



## FAMILY COPING STRATEGIES FOR LEUKEMIA DIAGNOSIS: SOCIAL AND RELIGIOUS ASPECTS

### ESTRATÉGIAS DE ENFRENTAMENTO FAMILIAR DO DIAGNÓSTICO DE LEUCEMIA: ASPECTOS SOCIAIS E RELIGIOSOS

### ESTRATEGIAS DE ENFRENTAMIENTO FAMILIAR EL EN DIAGNÓSTICO DE LEUCEMIA: ASPECTOS SOCIALES Y RELIGIOSOS

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#### ABSTRACT

**Objective:** to analyze the discourse of family members of children with leukemia concerning coping with the disease. **Method:** this is a descriptive exploratory study with a qualitative approach, carried out with nine carers between March and May 2012. Data were produced from semi-structured interviews, recorded and transcribed; then, for analysis, we used the thematic analysis, sorting, classification and analysis itself. The project was approved by the Research Ethics Committee, Protocol 0046. **Results:** we found that many parents blame themselves for the emergence of the disease and that the main source of relief is religiosity; they have reported the importance of family support and major change in everyday life due to the long treatment of the child. **Conclusion:** depending on the culture and social environment of the person involved, ways of coping can be varied, however, family support in the disease process and fight for the cure of the disease have proved important. **Descriptors:** Leukemia; Family; Emotions.

#### RESUMO

**Objetivo:** analisar o discurso dos familiares de crianças com leucemia quanto ao enfrentamento da doença. **Método:** estudo exploratório-descritivo, com abordagem qualitativa, realizado com nove acompanhantes entre março e maio de 2012. Os dados foram produzidos a partir de entrevista semiestruturada, gravada e transcrita; em seguida, para a análise, utilizou-se a análise temática: ordenação, classificação e análise propriamente dita. O projeto foi aprovado pelo Comitê de Ética em Pesquisa, Protocolo 0046. **Resultados:** identificou-se que muitos pais se culpam pelo surgimento da patologia e que a principal fonte de alívio é a religiosidade, relataram a importância do apoio familiar e afirmaram grande mudança no cotidiano devido ao longo tratamento do filho. **Conclusão:** dependendo da cultura e do meio social do envolvido, formas de enfrentamento podem ser diversificadas, no entanto, o apoio familiar no processo de adoecimento e luta pela cura da doença revelou-se importante. **Descritores:** Leucemia; Família; Emoções.

#### RESUMEN

**Objetivo:** analizar el discurso de los familiares de niños con leucemia delante del enfrentamiento de la enfermedad. **Método:** estudio exploratorio-descriptivo, con abordaje cualitativa, realizado con nueve acompañantes entre marzo y mayo de 2012. Os datos fueran producidos a partir de entrevista semiestruturada, grabada y transcrita; después, para el análisis, se utilizó el análisis temático: ordenación, clasificación y análisis propriamente dita. El proyecto fue aprobado por el Comité de Ética en Investigación, Protocolo 0046. **Resultados:** se identificó que muchos padres se culpan por surgimiento de la patología y que la principal fuente de alivio es la religiosidad, relataran la importancia del apoyo familiar y afirmaran un cambio grande en el cotidiano debido el largo tratamiento del hijo. **Conclusión:** dependiendo de la cultura y del medio social envuelto, maneras de enfrentamiento pueden ser diversificadas, sin embargo, el apoyo familiar en el proceso de enfermedad y lucha por cura de la enfermedad se reveló importante. **Descritores:** Leucemia; Familia; Emociones.

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## INTRODUCTION

Diagnosis of cancer in the pediatric population is a major challenge for health professionals, for the family of the child and for the patient himself, because major changes occur in child and family's routine, generating a lot of anxiety to clinical response to treatment. Even with the improvements in survival rates, leukemia is still associated with a symbolic representation of death, incurability, loss, suffering and lack of control of the body.<sup>1</sup>

According to the National Cancer Institute (INCA), in Brazil, about 7,000 new cases of cancer in children appear every year and the increase in patient survival is due to developments in pharmaceutical research, the use of more accurate diagnostic methods, psychosocial support, early detection of diagnosis and multidisciplinary care. Pediatric cancer is the third leading cause of infant mortality, behind only to violent deaths and infectious diseases.<sup>2</sup>

Leukemia is a disease that affects the process of blood cell formation, producing defective cells to multiply. It can be classified into four different types, depending on the affected line (lymphoid and myeloid) and on stage of maturation of these cells (acute and chronic). It is the most common type of childhood cancer in children under 15 in most populations, representing about 30% of the total, which generally have a higher incidence in the first five years of life.<sup>3</sup>

Additionally, of the leukemia in children, 85% correspond to acute lymphoblastic (ALL), 10% to acute myeloid (AML) and only 5% to chronic myelogenous form (CML). The peak incidence of ALL occurs between two and four years old, with the highest incidence in Caucasian and male.<sup>3</sup>

In Brazil, in 2008, the pediatric department of the National Cancer Institute<sup>4</sup> held 9,120 clinical attendances and 5,556 chemotherapy applications, and also recorded 1,056 hospitalizations. With opening of the Pediatric Emergency Department in March 2009, it was estimated an increase of up to 3,000 annual emergency attendances. However, there was an expected reduction of up to 50% in waiting time and 10% the total number of admissions.<sup>4</sup>

It is known that the focus of attention in the health professional practice is the individual patient, but it is for the family/caregiver to stay on the brink of events, always present and participating in their treatment in the hospital. Even today, family caregivers are perceived as a resource

for the benefit of the individual, but not as a hospital attention object.<sup>5</sup>

Parents play a key role in diminishing suffering and assisting in welfare, but, in turn, they are marginalized, their work is not appreciated and they are not accepted as people who are facing a painful process and who need help, support and orientation. The caregiver is a "valued" individual to help in this care procedure. It is expected that they take care "naturally", but they are people who are also in need of assistance and support.<sup>5</sup>

So, the family members, especially the primary caregivers, tend to face new challenges with the appearance of diagnosis. They are the beginning and the continuation of education and cooperation in a complex and long-term treatment. So when it comes to children, the primary caregiver is the mother, who was elected as the member of the family, whose moral duty is to stay with the child in the hospital and feels compelled to care for the child, since the child himself elects her as protector amongst the other family members and she assumes that no one is prepared, like her, to care for and protect her child.<sup>6</sup>

In an attempt to adapt to the new reality, the discovery of the disease, various coping measures are taken by the family. These confrontations arise from cognitive and behavioral adaptations, such as religion or spirituality, family reorganization, social support and other.

The concept of coping has been studied by different areas of knowledge. Sociology defines coping as the ways in which the social order adapts to crises. Biology comprises the confrontation as the ability of organisms to adapt to harmful agents. Psychology considers it to be the individual's adaptation to different stages of development to stressful situations.<sup>7</sup>

Confrontation, within the religion, can be defined as cognitive or behavioral strategies arising from religion to cope with stressful events, as many people attribute to God the resolution of health problems and turn to Him as cognitive and emotional resource to face such problems.<sup>6</sup>

Since the moment of revelation of medical diagnosis, several transformations within the family occur, which usually affects them in a devastating manner, causing many conflicts, insecurities, anxieties and fear for caregivers of these children. In this context, it is necessary to find an answer to the following question: what coping strategies for leukemia diagnosis are used by family members or

caregivers of children? The objective of the study is:

- To analyze the discourse of family members of children with leukemia regarding coping with the disease.

## METHOD

This article was compiled from Monograph << **Parents' perception of coping strategies on leukemia in children** >> presented to the course of Bachelor of Physiotherapy, University Center of João Pessoa/UNIPÊ. João Pessoa/PB, 2010.

This is an exploratory and descriptive qualitative study, conducted with nine caregivers (parents) of children with Acute Lymphoblastic Leukemia that were hosted or had some connection with the care home to children with cancer.

Patients were randomly selected from March to May 2012, according to the following inclusion criteria: parents of children with a clinical diagnosis of Acute Lymphoblastic Leukemia; patient should be between 1 and 18 years old; parents who were watching the child at the support center.

For data collection, it was used semi-structured interview technique, which was recorded after permission from parents or caregivers in order to capture the speech in full to represent the child care context. Two guiding questions were formulated, which served to the apprehension of reality, namely: what feelings did you feel after knowing your child's diagnosis of leukemia? What coping strategies did you use after confirmation of the diagnosis of leukemia?

The criterion for closure of interviews was saturation, soon after, data were analyzed, based on the principles of thematic interpretation<sup>8</sup> according to the following steps: ordering, classification and final analysis.

From the transcript of the interviews, we proceeded to exhaustive reading of the material in order to organize the testimonials. Later, themes found were reassembled in order to build the relevant structures for the final analysis.

In view of the provisions of Resolution No. 466/12 of the National Health Council, the project was submitted and approved under the Protocol 0046 of the Research Ethics Committee of the University Center of João Pessoa/UNIPÊ. Parents were informed about the purpose of the study, assuring them the right not to participate in it, the anonymity and, including the dissemination of data. All participants signed the Informed Consent

Form, receiving a copy with the signature of the researchers in charge. In the presentation of results, we used the letter "C" to identify the caregiver, followed by Arabic numerals that represent the sequence of interviews.

## RESULT AND DISCUSSION

### • Characterization of the research subjects

Participants were nine mothers and a father of children with leukemia, which were undergoing follow-up treatment and were housed in a reference center in oncology, "children's home." Ages of the participants ranged from twenty to fifty-nine full years, with eight of them married, one legally separated and a widower. Children were mostly male, corresponding to seven children ranging in age from one to eighteen years old and diagnosis of the disease ranging from one to six years.

### • Family coping strategies for diagnosis of leukemia

These findings emphasize the fragility of the family after the impact of the diagnosis. Therefore, one of the first feelings that arise during this initial process is the feeling of loss, which may be a reaction to denial, distress and depression, by having the hope of recovery of their loved one. For the caregiver, denying the diagnosis can help them to keep next to their loved one, helping him both physically and emotionally.

*I did not even think it could have been this kind of disease. [...] They are saying something she had never had and that you do not even know what will happen, that was what I thought.* <sup>(C6)</sup>

*I did not think this would happen to me. I say to me because he is a piece of me.* <sup>(C1)</sup>

Not finding an explanation, a meaning for the reason of the disease causes distress. It is observed that family members are always looking for excuses, someone to blame, to explain the disease. Studies<sup>9</sup> claim that this time, so fearful for parents, generates a feeling of guilt front of the child's illness situation. In this sense, feeling responsible for the child's illness adversely affects parents, which can trigger higher levels of stress manifestations. Thus, given the frustration of that moment of uncertainty and pain, the family feels guilty, as if they had failed at some point during the child's life, in the responsibility to protect them.<sup>10</sup>

It is noteworthy that, "*blaming themselves*" was one of the features present in the patients' parents, making assume that the presence of this feeling entails an

additional emotional burden to that already caused by the disease itself.

*Sometimes I wonder what did I for this to happen [...] Was it my fault?* <sup>(C8)</sup>

*I think this was my fault [...] Somehow, it certainly was [...].* <sup>(C5)</sup>

Facing the diagnosis and in attempt to live with cancer, there is a need to find the point of origin of the disease<sup>11</sup>. After realizing the child's disease, mothers often evidence some feelings, such as guilt, because parents feel responsible for having originated a disabled child; anxiety; anger and fear of the future<sup>12</sup>, as it can be seen in the statements.

We must respect the period of bewilderment and fear, because it requires a significant time to trigger all reactive actions. It is trying to adapt to the new reality that the family seeks a reorganization to face the experience of living with cancer disease. There are several aspects that can help in the development of the acceptance process and the fight against disease. This possibility to deal with stressful or excessive situations for the individual is defined as coping.

Studies appoint this confrontation as coping, which are cognitive and behavioral adjustments to reduce suffering and control specific demands<sup>13</sup>. Religious coping, in turn, is set when an individual turns to religion to cope with stress, that is, the use of religious beliefs and behaviors to facilitate the resolution of problems and prevent or reduce negative emotional consequences. Therefore, some authors refer that it is a process in which the individual controls the demands of the relation with the environment to meet the potential stressors before they become a threat.<sup>14</sup>

For parents, faith in God is a way to strengthen and aid in fighting the disease:

*I clung to God very, very much. He is in first place, is he not? [...] God in heaven and the doctor on earth to take care of my son.* <sup>(C8)</sup>

*I clung to Jesus, and then I prayed a lot, asking God to protect my son because he is very important to me. I always had faith in God, I never gave up and I know that everything will be all right.* <sup>(C7)</sup>

*I believe that God is above everything and everyone and He will make my son get better, I am sure [...] Because I know that only God and the love I feel for my son can save him, right?* <sup>(C1)</sup>

It is evident in the statements above that faith is an essential mechanism in the fight and coping with the disease. The acceptance process is accompanied with this religious attachment, enabling that they become stronger to overcome all this feeling of pain.

It is a source of strength, perseverance, optimism and hope in their children's healing. It is noteworthy that all the interviewees mentioned as a major factor the divine strength to help in overcoming the disease, even though this acceptance has come tardy.

Seeking support in religion, through the invocation of God, is an accessible strategy in disease situation, because the power attributed to God allows satisfaction of needs that cannot be controlled.<sup>15</sup>

Both coping strategy focused on the problem as on the emotion was used from the diagnosis to the time of treatment. Among protective factors used by patients and their families are personal issues, beliefs and values, courage, faith, positive thinking and healing will.<sup>16</sup>

Family reorganization is another very important coping mechanism. Acceptance and family support during the treatment phase brings relief and comfort for the patient, helping them in advance of their recovery. As it can be seen in the statements, family help, not only conforms parents, but also decreases the overhead that is imposed to them.

Relatives are important sources of support in coping with the illness and hospitalization process of a child.<sup>17</sup> Participation of family minimizes maternal suffering and establishes the consolidation of the bond, which is important to cope with illnesses, as shown in the following statements:

*My family supported me and helped me a lot. My sisters and my mother gave much support [...].* <sup>(C7)</sup>

*When he feels bad, my mother comes and stays with me.* <sup>(C8)</sup>

*His father also helps me, you know? [...] When I am sad, he (husband) talks to me, even though this does not make me happy, but I feel I am not alone in this, right?* <sup>(C2)</sup>

Just as parents have to deal with the feelings of the patient with chronic disease and always be ready to support them, patients try to deal with the feelings of the rest of the family, that is, when parents receive assistance, they feel ready, but when this does not happen, there is a difficult relationship.<sup>18</sup>

Family is part of a core that we can call as social support. It is one of the main entities that help in coping with the disease process. This social support is defined as any material assistance or information, provided by a person or a group of people with whom patients and caregivers maintain contact, resulting in positive effects. By sharing anxieties and the disease status with other family members and friends, one can obtain

comprehension, often feeling supported by these people.

*I had a lot of support from everybody; people have always helped me a lot, even with some advice, a word, and at such times it helps a lot, right?* <sup>(C3)</sup>

*Teachers at school helped me a lot with the medicine. I have to thank them for the affection, care.* <sup>(C4)</sup>

*A neighbor lady used to come here to take care of him to help me.* <sup>(C9)</sup>

It is observed in the statements that the situation becomes less difficult when there is the support of others, causing the emotional burden to decrease. Thus, the shared feeling, through actions of hearing, feeling and being understood, generates comfort in the situation.

Importantly, mothers, by talking to other mothers who are going through the same experience of having a child in cancer treatment, feel more comforted and strong to face the therapeutic process.<sup>19</sup>

It may be emphasized that the social support offered by family, friends or others who are willing to help provide more comfort and support to individuals affected by the disease and their families.<sup>20</sup>

## FINAL CONSIDERATIONS

Due to what was presented, it can be concluded that there are several difficulties experienced by the mother and her family in cancer adaptation process, which is to live and care for a child with leukemia. Thus, it was possible to search subsidies in people who have experienced problems of such a hard coping so that, from this view in particular, coping alternatives could be found.

According to the interviewees, faith is the main coping mechanism of the disease. Religion is a source of strength, perseverance, optimism and hope of cure for the child. Another factor that helps these caregivers is the social support, which is any material assistance or information offered by people, whether they are or not directly related.

It can be concluded that the coping strategies can be varied, depending on the culture and social environment of the involved people, however, a factor proved undeniable, when the family helps and understands it is possible to experience the process of illness and fight for the cure of the disease in a "quiet" manner. Therefore, we emphasize the importance of further studies on this subject in order to contribute to a constructivist reflection in relation to the care of children with cancer and their families.

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