235; p≤0.001) appeared as the only predictor of PTG, as well as in the group of survivors. In both models, deliberate rumination was excluded. For survivors, age at diagnosis was also excluded since these variables did not show a significant path for PTG.

Both models showed evidence of residuals' independence (Survivors: dw=1.953/ residuals -1.276 to 1.791; Caregivers: dw=1.813/residuals -2,266 to 1.549)[27], The Variance Inflation Factor scores of our variables were 1,5 in the model of CC survivors and 1 in the caregivers' model. In both models, there was evidence that multicollinearity was not a problem since these values were below 5.

Table 4. Hierarchical Multiple Regression Models (Stepwise) to predict PTG among CC survivors and parents

	Variables	Beta	SE B	β	R^2	Adjusted R^2
Survivors	Step 1				0.683**	0.675**
(N=43)	Challenge to core beliefs	.779	.083	0.826**		
Parents	Step 1				0.304**	0.287**
(N=43)	Challenge to core beliefs	.592	.140	0.552**		

Note. **p≤0.001

5. Discussion

Findings showed that both caregivers and survivors could perceive positive changes regarding the CC experience as described in previous studies[3,20], and changes in core beliefs examination are the main predictor of PTG in both groups. Moreover, the study found differences between caregivers' and survivors' PTG, core beliefs, and rumination levels that highlighted the distinct cognitive processes implied in the pathway to reach positive life changes after the stress when caregivers showed more positive characteristics than CC survivors.

Parent´s involvement in the child's treatment implied in their PTG process in a different way than the survivor that was still a toddler, child, or adolescent, less able to fully assimilate what was happening[16,17,20]. While the PTG process is not limited to deliberate changes in life after a stressful event, caregivers may be more able to intensively reflect on the CC experience, making positive changes for their life, playing different roles during the children's treatment and in the family, having higher control over the situations, with more realistic and consolidated memories[9]. In addition, caregivers may have a better ability to relate to the traumatic event, find meaning in life, value and reassessed their actions through the cancer experience[17].

Our findings are similar to another study in which mothers had higher PTG than their CC surviving children over 5 years old, and children who had CC before 5 years old did not show PTG (20). Cognitive maturation processes can take place and the younger these survivors have been diagnosed, the more difficulties they will have in engaging in PTG, which may involve more complex cognitive processes, like rumination and challenge to core beliefs. Besides, caregivers can use more emotion-focused coping strategies and use more strategies to ask for emotional support, which can help in better PTG with the traumatic experience[20,28]. Similar to what the literature points out, this study also found that PTG, challenge to core beliefs, and intrusive and deliberate rumination are correlated to positive life changes for both CC survivors and their caregivers[5,20].

The present study discussed a possible predictive model for PTG among CC caregivers and survivors. In both groups, the challenge to core beliefs seems to be the key to a higher PTG, as in other studies[9,10,29]. Thus, the discrepancy between previous core beliefs and new information demand survivors' and caregivers' flexibility beliefs, which result in a significant change in their world views. It remains unclear whether intrusive and deliberate rumination processes take place through

similar or different cognitive mechanisms. Further studies are needed to fill this gap. A systematic review found that deliberate rumination is primarily associated with PTG[15]. However, other studies understand that intrusive rumination, at some point in this process, may serve to stimulate attempts to engage in deliberate processing of the experience[10].

The study has some limitations that need to be considered, especially the higher age range of the disease experience and the time elapsed since the occurrence of the event until the data collection. Memory bias could have a large impact on the measurement of rumination since participants should answer based on the weeks immediately after the end of the treatment and some of them had been out of treatment for years when they participated in the research. This may explain the fact that deliberate or intrusive rumination does not appear in any of the predictive models. Also, as our sample is from Brazil, a developing country with high rates of poverty and social disparities[30], these families could experience additional stressful events that could impact PTG levels that we did not assess. Another limitation is being a cross-sectional study with a small convenience sample. Demographic and clinical variables had little impact on our results, which can be explained by the low number of participants and the heterogeneity of the sample, especially considering the time since the end of the treatment. So, further studies are needed to achieve more robust findings.

Our study was the first that compared caregivers-survivors dyad in a Latin American sample, which shows the importance of core beliefs to PTG among CC survivors and their caregivers. Based on a small and pioneering Brazilian study, we strengthened evidence on the role of cognitive variables in the PTG among caregivers and children after the stressful and traumatic CC experience. Caregivers showed higher levels of PTG and rumination processes indicating that cognitive maturity may be implied. Further research is essential as PTG is a complex and dynamic process, and other influential factors should be investigated, as, for example, other concurrent stressful events that children in Latin American suffer (i.e. poverty, violence). The results highlighted the importance of continued multidisciplinary support to the whole family to repair and change their beliefs after a traumatic event as childhood cancer, helping survivors and caregivers to make positive meaning and to adjust.

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