

# Illness Perception and Indicators of PTSD in Mothers of Childhood Cancer Survivors

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## Abstract

**Objective:** to investigate the relationship among illness perception, posttraumatic stress disorder (PTSD) and posttraumatic symptomatology in mothers of childhood cancer survivors. **Method:** *ex post facto* design. **Participants:** 16 mothers with a mean age of 41.87 years old ( $SD=8.68$ ). The instruments used regarding the illness perception (Revised Illness Perception Questionnaire for Healthy People [IPQ-RH]) and PTSD (Posttraumatic Stress Disorder Checklist – Civilian Version [PCL-C]) were answered through a digital platform. **Results:** According to the evaluation criteria of the PCL-C, eight mothers (50%) obtained PTSD diagnosis indicators. Regarding the posttraumatic symptomatology, 13 mothers (81.25%) presented increased arousal, 12 (75%) reliving and eight (50%) avoidance. Considering the global score of the PCL-C, the average was 43 points ( $SD=14.76$ ), indicating moderate level of PTSD indicators. Regarding the IPQ-RH, emotional representation dimension correlated positively with reliving ( $r=.615$ ;  $p<.05$ ), avoidance ( $r=.679$ ;  $p<.01$ ) and the total average of the PCL-C ( $r=.631$ ;  $p<.01$ ). The personal control dimension correlated negatively with avoidance ( $r=-.673$ ;  $p<.01$ ). **Conclusions:** the results showed that the experience of having a child with cancer can reflect negatively on the mental health of mothers, turning them into a population vulnerable to stress, especially when they maintain a negative emotional representation of the illness.

**Keywords:** Illness perception, Posttraumatic Stress Disorder, childhood câncer, survivors, mothers.

## Percepção da Doença e Indicadores de TEPT em Mães de Sobreviventes de Câncer Infantil

### Resumo

**Objetivo:** investigar a relação entre percepção da doença, transtorno de estresse pós-traumático (TEPT) e sintomatologia pós-traumática em mães de sobreviventes de câncer infantil. **Método:** *ex post facto*. **Participantes:** 16 mães com média de idade de 41,87 anos ( $DP=8,68$ ). Os questionários sobre percepção da doença (*Revised Illness Perception Questionnaire for Healthy People* [IPQ-RH]) e TEPT (*Post-traumatic Stress Disorder Checklist – Civilian Version* [PCL-C]) foram respondidos através de uma plataforma digital. **Resultados:** segundo os critérios de avaliação do PCL-C, oito mães (50%) apresenta-

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ram indicadores diagnósticos de TEPT. Em relação à sintomatologia pós-traumática, 13 mães (81,25%) apresentaram excitabilidade aumentada, 12 (75%) revivência e oito (50%) evitação. O escore global do PCL-C foi de 43 pontos ( $DP=14,76$ ), indicando nível moderado de sintomas de TEPT. No IPQ-RH, a dimensão representação emocional correlacionou-se positivamente com a revivência ( $r=0,615$ ;  $p<0,05$ ), evitação ( $r=0,679$ ;  $p<0,01$ ) e a média total do PCL-C ( $r=0,631$ ;  $p<0,01$ ). A percepção de controle pessoal correlacionou-se negativamente com a evitação ( $r=-0,673$ ;  $p<0,01$ ). Conclusões: a experiência de ter um filho com câncer repercute negativamente na saúde emocional das mães, tornando-as uma população vulnerável ao estresse, principalmente quando têm uma representação emocional muito negativa da doença.

**Palavras-chave:** Percepção da doença, Transtorno de Estresse Pós-Traumático, câncer infantil, sobreviventes, mães.

## Percepción de la Enfermedad y Indicadores de TEPT en Madres de Sobrevivientes de Cáncer en la Niñez

### Resumen

Objetivo: investigar la relación entre percepción de la enfermedad, Trastorno de Estrés Postraumático (TEPT) y sintomatología postraumática en madres de sobrevivientes de cáncer en la niñez. Método: *ex post facto*. Participantes: 16 madres con edad media de 41,87 años ( $SD=8.68$ ). Los cuestionarios sobre percepción de la enfermedad (*Revised Illness Perception Questionnaire for Healthy People* [IPQ-RH]) y TEPT (*Posttraumatic Stress Disorder Checklist – Civilian Version* [PCL-C]) fueron contestados a través de una plataforma digital. Resultados: según los criterios de evaluación del PCL-C, ocho madres (50%) presentaron indicadores diagnósticos de TEPT. En relación a la sintomatología traumática, 13 madres (81,25%) presentaron excitación, 12 (75%) reexperiencia y ocho (50%) evitación. La puntuación global del PCL-C fue de 43 puntos ( $SD=14.76$ ), lo que indica un nivel moderado de indicadores de TEPT. En lo que respecta IPQ-RH, la dimensión representación emocional se correlacionó de forma positiva con la reexperiencia ( $r=.615$ ;  $p<.05$ ), evitación ( $r=.679$ ;  $p<.01$ ) y la media total del PCL-C ( $r=.631$ ;  $p<.01$ ). La percepción de control personal se correlacionó de forma negativa con la evitación ( $r=-.673$ ;  $p<.01$ ). Conclusiones: la experiencia de tener un hijo con cáncer puede tener repercusiones negativas en la salud emocional de las madres, lo que hace con que sean una población vulnerable al estrés, principalmente cuando mantiene una representación emocional muy negativa de la enfermedad.

**Palabras clave:** Percepción de la enfermedad, Trastorno de Estrés Postraumático, cáncer en la niñez, sobrevivientes, madres.

Important advances have been achieved in recent decades with regard to the development of new technologies and treatments for childhood cancer (Bruce, 2006; Silva, Teles, & Valle, 2005). In 1970, the chances of curing a child with cancer were no more than 30% (Andréa, 2008). Currently, in developed countries, about 70% to 90% can be cured if diagnosed and treated early (Kamibepu et al., 2010). In Brazil, childhood cancer is the leading cause of death by disease among children and adolescents from one to 19 years old. Each year, about 11,530 new cases arise in the country, a total of 2,740 deaths.

Survival rates are still below expectations, but in some areas they may exceed 70% (National Cancer Institute [INCA], n.d.).

Childhood cancer is a group of diseases that have in common the growth of abnormal cells that affect the functioning of the body. The most common tumors are leukemias, lymphomas, and tumors of the central nervous system (INCA, n.d.; World Health Organization [WHO], 2014). Although the survival estimates are encouraging, affirming that a cancer is cured requires caution since there is the possibility of disease recurrence. The term survivor is used to refer

to the proportion of patients who completed the treatment and whose cancer is controlled (Arrais & Araújo, 2000).

Parents of childhood cancer survivors may experience psychological trauma due to the high level of stress associated with the disease and involvement in childcare. Some cases may evolve into a condition of Posttraumatic Stress Disorder (PTSD; Norberg, Pöder, Ljungman, & Essen, 2012). According to this, knowledge of a disease that endangers the life of a child was included as a traumatic event in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association [APA], 1995).

Different authors have investigated the presence of PTSD and posttraumatic symptoms in family members of child cancer survivors. For mothers, estimates show that 6.2% to 11% have diagnosis for PTSD (Alderfer, Labay, & Kazak, 2003) and 37% to 44% have high levels of posttraumatic symptoms (Barakat, Alderfer, & Kazak, 2006; Bruce, Gumley, Isham, Fearon, & Phipps, 2010). Despite its relevance, it is a subject that is still little studied in Brazil, which is confirmed by the absence of national articles addressing the subject.

PTSD is characterized by direct personal exposure to an external stressor or the testimony of situations that threaten life and someone else's integrity (criterion A; APA, 2008). The sense of threat influences cognitive processing resulting in overly negative assessments of trauma and/or its consequences, and poor elaboration of memories of traumatic events, which are easily activated by situational associations (Ehlers & Clark, 2000). According to the DSM-IV-TR (APA, 2008), PTSD symptoms include: persistent reliving of the traumatic event (recurrent and intrusive recollections, distressing dreams in which the event is replayed; criterion B); avoidance of associated stimuli and numbing of general responsiveness (deliberate efforts to avoid thoughts, feelings, conversations, activities, and people that provoke memories of the event; criterion C); increased arousal (anxiety, difficulty sleeping and exaggerated startle that were not present before the trauma; criterion D). The

complete condition should be present for more than a month (criterion E) and interfere with social and occupational functioning and other important areas of the individual's life (criterion F).

While reliving and increased arousal are considered involuntary responses, avoidance is configured as a deliberate strategy (Plumb, Orsillo, & Luterek, 2004) which can prevent the proper elaboration of trauma (Whealin, Ruzek, & Southwick, 2008). Regarding this, it was found that parents who avoided stimuli that generated stressful memories and negative emotions about the cancer of the children had more PTSD indicators and high levels of posttraumatic symptoms than those who did not avoid such stimuli a year and a half after treatment (Norberg, Pöder, & Essen, 2011).

Starting from the idea that parents' assessments of the cancer threat can prevent the elaboration of trauma, it is important to investigate the perceptions they have about the disease. In Health Psychology, the perception of the disease (Illness Perception) of patients and healthy people has been investigated following the Common-Sense Model (Leventhal, Brissette, & Leventhal, 2003; Leventhal, Nerenz, & Steele, 1984). According to this theory, stimulus of threat against health (e. g. diagnosis of childhood cancer of a child) generates the activation and development of representations of a certain disease from individual beliefs. Beliefs are structured from previous and vicarious experiences. Such beliefs can influence the behaviors and the way of coping with the situation (Figueiras, Machado, & Alves, 2002). Threatening stimuli activate two systems: one involving cognitive processes to regulate the objective threat to health and the other involving emotional processes to regulate stress, fear, and anxiety (Cameron & Jago, 2008).

At first, the perception of the disease has been divided into five dimensions: identity (possible symptoms of the disease), causes (factors that give rise to the disease), timeline (course of the disease over time, e.g. acute or chronic; cyclic), consequences (severity of the disease and its impact on physical, psychological, and social functioning) and control/cure (possibility of cure or control of the disease; Leventhal et

al., 1984). Later, the control/cure dimension was divided into personal control (perception of how much the patient can control or cure the disease) and treatment control (treatment efficacy in the control or cure of the disease) and two new dimensions were included in the model: coherence of the disease (perception of how much the individual understands the disease) and emotional representation (emotions involving the experience of illness; Moss-Moris et al., 2002).

Considering the relationship between the perception of the disease and PTSD, only one study was found in the national and international literature. It is a survey of cardiac patients. The results indicated that the perception of the disease was predictive of PTSD, with higher rates of disorder associated with the decreased treatment control dimension (Sheldrik, Tarrier, Berry, & Kinsey, 2006). Because of the importance and novelty of the theme, this study was designed to investigate the relationship between perception of the disease, PTSD, and posttraumatic symptoms in mothers of childhood cancer survivors. The hypothesis is the existence of positive linear correlations in which more negative perceptions of cancer, assessed through the Revised Illness Perception Questionnaire for Healthy People (IPQ-RH), are associated with higher scores in PTSD indicators and/or posttraumatic symptoms (reliving, avoidance, and increased arousal).

## Method

### Design

*Ex post facto* (Monteiro & Léon, 2007).

### Participants

The criteria for participation in the study included mothers of childhood cancer survivors whose children were diagnosed when they were between one and 19 years old. The disease should be in remission and the treatment finished for at least six months. Among the 17 mothers who answered the questionnaires, only one was excluded because the child had died as a result of childhood cancer. The average age of the 16 participants at the time of application of the instru-

ments was 41.87 years old ( $SD = 8.68$ ). When the cancer was diagnosed, mothers had a mean age of 33.80 years old ( $SD = 7.46$ ).

### Instruments

*Questionnaire of Sociodemographic and Clinical Data.* The information was divided into the mother's demographic data (current age, age at the child's diagnosis, current marital status, education, etc.) and clinical history of the surviving child (diagnosis time in years, age at diagnosis, type of cancer, etc.). The instrument also included a question that asked whether the mothers had experienced or not another potentially traumatic event during their lives (family member with serious illness, death in the family, death of a loved one, accident, violence, others). All data were reported by the mother.

*Posttraumatic Stress Disorder Checklist – Civilian Version (PCL-C).* This instrument is one of three versions of the PCL developed by Weathers, Litz, Herman, Huska and Keane (1993). The PCL-C is designed for the general population and is not related to a specific traumatic event. This instrument provides information on the presence or absence of PTSD indicators and posttraumatic symptoms. It is a self-report instrument consisting of 17 items based on criteria established by the DSM-IV (APA, 1995) for the diagnosis of Posttraumatic Stress Disorder (PTSD). Respondents should indicate how much they had been disturbed by the symptoms described in the instrument last month, by using a Likert scale of one (nothing) to five (very much). The rating of the instrument can be performed by grouping (clusters) or global score (cutoff). In the grouping, the participant presents PTSD if he or she scores three or more in at least one reliving item (criterion B - questions 1 to 5), three items of avoidance (criterion C - issues 6 to 12) and two items in increased arousal (criterion D - issues 13-17; International Society for Traumatic Stress Studies [ISTSS], 2014). The second form of evaluation is when the cutoff point is higher or equal to 40 (Schwartz et al., 2012). The PCL-C was used in a study of childhood cancer survivors (Schwartz & Drotar, 2006)

and the original English version has internal consistency of .96. In Brazil, the instrument was validated in individuals who experienced traffic accidents (Bringhenti, Luft, & Oliveira, 2010). Its semantic equivalence for Portuguese was found by Berger, Mendlowicz, Souza, and Figueira (2004) and used in this research.

*Revised Illness Perception Questionnaire for Healthy People (IPQ-RH)*. Instrument developed by Figueiras and Alves (2007) from the Revised Illness Perception Questionnaire (IPQ-R; Weinman, Petrie, Moss-Morris, & Horne, 1996) to assess the perception of the disease in healthy individuals according to the Common Sense Model. The instrument has been adapted into Portuguese and is divided into three sections: the first corresponds to the identity dimension, where the symptoms are presented (e.g. pain, shortness of breath, fatigue, etc.). The participants are invited to answer whether they believe it or not that these symptoms are related to the disease (in this case childhood cancer; Yes = 1; No = 2). The sum of the number of “Yes” answers determines the overall score of the identity subscale. The second section involves the acute/chronic length dimensions, consequences, personal control, treatment control, coherence, cyclic timeline, and emotional representation. The third section is related to the possible *causes* of the disease, divided into psychological and general attributions. It is also requested that the participant enumerates freely three causes that he or she considers to be related to the development of the disease. The second and third sections include a Likert scale ranging from the strongly agree to the strongly disagree option.

### **Data Collection Procedures**

Data collection was conducted over the Internet through a self-administered form available in the *Google Docs* tool. A website was created to promote the research, showing the inclusion criteria and informing about the implementation of the instruments (link of the research site: <http://pesquisa-unisinos-ici-familiares.webnode.com/>). A link on the website generated a new page with the Informed Consent Form (ICF). The participants answered the instruments only

after confirming the reading and the acceptance of the ICF. If they did not accept to participate, a new message thanking for the participation was presented and the data collection was finished. A copy of the ICF was sent by email to each of the respondents who had provided an email address on the same page in which the ICF was presented. The online collection occurred from August 2013 to March 2014.

The promotion of the research site occurred on social networks (*Facebook*), electronic means of dissemination (site) of the Children’s Cancer Institute (ICI-RS) and posters distributed at the institute. In addition, an active search was conducted through lists provided by ICI-RS, which keeps records of survivors and their families. Telephone calls were made by trained researchers, psychology major students, in order to invite the mothers of the survivors. Those interested in participating in the study were provided with the website link of the survey, which was sent by e-mail.

The data collection method, over the Internet, was determined because of the difficulty in having personal contact with the mothers of the survivors at the ICI-RS, which is located in Porto Alegre. In order for the child to undergo treatment in the capital, many families leave their cities and move to the capital temporarily. With the completion of the medical care, they go back home, and the systematic contact with the ICI-RS decreases. This aspect has hampered access to families and, for this reason, contacts have been carried out by telephone and social networks.

### **Ethical Procedures**

Project approved by the Ethics Committee of *Universidade do Vale do Rio dos Sinos* under number 13962113.8.1001.5344. Ethical procedures for research with humans were adopted. The web pages containing the ICF and instruments, as well as the database with information collected, were stored and the password protected in order to ensure the privacy and security of information. All participants accepted to participate in the survey and received a copy of the ICF sent to their e-mail.

### Data Analysis

Initially, descriptive analyzes to verify means, standard deviations, frequencies, and percentages were performed. Then Spearman's correlations were performed to investigate the possible relationship between the IPQ-RH dimensions and the PCL-C symptoms. All the analyses were conducted using SPSS (Statistical Package for Social Sciences) version 20.0 and a significance level of 5% was adopted.

Content analyzes were also performed (Bardin, 1977) for coding the responses obtained from the open question "Please, rank the three factors that seem to be able to cause cancer in children in order of importance" contained in the IPQ-RH instrument. Initially, the responses were described in full and, subsequently, grouped based on their content.

### Results

Regarding the sociodemographic data of the participants, most claimed to be married or living with a partner (56.25%;  $n = 9$ ). As for education and labor activity, 10 (62.5%) studied until high school and also worked. Half of the mothers had psychological counseling during the child's cancer treatment and only two (12.5%) were following up with a psychologist at the time of the survey. Most mothers (87.5%) said they had experienced another potentially traumatic event in life. Among these, "death" and "serious illness of a family member" were the most prevalent.

As for the clinical history of the child survivor of childhood cancer, the most common type of cancer was leukemia (56.25%,  $n = 9$ ). Regarding treatment, all underwent chemotherapy, six radiotherapy, seven surgery, and two marrow transplant. According to the mothers, four survivors have developed physical sequelae resulting from the disease or the treatment. Four survivors had relapsed, but none developed another type of cancer later. The average age of the children at diagnosis was 6.08 years old ( $SD = 3.98$ ), the treatment lasted for 28.33 months ( $SD = 20.55$ ) and the diagnosis had been held 7.80 years before ( $SD = 5.71$ ).

In accordance with the grouping criteria of the PCL-C, eight (50%) mothers had PTSD diagnosis indicators. In terms of symptomatology, 13 (81.25%) showed increased arousal, 12 (75%) reported reliving, and eight (50%) avoidance. Considering the overall score of the PCL-C, the average was 43 points ( $SD = 14.76$ ), indicating a moderate level of PTSD. The assessment, according to the cutoff point ( $\geq 40$  points), indicated that 10 (62.5%) mothers had symptoms that characterized the presence of PTSD. The average scores have identified moderate levels of the symptoms increased arousal ( $M = 15.31$ ,  $SD = 6.49$ ), avoidance ( $M = 15.31$ ,  $SD = 5.66$ ) and reliving ( $M = 12.38$ ,  $SD = 4.92$ ).

The results of the first section of the perception of the disease, related to identity dimension, demonstrated that mothers perceived childhood cancer as a very symptomatic disease, and the most often related symptoms were pain (93.75%), weight loss (81.25%), fatigue (81.25%), loss of strength (81.25%), headache (75%), upset stomach (75%), dizziness (68.75%) and nausea (62.5%). The dimensions of the second section were interpreted considering a range of one to five according to the Likert scale (Strongly Disagree to Strongly Agree). The mean timeline of acute/chronic, above three, indicated that mothers perceived childhood cancer as a more chronic than acute illness. As for the consequences, the average was above four, that is, the disease was perceived as having serious consequences. Regarding personal and treatment control, the means showed that mothers considered that both the behavior of the patient and the treatment can be effective in controlling childhood cancer. The mean of 3.06 of the consistency dimension indicated that the mothers felt that they partially understood the disease. Childhood cancer was also considered as a cyclical disease ( $M = 3.85$ ,  $SD = .54$ ). The means of the emotional representation, close to four, suggested that mothers considered the disease as serious and threatening.

**Table 1**  
Means, Standard Deviation, Higher and Lower Scores Regarding PTSD Symptoms (PCL-C) and Disease Perception (IPQ-RH)

	Means	SD	Higher	Lower	Variation
Reliving	12.3	4.9	05	21	05-25
Avoidance	15.3	5.6	08	25	07-35
Arousal	15.3	6.4	05	25	05-25
PCL-C Total	43.0	14.7	22	71	17-85
Chronic/acute Timeline	3.3	.5	2.6	4.6	01-05
Consequences	4.2	.5	3.2	5.0	01-05
Personal control	3.5	.9	3.5	5.0	01-05
Treatment Control	4.1	.4	3.3	5.0	01-05
Coherence	3.0	.9	1.6	4.3	01-05
Timeline	3.8	.5	2.6	4.6	01-05
Emotional representation	3.9	.8	2.0	5.0	01-05

In the third section of the IPQ-RH, referring to the possible causes of childhood cancer, the means suggested that mothers attributed more general causes (e.g. heredity, type of food, fate or bad luck;  $M = 23.44$ ;  $SD = 2.82$ ) than psychological causes (e.g. stress or concern, emotional state, personality;  $M = 10.12$ ;  $SD = 2.52$ ) to the onset of the disease. The answers to the open question "Please, the three factors that seem to be able to cause cancer in children rank in order of importance" were analyzed and categorized. The categories were adapted from Figueiras and Alves (2007):

1. Diet/Eating habits/Overweight;
2. Difficulty in relation to access to medical care;
3. Biological Questions/Hormones/Immunity;
4. Heredity/Genetics;
5. Personal attitude/Behavior;
6. Emotional state/Stress /Concerns;
7. Excess of work;
8. Mystical or religious beliefs;
9. Do not know;
10. Other. In Table 2, the main reasons reported by the mothers are presented, and Heredity/Genetics and Biological Questions/Hormones/Immunity were the most prevalent ones.

**Table 2**  
Main Causes Attributed by Mothers for the Development of Childhood Cancer in their Child

Causes	Order of attribution		
	First (%)	Second (%)	Third (%)
Heredity/Genetics	43.75	25	12.5
Biological/Hormonal/Immunity	25	18.75	31.25
Diet/Eating Habit/Excess of weight	12.5	6.25	-
Mystical or religious beliefs	-	12.5	-
Emotional State/Stress/Concerns	-	6.25	12.5
Difficulty to access health care	-	-	6.25
Others	18.75	12.5	6.25
Do not know	-	18.75	31.25

Spearman's correlation analysis, conducted to examine the relationship between the perception of the disease dimension (acute /chronic timeline, consequences, personal control, treatment control, coherence, cyclic timeline, and emotional representation) and the PTSD symptoms dimension (reliving, avoidance and increased arousal), indicated that the more negative the emotional representation of childhood cancer, the more symptoms of reliving (.615;  $p < .05$ ) and avoidance (.679;  $p < .01$ ). The lower the perception of personal control, the more symptoms of avoidance (-.673,  $p < .01$ ). Similarly, the more negative the representation of childhood cancer, the higher the total score on the PCL-C (.631;  $p < .01$ ). The subscale increased arousal was not correlated with the dimensions of disease perception.

### Discussion

The results showed significant relationships between disease perception, PTSD, and posttraumatic symptoms. The emotional representation dimension was positively correlated with avoidance symptoms, reliving, and the total means of PCL-C. The more negative the perceptions of the emotions associated with the disease, the more PTSD symptoms were presented, the greater the attempts to avoid stimuli related to the event and the more the presence of intrusive memories about the experience. The personal control dimension was negatively correlated with the symptom avoidance, suggesting that the lower the perception of control and cure of cancer, the more frequent were the attempts to avoid thoughts and activities that provoked memories of the event.

The Common-Sense Model proposes that emotional regulation plays an important role in stress management (Cameron & Jago, 2008). The results showed that mothers perceived childhood cancer as a threat that generated a lot of fear and anxiety. Avoidance seems to have been employed as a strategy to deal with negative emotional states associated with the child's cancer experience. Avoidance can be considered an effective coping strategy in the short run as

it provides temporary relief. Nevertheless, in the long run, the attempts to dismiss negative emotions end up making them more intense and hindering the elaboration of traumatic memories. Avoidance can also adversely impact on the health care of the child with cancer. There is evidence that parents of childhood cancer survivors can avoid monitoring doctor visits as an effort to avoid the negative stress that the situation entails (Norberg et al., 2011)

The findings reinforce the notion that mothers of childhood cancer survivors are a group highly vulnerable to stress (Norberg et al., 2012). Indicators of moderate levels of PTSD have been identified in 50% and 62.5% of the sample according to the evaluation criteria used, with the rates found in the literature varying from 6.2% to 11% for the presence of PTSD (Alderfer et al., 2003) and 37% to 44% for the manifestation of symptoms (Barakat et al., 2006; Bruce et al., 2010). Lee and Santacroce (2007) point out the importance of investigating not only the possible presence of the disorder, but also to the existence of the symptoms. Presenting one of the groups of symptoms represents suffering, difficulties and losses in different areas of functioning. In terms of prevalence, 75% of mothers had reliving, indicating that even after months or years of the end of the treatment, they may have recurring memories and even distressing dreams involving the traumatic experience. Half of them reported symptoms of avoidance, characterized by the dismissal of thoughts and activities related to the traumatic event. The symptoms of increased arousal, found in 81.25% of the sample indicated the presence of anxiety and hyperarousal.

The distinctions between the prevalence observed in this study and the rates found in international studies may be related to socio-cultural aspects, instruments used, evaluation parameters, and sample size. In addition to the small number of participants, the sample was characterized by heterogeneity (mothers of children affected by different tumors, subjected to various treatments, with experiences of other traumatic events, etc.). Thus, the results should be interpreted cautiously, as well as the extrapolation of the findings to other populations. Fur-

ther studies should consider these aspects in order to improve the analysis of correlations, and may find other relevant and useful evidence for the in-depth understanding of the population investigated.

Although the PCL-C has been helpful in identifying possible cases of PTSD, for confirmatory diagnosis it is essential to have the clinical evaluation by a trained professional. Most mothers (87.5%) said they had experienced another potentially traumatic event in life. Among these, "death" and "serious illness of a family member" were the most prevalent. Even though the participants were instructed to answer the instruments relating their responses to childhood cancer, other stressful events may have influenced the results. There are predisposing variables, such as personality traits or causal antecedents that lower the threshold for the onset of symptoms or worsen its evolution. For this reason, besides the use of questionnaires or scales, it is important to conduct a clinical investigation so that the presence of the disorder is identified (Bringhenti et al., 2010).

Although the prevalence and severity of PTSD symptoms has been high, it might have been underestimated. It is possible that mothers with more severe symptoms have avoided answering the survey instruments in order to evade content perceived as negative, threatening and emotionally charged. This aspect may also have led to the reduced sample size.

Regarding the perception of the disease, measured by the IPQ-RH, it was found that mothers perceived childhood cancer as very symptomatic. It is possible that the adverse effects caused by the child's treatment may have been considered, since all underwent chemotherapy and a significant number held radio-therapy and surgery. Chemotherapy, for example, may cause side effects such as nausea, vomiting, and fatigue.

Regarding the consequences, mothers considered that cancer imposes many difficulties to the patients and those close to them. This perception is consistent with the context in which the experience of childhood cancer is inserted. The suffering imposed by the discovery

of the disease and by the effects of treatment, adds to problems of domestic order, such as managing the running of the house, taking care of other children and marriage. Mothers usually need to be absent from work or leave work for not feeling able to perform their jobs as a result of concerns about the sick child. In addition, the family is likely to face financial difficulties, since the treatments are expensive and made in large urban centers. Patients and family members living in other cities need to leave their homes to stay in hospital for long periods (Andrea, 2008; Ortiz, 2003).

Mothers also considered childhood cancer a chronic and cyclical disease. The notion of chronicity of childhood cancer involves the perception that it lasts for a long time and, even after a successful treatment, it is possible that the disease reappears and has no cure. Another idea is that the symptoms come and go in cycles, making childhood cancer unpredictable. As regards the personal and treatment control dimensions, mothers believed that the attitudes and behaviors of the sick child could determine the course of the disease. The treatment was perceived as effective in the control/cure of childhood cancer. These perceptions seem consistent with the fact that their children faced cancer and treatment has helped to make them survivors. Conversely, it is possible that mothers who lost their children because of cancer have lowered perceptions of personal and treatment control.

The analysis of the coherence dimension showed that mothers considered that they did not fully understand childhood cancer. The specific literature in this area indicates that one of the most common questions parents ask is: Why does my child have cancer? The explanations of the medical staff about the disease and treatment, while important, are not generally sufficient to appease the family anxieties (Ortiz, 2003).

As for the emotional representation, mothers considered childhood cancer a disease which generated fear, anxiety and threat to life. Despite the increased survival of children and adolescents with cancer, the disease still carries the social stigma that it invariably leads to death

(Ortiz, 2003). When finding that a child has cancer, the mother may experience anger, pain or denial. Later, mothers tend to show depressive symptoms and guilt for failing to protect the child from suffering (Méndez, Orgilés, López-Roig, & Espada, 2004). With the end of treatment, the mothers may have an exaggerated fear that the child might become ill again (Perina, Mastellaro, & Nucci, 2008), which corroborates the findings of this study.

As for the causes of cancer, mothers attributed more general causes (e. g., heredity, type of food, fate or bad luck) that psychological causes (e. g., stress or concern, emotional state, personality). When cancer affects an adult, the media, common sense and healthcare professionals themselves often attribute it to factors such as the lifestyle of the patient (e. g., smoking, poor diet, sedentary lifestyle, etc.) and to the emotional state (e. g., excess of concerns). In the case of childhood cancer, there is no scientific consensus on the causes, which hampers prevention (INCA, n.d.) and understanding from family (Andrea, 2008).

### Conclusion

This study, a pioneer in the national context, led to greater understanding of the relationship between disease perception, PTSD and post-traumatic symptoms in mothers of childhood cancer survivors. The results allowed the confirmation of the hypothesis that very negative perceptions of childhood cancer may be associated with avoidance symptoms, reliving and the total means of PCL-C. The high prevalence of posttraumatic symptoms and PTSD diagnostic indicators showed the psychological distress and high vulnerability of this group. The clinical relevance of the results reinforces the need to develop interventions and care strategies aimed at mothers of childhood cancer survivors. In this sense, the role of Psychology should not be restricted to the time of diagnosis and the treatment period, as the negative repercussions of the experience can accompany mothers even after the end of a successful treatment.

The results of this study should be interpreted with caution due to the small number of participants and non-randomness of the sample. As this is a cross-sectional study, causality has not been determined. The novelty of the theme in Brazil suggests that further studies with more robust designs should be developed to investigate the presence of PTSD and its relationship with other relevant variables in mothers of survivors. For example, the association with predisposing comorbid conditions such as depression and anxiety. In further studies, the changes proposed by the DSM-5 for PTSD should be considered. In addition, intervention protocols aimed at preventing PTSD in mothers with children diagnosed with cancer can be developed and tested in further researches.

### References

- Alderfer, M. A., Labay, L. E., & Kazak, A. E. (2003). Brief report: Does posttraumatic stress apply to siblings of childhood cancer survivors? *Journal of Pediatric Psychology*, 28(4), 281-286. doi:10.1093/jpepsy/jsg016
- American Psychiatric Association. (1995). *DSM-IV™: Manual diagnóstico e estatístico de transtornos mentais* (4<sup>th</sup> ed., M. R. Jorge, Consultoria & Coordenação). Porto Alegre, RS: Artes Médicas.
- American Psychiatric Association. (2008). *DSM-IV-TR™: Manual diagnóstico e estatístico de transtornos mentais: Texto revisado* (4<sup>th</sup> ed., M. R. Jorge, Consultoria & Coordenação). Porto Alegre, RS: Artes Médicas.
- Andrea, M. L. M. de. (2008). Oncologia pediátrica. In V. A. de Carvalho (Ed.), *Temas em psico-oncologia* (pp. 477-495). São Paulo, SP: Sumus.
- Arrais, A. R., & Araújo, T. C. (2000). Recidiva X cura: A vivência paradoxal da sobrevivência ao câncer na infância. *Revista Brasileira de Cancerologia*, 45(3), 9-19, 2000. Retrieved from [http://www.inca.gov.br/rbc/n\\_45/v03/artigo2.html](http://www.inca.gov.br/rbc/n_45/v03/artigo2.html)
- Barakat, L. P., Alderfer, M. A., & Kazak, A. E. (2006). Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of Pediatric Psychology*, 32(4), 413-419. doi:10.1093/jpepsy/jsg016

- Bardin, L. (1977). *Análise de conteúdo*. Lisboa, Portugal: Edições 70.
- Berger, W., Mendlowicz, M. V., Souza, W. F., & Figueira, I. (2004). Equivalência semântica da versão em português da *Post-traumatic Stress Disorder Checklist – Civilian Version* (PCL-C) para rastreamento do transtorno de estresse pós-traumático. *Revista de Psiquiatria do Rio Grande do Sul*, 26(2), 167-175. doi:10.1590/S0101-81082004000200006
- Bringhenti, M. E., Luft, C. D. B., & Oliveira, W. F. (2010). Transtorno de estresse pós-traumático em acidentes de trânsito: Validação da escala. *Psico-USF*, 14(2), 193-203. doi:10.1590/S1413-82712010000200007
- Bruce, M. (2006). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical Psychology Review*, 26, 233-256. doi:10.1016/j.cpr.2005.10.002
- Bruce, M., Gumley, D., Isham, L., Fearon, P., & Phipps, K. (2010). Post-traumatic stress symptoms in childhood brain tumour survivors and their parents. *Child: Care, Health and Development*, 37(2), 244-251. doi:10.1111/j.1365-2214.2010.01164.x
- Cameron, L. D., & Jago, L. (2008). Emotion regulation interventions: A common-sense model approach. *British Journal of Health Psychology*, 13, 215-221. doi:10.1348/135910708X288800
- Ehlers, A., & Clark, D. M. (2000). A cognitive model of posttraumatic stress disorder. *Behavior Research and Therapy*, 38(4), 316-145. doi:10.1016/S0005-7967(99)00123-0
- Figueiras, M. J., & Alves, N. C. (2007). Lay perceptions of serious illnesses: An adapted version of the Revised Illness Perception Questionnaire (IPQ-R) for healthy people. *Psychology and Health*, 22(2), 143-158. doi:10.1080/14768320600774462
- Figueiras, M. J., Machado, V. A., & Alves, N. C. (2002). Os modelos do senso-comum das cefaleias crônicas nos casais: Relação com o ajustamento marital. *Análise Psicológica*, 20(1), 77-90. Retrieved from [http://www.scielo.oces.mctes.pt/scielo.php?pid=S0870-82312002000100008&script=sci\\_arttext](http://www.scielo.oces.mctes.pt/scielo.php?pid=S0870-82312002000100008&script=sci_arttext)
- International Society for Traumatic Stress Studies. (2014). *Assessing trauma – Posttraumatic Stress Disorder Checklist (PCL)*. Deerfield, IL: Author. Retrieved from <http://www.istss.org//AM/Template.cfm?Section=Home>
- Kamibeppu, K., Sato, I., Honda, M., Ozono, S., Sakamoto, N., Iwai, T, ...Ishida, Y. (2010). Mental health among young adult survivors of childhood cancer and their siblings including posttraumatic growth. *Journal of Cancer Survivorship*, 4, 303-312. doi:10.1007/s11764-010-0124-z.
- Lee, Y., & Santacroce, S. J. (2007). Posttraumatic stress in long-term young adult survivors of childhood cancer: A questionnaire survey. *International Journal of Nursing Studies*, 44(8), 1406-1477. doi:10.1016/j.ijnurstu.2006.07.002
- Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behavior* (pp. 42-61). London: Routledge.
- Leventhal, H., Nerenz, D., & Steele, D. J. (1984). Illness representation and coping with health threats. In A. Baum, T. A. Revenson, & J. E. Singer (Eds.), *Handbook of Health Psychology* (pp. 219-252). London: Lawrence Erlbaum.
- Méndez, X., Orgiléz, M., López-Roig, S., & Espada, J. P. (2004). Atención psicológica en el cáncer infantil. *Psicooncología*, 1(1), 139-154. Retrieved from <http://revistas.ucm.es/index.php/PSIC/article/view/PSIC0404110139A>
- Monteiro, I., & Léon, O. G. (2007). A guide for naming research studies in Psychology. *International Journal of Clinical and Health Psychology*, 7(3), 847-862. Retrieved from <http://www.redalyc.org/articulo.oa?id=33770318>
- Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, 17(1), 1-16. doi:10.1080/08870440290001494
- National Cancer Institute. (n.d.). *Câncer – O que é*. Rio de Janeiro, RJ: Author. Retrieved from <http://www2.inca.gov.br/wps/wcm/connect/cancer/site/oquee>
- Norberg, A. L., Pöder, U., & Essen, L. V. (2011). Early avoidance of disease and treatment related distress predicts post-traumatic stress in parents of children with cancer. *European Journal of Oncology Nursing*, 15(1), 80-84. doi:10.1016/j.ejon.2010.05.009
- Norberg, A. L., Pöder, U., Ljungman, G., & Essen, L. (2012). Objective and subjective factors of predictors of post-traumatic stress symptoms in

- parents of children with cancer – A longitudinal study. *PlosOne*, 7(5), 1-8. doi:10.1371/journal.pone.0036218
- Ortiz, M. C. M. (2003). *À margem do leito: A mãe e o câncer infantil*. São Paulo, SP: Arte e Ciência.
- Perina, E. M., Mastellaro, M. J., & Nucci, N. A. G. (2008). Efeitos tardios do tratamento do câncer na infância e na adolescência (pp. 496-504). In V. A. Carvalho (Ed.), *Temas em psico-oncologia*. São Paulo, SP: Sumus.
- Plumb, J. C., Orsillo, S. M., & Luterek, J. A. (2004). A preliminary test of the role of experiential avoidance in post-event functioning. *Journal of Behavior Therapy and Experimental Psychiatry*, 35(3), 245-257. doi:10.1016/j.jbtep.2004.04.011
- Schwartz, L., & Drotar, D. (2006). Posttraumatic stress and related impairment in survivors of childhood cancer in early adulthood compared to healthy peers. *Journal of Pediatric Psychology*, 31(4). doi:10.1093/jpepsy/jsj018
- Schwartz, L. A., Kazak, A. E., Derosa, B. W., Hocking, M. C., Hobbie, W. L., & Ginsberg, J. P. (2012). The role of beliefs in the relationship between health problems and posttraumatic stress in adolescent and young adult cancer survivors. *Journal of Clinical Psychology in Medical Settings*, 19(2), 138-146. doi:10.1007/s10880-011-9264-1
- Sheldrik, R., Tarrier, N., Berry, E., & Kincey, J. (2006). Post-traumatic stress disorder and illness perceptions over time following myocardial infarction and subarachnoid haemorrhage. *British Journal of Health Psychology*, 11(3), 387-400. doi:10.1348/135910705X71434
- Silva, G. M. da, Teles, S. S., & Valle, E. R. M. do. (2005). Estudo sobre as publicações brasileiras relacionadas a aspectos psicossociais do câncer infantil – Período de 1998 a 2004. *Revista Brasileira de Cancerologia*, 51(3), 253-261. Retrieved from [http://www.inca.gov.br/rbc/n\\_51/v03/pdf/revisao4.pdf](http://www.inca.gov.br/rbc/n_51/v03/pdf/revisao4.pdf)
- Weathers, F. W., Litz, B. T., Herman, D. S., Huska, J. A., & Keane, T. M. (1993). The PTSD Checklist (PCL): Reliability, validity, and diagnostic utility. *Annual Meeting of International Society for Traumatic Stress Studies*. San Antonio, TX: International Society for Traumatic Stress Studies. Retrieved from <http://www.istss.org/PosttraumaticStressDisorderChecklist.htm>
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11(3), 431-445. doi:10.1080/08870449608400270
- Whealin, J. M., Ruzek, J. I., & Southwick, S. (2008). Cognitive-behavioral theory and preparation for professionals at risk for trauma exposure. *Trauma, Violence & Abuse*, 9(2), 100-113. doi:10.1177/1524838008315869.
- World Health Organization. (2014). *Cancer*. Geneva, Switzerland: Author. Retrieved from <http://www.who.int/topics/cancer/en/>

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