

## Stress vulnerability: parents that take care of cancer bearing children

Vulnerabilidade ao estresse: pais cuidadores de filhos com câncer

Vulnerabilidad al estrés: pais cuidadores de hijos con cáncer

Anna Luiza Correia Fontes<sup>1</sup>, Anna Cláudia Freire de Araújo Patrício<sup>2</sup>, Lidianne Mariz de Lima<sup>3</sup>, Thayná Dias dos Santos<sup>4</sup>, Lazuir Braga Matos do Nascimento<sup>5</sup>, Richardson Augusto Roseando da Silva<sup>6</sup>

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### ABSTRACT

**Objective:** The study's purpose has been to further investigate the stress experienced by parents that take care of cancer bearing children. **Methods:** It is an exploratory and cross-sectional study with a quantitative approach, which was performed with 22 mothers who received support at the House of the Child with Cancer located in João Pessoa city, Paraíba State, Brazil. Data were collected from March to May 2016 through a sociodemographic and stress vulnerability questionnaire. Data were processed using parameters as the absolute and relative frequency, average and standard deviation, minimum and maximum. The study was approved by the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] N°. 49175015100005176. **Results:** It was verified that 59.1% (13) were male children and 100% (22) female (mothers) who cared for their children; the most prevalent treatment was chemotherapy; 100% of caregivers presented high vulnerability to developing stress. **Conclusion:** The multiprofessional assistance is needed not only for the child diagnosed having cancer, but also for the caregiver and the family that participates and assistance during moments of suffering.

**Descriptors:** Neoplasms, Child, Psychological stress, Parents.

### RESUMO

**Objetivo:** Investigar o estresse vivenciado por pais ou mães que cuidam de filhos com câncer. **Métodos:** Pesquisa quantitativa realizada com 22 mães que recebiam apoio na Casa da Criança com Câncer em João Pessoa/Paraíba, Brasil. Os dados foram coletados entre março e maio de 2016 por meio de questionário sociodemográfico e de vulnerabilidade ao estresse. Os dados foram processados pela frequência absoluta e relativa, média e desvio padrão da média, mínimo e máximo. Aprovado CAAE: 49175015100005176. **Resultados:** Verificou-se que 59,1% (13) eram crianças do sexo masculino e 100% (22) mulheres (mães) que cuidavam dos filhos; o tratamento mais prevalente foi à quimioterapia; 100% dos cuidadores apresentaram alta vulnerabilidade de desenvolver estresse. **Conclusão:** É necessária uma assistência

1 Nurse, Specialist's Degree in Oncology, Surgical and Molecular Hematology. E-mail address: annaluizafontes@hotmail.com.

2 Nurse, PhD student enrolled in the Nursing Postgraduate Program by the UFRN. E-mail address: claudia.freirearaujo@gmail.com.

3 Nursing Undergraduate by the UNIPÊ. E-mail address: lidianne@outlook.com.

4 Nursing Undergraduate by the UNIPÊ. E-mail address: thaynaadds@hotmail.com.

5 Nurse. E-mail address: lazuirlbm@gmail.com.

6 Nurse, PhD Professor of the Nursing Postgraduate Program at UFRN. E-mail address: rirosendo@hotmail.com.

multiprofissional direcionada não apenas à criança diagnosticada com câncer, mas ao cuidador e à família que participa e auxilia em todos os momentos de sofrimento.

**Descritores:** Neoplasias, Criança, Estresse Psicológico, Pais.

## RESUMEN

**Objetivo:** Investigar el estrés vivido por padres o madres que cuidan hijos con cáncer. **Método:** Investigación cuantitativa realizada con 22 madres que recibían apoyo en la Casa del Niño con Cáncer en João Pessoa/Paraíba, Brasil. Los datos fueron recolectados entre marzo y mayo de 2016 a través de cuestionario sociodemográfico y de Vulnerabilidad al estrés. Los datos fueron procesados por la frecuencia absoluta y relativa, media, desviación estándar de la media, mínimo y máximo. Aprobado CAAE: 49175015100005176. **Resultados:** Se verificó que el 59,1% (13) eran niños del sexo masculino y 100% (22) mujeres (madres) que cuidaban a los hijos; El tratamiento más prevalente fue a la quimioterapia; 100% de los cuidadores presentaron una alta vulnerabilidad de desarrollar estrés. **Conclusión:** Es necesaria una asistencia multiprofesional dirigida no sólo para el niño diagnosticado con cáncer, sino al cuidador y la familia que participa y auxilia en todos los momentos de sufrimiento.

**Descriptores:** Neoplasias, Niño, Estrés Psicológico, Padres.

## INTRODUCTION

Infantile cancer corresponds to a group of several diseases that have in common the proliferation of abnormal cells and which can manifest in different places and in different organisms.<sup>1</sup>

Accordingly, there are different cases of tumors more frequent in childhood and adolescence, then being the first cause of death (with a total of 7%) in the age group from 1 to 19 years old. Still, it is estimated that there will be approximately 12,600 new cases of children and adolescents in Brazil per year in 2016 and 2017, of which there will be 2,750 cases in the Northeast region.<sup>1</sup>

Nowadays, infantile cancer is considered as a chronic pathology that, by encompassing several diseases that present uncontrolled proliferation of abnormal cells, directly affects the cavities of the blood system and the supporting tissues. This disease can invade tissues and organs where they can spread to different regions of the body or focus on only one of them, and varies according to the types of cells in the body.<sup>1,2</sup>

The treatment is specific for each type of cancer, being carried out individually and in a varied way from the extension of the disease. Thus, therapy is intensive, resulting in side effects in the patient, such as nausea, fever, alopecia, and others, promoting greater interaction among family members, who must deal with concerns, denial and stress, finding themselves vulnerable from diagnosis to the treatment.<sup>2</sup>

When the news of the diagnosis of a family member with cancer, the family enters in a situation of emotional exhaustion in the other elements of this group, and one of the first feelings that appear is the stress, composed of multiple events that lead to its intensification.<sup>3</sup>

Even with technological advances relevant to health care in the treatment and diagnosis of cancer, it still greatly feared, being in parallel with death, so that triggers an

emotional reaction that requires psychological care to deal with the feelings of the family, of the patient, and the other professionals involved in the clinical environment.<sup>4</sup>

The term stress was first used by Selye (1956) that characterized as General Adaptation Syndrome (GAS), in which it stems from an event that requires an effort of the individual in terms of adequacy. This active environment is called the stressor, triggering the rupture of the individual's internal homeostasis, causing the body not to have control over its constancy.<sup>5</sup>

Stress is a state in humans that occurs abnormal wear of the body and/or a decrease caused capacity, most of the time, by a prolonged inability to tolerate, overcome or adapt to the psychic nature demands that the environment provides.<sup>6</sup>

Only from the 19<sup>th</sup> century did speculation begin on the possible relations between the relevant emotional events and physical and mental illnesses that received diverse attention from the scientific class only from the 20<sup>th</sup> century.<sup>7</sup>

Consequently, as often stress the occupational setting, there are several studies on burnout syndrome, which is a psychological disease produced in response to chronic interpersonal stressors that health professionals experience in the clinical setting. This expression comes from the English language, which means to burn, extinguish, extinguish, showing perfectly the characterization of the individual who suffers from this disease.<sup>5</sup>

Given the aforementioned, this research came about from the following question: Is there vulnerability to stress in parents who take care of their cancer bearing children?

The study's goal was to investigate the stress experienced by parents that take care of their cancer bearing children.

## METHODS

It is an exploratory and cross-sectional study with a quantitative approach. The research was carried out in the House of the Child with Cancer located in *João Pessoa* city, *Paraíba* State, Brazil.

Parents or mothers of children diagnosed with cancer who were supported by the House of the Child with Cancer and were responsible for the custody of the child were selected for the study. Parents who did not provide care for the child with cancer were excluded.

Considering inclusion and exclusion criteria, the site of data collection has 32 parents who accompany children having cancer. Twenty-two parents linked to the House of the Child with Cancer have participated in this study. Data were collected over the period from March to May 2016.

For data collection, a questionnaire was used for sociodemographic data containing the following variables: related to the parents (age, marital status, schooling), related to the child (the cancer type, treatment time, gender, age, schooling, which treatment receives).

The validated stress vulnerability questionnaire (23 QVS)<sup>8</sup> was also used with the fundamental purpose of evaluating the vulnerability that a given individual presents

to a stress-inducing situation. This instrument is composed of 23 questions with five Likert-style response options: I agree at all (0 points), I strongly agree (1 point), neither agree nor disagree (2 points), strongly disagree (3 points) and disagree absolutely 4 points). This instrument is evaluated so that the higher the overall score, the more predictable an individual is vulnerable to stress. Since the questions numbered 1,3,4,6,7,8,20 corrected from left to right (with values 0,1,2,3 and 4), the rest are corrected in the opposite direction.

These scores are summed to allow classification of vulnerability to stress. The score of 28 or higher indicates people who are more vulnerable to stress and the score below 28 corresponds to the least vulnerable individuals.<sup>8</sup>

The data was transcribed into the Microsoft Office Excel version 2013 for Windows program and subsequently exported and processed by the Statistical Package for Social Sciences program - SPSS - version 19.0.

The data that comprise the sociodemographic questionnaire were defined by the performance of descriptive statistics with absolute and relative frequency. The second part related to Stress was performed the absolute and relative frequency, average and standard deviation, minimum and maximum.

The study was approved by the Ethics and Research Committee from the *Centro Universitário de João Pessoa (UNIPÊ)* under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 49175015100005176. All participants were asked to sign the Free and Informed Consent Term in accordance with the Resolution No. 466/2012 from the National Health Council that guides the research involving human beings.<sup>9</sup>

## RESULTS

The sociodemographic data from the study's participants revealed average age of the parents of 34.2±8.1 years old, and of the children of 9.7±5.5 years old. **Table 1** shows the information related to the profile.

**Table 1** - Sociodemographic profile of the study's participants. *João Pessoa* city, *Paraíba* State, Brazil. n=22.

Variable	n	%
<b>Related to the parents</b>		
<b>Gender</b>		
Female	22	100%
<b>Marital status</b>		
Single	10	45.5%
Married	11	50%
Widow	1	4.5%
<b>Schooling</b>		
Illiterate	2	9.1%
Literate	7	31.8%
Complete primary education	9	40.9%
High school	3	13.6%
Higher education	1	4.5%

Variable	n	%
<b>Related to the child</b>		
<b>Gender</b>		
Female	9	40.9%
Male	13	59.1%
<b>Schooling</b>		
No education	2	9.1%
Infantile Education	7	31.8%
Elementary School I	7	31.8%
Elementary School II	5	22.7%
High School	1	4.5%

Studying the type of cancer developed by the children, the **Table 2** reveals some varieties that were raised from the research performed.

**Table 2** - Types of treatments that the children diagnosed having cancer underwent. *João Pessoa* city, *Paraíba* State, Brazil. n=22.

Cancer type	n	%
Pilocytic Astrocytoma	1	4.5%
Kidney cancer	1	4.5%
Papilliferous Carcinoma	1	4.5%
Leukemia	9	40.9%
Acute lymphoid leukemia	3	13.6%
Lymphoma	3	13.6%
Osteosarcoma	1	4.5%
Sarcoma	1	4.5%
Malignant Brain Tumor	1	4.5%
Wilms Tumor	1	4.5%

Considering both the treatment type and how long it has been done, **Table 3** shows the form adopted for fighting against cancer and for how long the child is performing each type of therapy.

**Table 3** - Information related to the study participants' treatment. *João Pessoa* city, *Paraíba* State, Brazil. n=22.

Variable	n	%
<b>Treatment type</b>		
<i>Bactrin</i> <sup>*</sup>	1	4.5%
<i>Depakote</i> <sup>*</sup> and <i>Metotrexato</i> <sup>*</sup>	1	4.5%
<i>Depakote</i> <sup>*</sup> , <i>Rivotril</i> <sup>*</sup> and Leptic drug	1	4.5%
Ludotherapy	1	4.5%
<i>Porimontol</i> <sup>*</sup> and <i>Gilvec</i> <sup>*</sup>	1	4.5%
<i>Purinethol</i> <sup>*</sup>	1	4.5%
Chemotherapy	9	40.9%
Chemotherapy and radiation therapy	2	9.1%
Not informed	5	22.7%
<b>Treatment time</b>	A= 3.2 SD= 2.9 Max= 10 years Min= 1 month	

A= average. SD= standard deviation.

Considering the vulnerability to stress in parents who care for children with cancer, **Table 4** explains the degree of risk that they find as caregivers.

**Table 4** - Vulnerability to stress in parents who care for cancer bearing children. *João Pessoa* city, *Paraíba* State, Brazil. n=22.

Stress vulnerability	n	%
Parents more vulnerable to stress (score greater than 28 points)	22	100%
Parents less vulnerable to stress (score less than 28 points)	0	0
<b>Stress vulnerability score</b>	A= 63.18 DS= 6.7 Min= 49 Max=79	

A= average. SD= standard deviation.

## DISCUSSION

By being a caregiver of children having cancer, a member of the family group is assigned to assume the role of companion, taking into account the degree of kinship, empathic relationship, geographical proximity and even lack of choice immediately. This relationship results in the development of physical and emotional tension, leading the caregiver to the exhaustion of taking responsibility for dealing with the patient.<sup>3</sup>

A higher prevalence of boys is observed in **Table 1**, corroborating with data from the *Instituto Nacional do Câncer (INCA)* [National Cancer Institute].<sup>10</sup> The health-care process experienced by parents who care for children with cancer may become even more significant, as many fear the death of their children, the possibility of having a prosperous life, dreams and achievements, leading to increased stress in the family, because many of the relatives are apprehensive and emotionally unstructured with the possibility of death.<sup>3</sup>

The most frequent diagnosis in the research was the Leukemia in line with Brazilian statistics presented by *INCA*, which reveal 25% of the cases of childhood neoplasm to be of this type in *João Pessoa* city, *Paraíba* State, where this research was collected.<sup>10</sup>

Parents, when faced with some type of cancer in the child, go into shock, confusion, fear, and tension, reaching the rest of the family with worries. Parents, as they take care of the role of caregiver, seek information about the type of cancer that the child presents, knowing and understanding it, so that they can feel able to take care of the child, resulting in decreased stress and anxiety.<sup>11</sup>

**Table 3** shows that the type of treatment most used for cancer cases in children was chemotherapy, as was approached by the Portuguese Association Against Leukemia.<sup>12</sup>

Chemotherapy is a treatment that uses drugs to destroy the cells that make up a tumor. This treatment has the side effects of weakness, diarrhea, weight gain, mouth sores, hair loss and other body hairs, nausea, vomiting and dizziness.<sup>1</sup>

In the other forms of treatment of the study subjects, specialized drugs were used for each type of cancer, such as *Bactrin*®, *Depakote*® and *Metotrexato*®, *Porimontol*® and *Gilvec*®, and *Purinethol*®, which totaled 4.5% each.

The use of drugs to treat cancer results in many side effects that may require specific treatments or changes in the therapeutic plan of cancer, being more frequent the hair loss, anxiety, nausea, vomiting, anemia, fatigue and renal and digestive alterations. Much of these effects are transient, varying between patients and the function of the type of drug combination used.<sup>1</sup>

We also observed play activities adopted in the treatment offered to children with cancer who are hospitalized, such as watching television, using computers, games, and toys, making drawings, toys and clowns. Such activities become a means of fun, of feelings of joy, distraction, and interaction with other people, characterizing them as essential elements in the caring process, which offers the well-being of caregivers, reducing the discomfort of all people.<sup>13</sup>

The average time that the children were submitted to the treatment of infantile cancer, still according to **Table 3**, is conditioned in 3.2 years, with a standard deviation of 2.9 years and the maximum time presented was 10 years.

When parents spend a few years caring for their children with cancer, they show high levels of stress, and it is painful to go about their normal lives because they do not feel safe for other caregivers to offer their services. Parents become more confident when they help their children cope with the illness and the ongoing process of hospitalization.<sup>14</sup>

Parents who care for their children with cancer feel weak and powerless; they put hope in health professionals who exude the concrete possibilities that generate changes in the clinical picture of the child. Thus, the parents get along with the team, creating expectations and demonstrating the need for strengthening, care, and support.<sup>4</sup>

The stress vulnerability of parents who care for their children with cancer is highlighted since 100% have either vulnerable or compatible symptoms. These symptoms are heightened by other factors such as gender, psychological stress intensifier of the child's family environment of cancer. When inserting the woman (mother) in the process of care of the sick child, there are innumerable activities such as: being a mother, wife, knowing the pathology of the child, housewife, exercising professional activity. Furthermore, when he realizes that he has performed some task unsatisfactorily, he creates feelings of inadequacy and is burdened with multiple obligations.<sup>3</sup>

In order to alleviate the effects of the treatment period of children with cancer, it is advisable to massage anti-stress that promotes different sensations when performed by trained professionals, since relaxation and emotional support directly benefits the various organic processes, such as improved perception, body sensitivity, body awareness, decreases anxiety level, relieving the effects of stress such as hypertension, ulcers, indigestion, infectious problems, insomnia, headaches, anxiety, and depression.<sup>2</sup>

Actions to minimize the stress of family members, especially of the person caring for the child in cancer treatment, contribute to the relief of tension, potentiate hope, reduce stress, and increase confidence in treatment.<sup>3</sup>



A professional mediator and facilitator is the psychologist who plays an important role in helping patients and their parents to cope, as well as in the interaction with other professionals of the multidisciplinary team linked to hospitalization of the child with cancer.<sup>4</sup>

Still considering the importance of the participation of multidisciplinary teams, it is necessary to have a holistic view that considers not only the patient, but those family members who take care of daily and participate in the routine of treatment. It is relevant that the nursing team characterized as those who spend most of the time in the hospital environment, see the need for psychological support, promote a calm environment that reassures those involved, provide information about the disease and treatment, apply the nursing process consistent with the reality and necessity of the customer.<sup>15</sup>

## CONCLUSIONS

This research aimed to investigate the stress experienced by parents who take care of their children with cancer, and the stress vulnerability was detected in all caregivers.

The research pointed out that stress is directly linked to the caregiver of the child having cancer, because of coexistence with uncertainty, anxiety, despair, hope, lead these people to want to act immediately, so that the child and the adolescent have an immediate recovery.

The women interviewed had a stressful social situation, perhaps because they were caring for children with cancer in the hospital environment, either because of the complexity of hospital admissions or because of the age group of the children, the majority of whom are in the first series of Infantile Education and Elementary School. Besides the fact that many of them are undergoing chemotherapy and radiotherapy sessions, involving all those unwanted impasses of the reactions to the drugs that happen to the organism.

The family plays a very important role in the treatment, recovery, and encouragement of cancer bearing children.

Hence, the need for multiprofessional care is underlined not only for the child diagnosed with cancer, but also for the caregiver and the family that participates and assists during moments of suffering. It is considered essential for achieving the therapeutic success, as it will enable reduction of physical, mental and biological suffering.

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### Corresponding author

**Anna Cláudia Freire de Araújo Patrício**

**Address:** Avenida Senador Salgado Filho, s/n - Lagoa Nova, Natal, Rio Grande do Norte, Brazil

**Zip Code:** 88.054-260

**Telephone number:** +55 (84) 3215-3196

**E-mail address:** [claudia.freirearaujo@gmail.com](mailto:claudia.freirearaujo@gmail.com)

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