

**170 - DEVELOPMENT OF A CHILD WITH CONGENITAL LEUKEMIA AND MATERNAL RESILIENCY**

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**INTRODUCTION**

The cancer comes today as the third death cause for disease in Brazil between 1 and 14 years and, according to Steuber and Nesbit (1997) the incidence rate has been growing around 1% a year. Among the several cancer types the leukemias constitute the evil neoplasia more common of the childhood, corresponding about 25% to 30% of the cases (RODRIGUES and CAMARGO, 2003; ELM et al, 2002).

In the just born the leukemia is extremely rare, representing about 1% of all the cases of infantile leukemia. The leukemia is classified of congenital nature when diagnosed in the first 28 days after the birth and neonatal when the child shows between Wednesday and sixth week of life (Sande, Arceci and Lampkin, 1999). In agreement with the kinetics of the cellular growth in the leukemia is reasonable to suppose that when the disease is diagnosed in the first four weeks of life, it has originated if in the maternal uterus.

It is believed that the etiology of the congenital leukemia and neonatal this related to congenital anomalies and the mother's exhibition during the gestation to chemical substances. To this respect she have been identifying mutations of chromosomes that are common in the congenital leukemia and neonatal (Zipurdky et al, 1994; Grier and Weinstein, 1993). In the children with Syndrome of Down the incidence of congenital leukemia or neonatal is twenty times higher than in the remaining of the population.

In the newly born the skin manifestations are common, in many cases can present infiltration skin nodular. The nodules can measure approximately of 2 mm to 3 cm of diameter and they can be tangible as tumors fibromatosy of the deep subcutaneous fabric. The hepatomegaly and the splenomegaly are also frequent. Those children usually present little weight earnings, fever, diarrhea, severe paleness and breathing and heart inadequacy secondary the leukocytosis. The anemia and the low platelets are frequent, could take to intracranial hemorrhages. Sepsis, pneumonia, and other infections result of the functional neutropenia and breathing depression. The children also can show sleepiness, little appetite and umbilical bleeding, gastrointestinal and genitourinary. (Sande, Arceci and Lampkin, 1999; Elm et al, 2002). According to Sande, Arceci and Lampkin (1999) during the process of disease and treatment, for the high breathing risk and of infections the neonatos frequently request intensive cares, needing to stay in atmosphere of the hospital. As soon as diagnosed the leukemia the treatment with appropriate chemotherapy it should be instituted.

Data of United States Cancer Institute show that 72% to 95% of patients with cancer in treatment presented an increase in the levels of fatigue that result in a significant decrease in the functional capacity, leading to a great loss in the life quality. The combinations of metabolic modifications and the psychological stress take the patients to begin a vicious cycle of loss of muscular mass, hindering the growth and the child's global development.

During whole the process of disease and treatment the responsible for the child, usually is a function of the mother, accompanies the child in the internment period and suffering a great psychological and physical waste. Besides the emotional disturbance, of the suffering when seeing the sick son, of the social isolation, of the great change in the life routine, among other factors, they also have the prejudiced sleep quality, they feed in an inadequate way and neglecting of your own health for the fact of the attention to be only centered in the child.

The responsible for the child should be plenty resilient to support all stress of that process and to contribute with the child's cure. The resiliency, according to Placco (2001), it is the capacity to answer from a more consistent way to the challenges and difficulties, of reacting with flexibility and capacity recovery before challenges and unfavorable circumstances, tends an attitude optimistic, positive and persevering and maintaining a dynamic balance during and after the collisions, a personality characteristic that, activated and developed, it makes possible to the subject to overcome and to the pressures of his world, to develop a realistic self-confidence and an self protection sense that it doesn't disrespect the opening to the new, to the change, to the other and the underlying reality.

According to Ferreira (1975), the term resiliency came from the Physics and it refers to the property that the energy stored in a deformed body it is returned when it interrupts the tension of the elastic deformation. An example very used to represent the term is like an elastic band that, after an initial tension, it returns to the same state. In the Psychology, the definition of the term resiliency is not as necessary as in the Physics and in the Engineering, mainly considering the multiplicity and the complexity of factors and the varied that should be mischievous in bill in the study of the human phenomena (POLETTI, WAGNER and KOLLER, 2004).

In the ecological perspective, the human development is studied through the interaction between person and atmosphere, where the person and his atmospheres are seen as mutual formation system, where each system changes in elapsing of the time and each one of them adapts as answer to the changes happened in the first (YUNES and SZYMANSKI, 2001).

Thus, in the glance of the ecological perspective, a child's mother's resiliency with congenital leukemia can soften or to exacerbate the suffering lived by both during the process of disease and treatment of the cancer. So that report describes a child's case with leukemia congenital, with emphasis in the child's development and in the profile of the mother's resiliency.

**PRESENTATION OF THE CASE**

The information were obtained through consultation to the child's handbook hospital, evaluation of the child's development using the Manual for Surveillance of the Infantile Development in the Context, developed by the Program of Integral Attention the Diseases Prevalence in the Childhood (AIDPI, 2005) to evaluate the infantile development from 0 to 2 years, recommended by the Pan-American Organization of the Health (OPAS/OMS), classifying it as probable delay in the development, normal development and normal development with risk factors, besides the application of the questionnaire Resiliency-MAP (Essi Systems, 2000) with the mother, with the objective of tracing the resiliency profile.

Indeed a child, of the feminine sex, with nine months and nine days of age (it dates of the evaluation), third son of an originating from couple a municipal district of the interior of the state of Santa Catarina, South of Brazil, coming interned for treatment chemotherapy in the infirmary of Onco-Hematology of the Infantile Hospital Joana of Gusmão, reference in the

attendance to the child with cancer in the state.

The mother affirmed to have accomplished accompaniment monthly exams during all gestation, without any problems, except blood pressure fall. The childbirth was normal, (nine months) and according to the mother the child was born "purple", obtaining note 7 in the agar 1st minute and 8 in the 5°minuto. The weight to the birth was of 3130 g, length of 49 cm and cephalic perimeter of 34 cm. In the discharge oh the hospital it weighed 3050 g, in the 22nd day after the birth it weighed 4000 g, the stature it was of 53 cm and the cephalic perimeter of 37 cm. the child didn't have any serious disease, except episodes of fever as manifestation of the leukemia. In the 26th day of life the child had the diagnosis confirmed cytopatologic of leukemia sharp lymphocytic of high risk and congenital character, been interned and beginning the treatment immediately.

According to the mother, the child's development it is late in function of the process of disease and treatment, because the weight and the stature are below the normal and in the evaluation with the Manual for Surveillance of the Infantile Development in the Context, the child presented "possible delay in the development", with absence of two marks for your age and percentile below the expected. While the mother, according to the classification of Resiliency-MAP presented a profile of negative resiliency, in other words, below the expected.

## DISCUSSION

### The child's development

The child presented percentile lower of the expected for your age, with low weight and stature, but in the cephalic perimeter the measure (44 cm) which was normal for his age according to CDC - Centers for Disease Control and Prevention (NCHS, 2000). That growth below the expected is justified for the appetite reduction and infection of the treatment gastrointestinal provoked by the own disease and/or collateral effects of the chemotherapy (SANDE, ARCECI and LAMPKIN, 1999; ELM et al, 2002).

### Evaluation in the strip of the nine months:

In the evaluation of the child's behavior, the same presented difficulty in accomplishing two tasks in the evaluation of the strip of the nine months (pictures below), equivalent your chronological age, being classified with "possible delay in the development" (AIDPI, 2005). She was not capable to duplicate syllables and to sit down without support holding an object with the hands. The child got to be in the seated posture, however as she was not with the complete subsequent support, she didn't feel safe to manipulate the object.



Seek and hide



Objects one hand from to another



Syllable duplication



Seat without support

### Evaluation in the strip of the six months:

As the child presented difficulty in two tasks for your age group, following the instructions of the Manual for Surveillance of the Infantile Development in the Context of AIDPI (2005), a new evaluation of the child was accomplished by the previous age group, strip of the 6 months.

In that strip, the child got to accomplish all the tasks without presenting great difficulties, as they illustrate the pictures below:



Seat toy



Take objects to the mouth



Find the sound



Roll

The small delay in the child's development seems to be related directly with the process of disease and/or the proper treatment. For passing larger part of your life inside of the hospital atmosphere the child had great restrictions in her development, as the conviviality lack with other children, the space lack and appropriate toys to her age, few visual, sensorial and tactile incentives, besides the privation of the conviviality with her parents.

#### **Profile of the mother's resiliency**

The result of each scale falls into one of four Performance Zones which represents varying levels of strength or difficulty in the areas being measured. The top two zones of the grid reflect degrees of strength and the bottom two zones reflect degrees of vulnerability. The four performance zones are: Optimal (highest level of effectiveness and renewal, even when under pressure); Balance (effective and steady performance in most situations); Strain (Often run into difficulty, feel overwhelmed or depleted); Caution (significant difficulty and distress, impaired functioning or effectiveness).

The mother presented a lower resiliency profile (TABLE 1). In scale of Non work resources she obtained a low score, what reflects conflicts with your partner or frustration with your social net of support. To Self esteem she was in balance representing that the mother feels pride of who they are and believe that they deserve love. The tension state in the positive Outlok means pessimism and the tendency to see the world as melancholic and without hope, always waiting for the worst. The negative results in Personal power and purpose in life demonstrates that woman is without hope feeling victimized and unable to take action, besides being alienated, feeling detached and aimless. The self care in balance shows that she uses the time well, supplying your needs for a good health. The direct action and situation mastery are in caution, indicating an inability to accomplish tasks, hesitation in the hour of to act or to avoid to complete an action, besides an effort frustrated in the attempt of controlling the uncontrollable. The balance in the adaptability demonstrates flexibility in trying with new strategies the resolution of problems. The tension state in time management appears for a disorganized person, which leads to a cycle of missed deadlines and frustration. Support seeking and the expression in balance demonstrates a person with solid nets of friendship, somebody that gets notice your feelings, besides to demonstrate them to who is necessary. A low score in empathizing reflects a person unable to place in the place of the other, carrying resentments. The behavioral health in balance represents cares with the health, how to avoid to eat too much, to smoke and abuse of alcohol. On the other hand the negative results in the physical health and emotional health indicate muscular tension, headache, or stomach and anguish manifestations, that can elapse of concern feelings, depression, and exhaustion.

**TABLE 1: Classification of the child's mother's resiliency in study:**

|                    |         |
|--------------------|---------|
| Non work resources | caution |
| Self esteem        | Balance |
| Positive outlook   | Strain  |
| Personal power     | Caution |
| Purpose in life    | Caution |
| Self care          | Balance |
| Direct action      | Caution |
| Situation mastery  | Caution |
| Adaptability       | Balance |
| Time management    | Strain  |
| Support seeking    | Balance |
| Expression         | Balance |
| Empathizing        | Strain  |
| Behavioral health  | Balance |
| Physical health    | Caution |
| Emotional health   | Strain  |

Source: Primary data.

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Although presenting a low resiliency profile, it was noticed that the mother has a positive vision and resources to face moments of difficulty. Perhaps the result has been negative for the fact of meeting in most of the time in the hospital atmosphere, what alters in a considerable way your daily one. The one that more seems to be harming your resiliency is the lack of support of your social net, besides the concern and longing caused by the other children's distance and husband.

#### **CONSIDERATIONS**

We believed that the possible delay in the child's development is due to the process of disease and treatment of the leukemia, demonstrating the relevance of the detection of problems in the development and turning fundamental the precocious intervention, with the intention of stimulating the child's potential maximum, turning that process continuous, flexible, involving the mother and professionals of health.

The mother, for being the relative with larger conviviality with the child needs to have your stimulated resiliency so she can overcome

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#### **DEVELOPMENT OF A CHILD WITH CONGENITAL LEUKEMIA AND MATERNAL RESILIENCY**

In the just born, the leukemia is extremely rare, representing about 1% of all the cases of infantile leukemia. Under the glance of the ecological perspective, a child's mother's resiliency with congenital leukemia can soften or to exacerbate the suffering lived by both during the process of disease and treatment of the cancer. Thus, that report describes a child's case with leukemia congenital, with emphasis in the child's development and in the profile of the mother's resiliency. The child presented a low percentile of the expected for your age, with low weight and stature, but in the cephalic perimeter the measure (44 cm) what is normal for your age. In the evaluation of the child's behavior, the same presented difficulty in accomplishing two tasks in the evaluation of the strip of the nine months, equivalent your chronological age, being classified with "possible delay in the development". The mother presented a lower resiliency profile. We believed that the possible delay in the child's development is due to the process of disease and treatment of the leukemia, demonstrating the relevance of the detection of problems in the development and turning fundamental the precocious intervention, with the intention of stimulating the child's potential maximum. The mother's resiliency should be stimulated to optimize the treatment and the child's recovery.

**Key-words:** resiliency, child development, leukemia.

#### **DÉVELOPPEMENT D'UN ENFANT AVEC LEUCÉMIE CONGÉNITALE ET RESILIENCY MATERNEL**

Dans les petits enfants, la leucémie est extrêmement rare, en représentant 1% de tous les cas de leucémie d'enfant approximativement. Sous le coup d'oeil de la perspective écologique, les resilienci de la mère d'un enfant avec la leucémie congénitale peuvent adoucir ou exacerber la souffrance vécu par les deux pendant le processus de maladie et traitement du cancer. Ainsi ceci, ce rapport décrit le cas d'un enfant avec la leucémie congénital, avec accentuation dans le développement de l'enfant et dans le profil du resilienci de la mère. L'enfant a présenté un bas centile des attendu pour votre âge, avec bas poids et taille, mais dans le périmètre céphalique la mesure (44 centimètre) était normal pour votre âge. Dans l'évaluation du comportement de l'enfant, la même difficulté présentée dans accomplir deux tâches dans l'évaluation de la bande des neuf mois, équivalent votre âge chronologique, être classé avec " délai possible dans le développement ". la mère a présenté un profil négatif de resiliency. Nous croyions que le délai possible dans le développement de l'enfant est dû au processus de maladie et traitement de la leucémie, pendant que démontrer la pertinence de la découverte de problèmes dans le développement et devenir fondamental l'intervention précoce, avec l'intention de stimuler le maximum potentiel de l'enfant. Les resilienci de la mère devraient être stimulés pour optimiser le traitement et la récupération de l'enfant.

**Mots-clef:** resilienci, développement D'enfant, leucémie.

#### **EL DESARROLLO DE UN NIÑO CON LEUCEMIA CONGÉNITA Y RESILIENCY MATERNAL**

En los recién llevados, la leucemia es sumamente rara, mientras representando 1% del todos los casos de leucemia infantil aproximadamente. En la perspectiva ecológica, la resiliencia de la madre de un niño con la leucemia congénita puede ablandar o exacerbar el sufrimiento vivido por ambos durante el proceso de enfermedad y tratamiento del cáncer. Así siendo, ese informe describe el caso de un niño con la leucemia congénito, con el énfasis en el desarrollo del niño y en el perfil del resiliencia de la madre. El niño presentó un percentil bajo de los esperamos para su edad, con el peso bajo y estatura, pero en el perímetro cefálico la medida (44 centímetro) era normal para su edad. En la evaluación de la conducta del niño, la misma dificultad presentada logrando dos tareas en la evaluación de la tira de los nueve meses, equivalente su edad cronológica, siendo clasificado con "el posible retraso en el desarrollo". la madre presentó un perfil negativo de resiliency. Nosotros creímos que el posible retraso en el desarrollo del niño es debido al proceso de enfermedad y tratamiento de la leucemia, mientras demostrando la relevancia del descubrimiento de problemas en el desarrollo y poniéndose fundamental la intervención precoz, con la intención de estimular el máximo potencial del niño. Los resiliencia de la madre deben estimularse para perfeccionar el tratamiento y la recuperación del niño. **Palabras-llave:** el resiliencia, desarrollo Infantil, leucemia.

#### **DESENVOLVIMENTO DE UMA CRIANÇA COM LEUCEMIA CONGÊNITA E RESILIÊNCIA MATERNA**

Em crianças recém-nascidas, a leucemia é extremamente rara, representando cerca de 1% de todos os casos de leucemia infantil. Sob o olhar da perspectiva ecológica, a resiliência da mãe de uma criança com leucemia congênita pode amenizar ou exacerbar o sofrimento vivido por ambas durante o processo de doença e tratamento do câncer. Sendo assim, esse relato descreve o caso de uma criança com leucemia linfóide congênita, com ênfase no desenvolvimento da criança e no perfil de resiliência da mãe. A criança apresentou um percentil baixo do esperado para a sua idade, com baixo peso e estatura, mas na perimetria céfálica a medida (44 cm) estava normal para sua idade. Na avaliação do comportamento da criança, a mesma apresentou dificuldade em realizar duas tarefas na avaliação da faixa dos nove meses, equivalente a sua idade cronológica, sendo classificada com "possível atraso no desenvolvimento". A mãe apresentou um perfil negativo de resiliência. Acreditamos que o possível atraso no desenvolvimento da criança seja decorrente do processo de doença e tratamento da leucemia, demonstrando a relevância da detecção de problemas no desenvolvimento e tornando fundamental a intervenção precoce, com o intuito de estimular o potencial máximo da criança. Deve-se estimular a resiliência da mãe para otimizar o tratamento e a recuperação da criança. **Palavras Chaves:** resiliência, desenvolvimento infantil, leucemia.