

85 - PERCEPTION OF COMPANION OF CHILDREN WITH LEUKEMIA ON CHEMOTHERAPY: THE INFLUENCE OF A GROUP OF INFORMATION

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INTRODUCTION

The childhood cancer represents a group of diseases that have in common the uncontrolled proliferation of abnormal cells and can occur anywhere on the body (Inca, 2006). Being a disease much feared by the population due to its stigma, as it is perceived as a death sentence (Beck, 2007). The diagnosis of the disease in the family leads to feelings of sadness and doubt in the outcome of chemotherapy (Beltrão, 2007). Aggressive therapy, cause toxic effects and adverse reactions side effects that are striking for children, such nausea, vomiting, nucosite, alopecia and pain (Mohallem, 2007). These effects leave their children confined to bed and with impaired physical mobility and inability to care, preventing them from walking, playing, sleeping and eating by changing the psychosocial state, interfering with self-esteem, self-image and mood, impairing the interaction of various motor functions: perceptivomotora, neuromotor and psychomotor.

The hospital also contributes to changes in emotional behavior of children. "The hospitalization of a child is always a delicate situation that creates stress for her and the family" (Silva, 2000). Anxiety, depression are the most frequent symptoms (Beck, 2007).

This all requires a family of continuous action, a strength and understanding, which often becomes difficult for her. The family needs to understand all the stages of treatment and the importance of it, as well as changes in behavior and attitudes of the child.

A multidisciplinary team should be integrated in the monitoring of the child in the family, care should be holistic and humane in all biopsychosocial aspects involving the child, family and the person accompanying the child during hospitalization, focusing on the effects of drugs and the impact of these on the child's behavior and explaining the importance of treatment and care of the child during hospitalization and at home, to the success of treatment.

Purpose

To analyze the perception of relatives of children with leukemia about the disease and chemotherapy.

METHOD

This is a descriptive study with a qualitative approach, carried out in pediatric inpatient units and bed days of the Ophir Loyola Hospital. The participants were 10 (ten) caretakers of children undergoing chemotherapy aged between 01 and 10 years of both sexes. The study took place in two phases:

First, meetings were held weekly from October 2008 to January 2009 with accompanying guidelines for through talks with the participation of the multidisciplinary team (groups of information).

In the second phase of the research were interviewed (10) companions who will participate in lectures group information. The study was based on the resolution 196/96. As approved by the IRB with the protocol No. 2688/08. The interviews were recorded in MP3 and transcribed.

The data were analyzed using the technique of content analysis (Bardin, 2007). After organizing and holding the material, the contents were analyzed in a single core meaning: the perception of accompanying child on acute leukemia and chemotherapy in an emerging category: the perception of the companions on the information received from the groups of information and subcategories: understanding of the companion on the disease, understanding of the companion on the illness and treatment.

RESULTS AND DISCUSSION

Understanding is the acquisition, interpretation, selection and organization of information received by the senses. From the standpoint of psychological or cognitive, perception also involves the mental processes, memory and other aspects that may influence the interpretation of the data received.

Category 1 - The perception of the companions on the information received from the groups of information.

All companions who were interviewed expressed in their statements that the information contributed greatly to understanding the disease and treatment, as noted in the speech of A4 and A6.

More information about the disease that my daughter had, as the type of treatment, how long, what care they had ... was [sic] very important to her, for me also (A4);

Early on, I knew nothing, I was giddy like a cheap ... (A6).

The families and children need to receive very clear information about the disease and treatment for better coping. Disclosure of cancer diagnosis for families, especially for mothers, is a time of conflict, desperate because of their stigma (Beltrão, 2007).

The initial phase is very difficult for the family, it is time to unravel. The impact of the diagnosis leads to a meshwork of feelings represented by a deep pain, fear and impatience. The family must learn to deal with a situation involving the hospital and deal with the sick child, to understand the disease and treatment (Crepaldi, 2006).

Each family absorbs information differently. Therefore it is necessary for the multidisciplinary team is able to meet the child and family, providing information and explaining their perceptions, helping them to find solutions of problems related to treatment (Costa, 2003).

Knowledge about the disease provides a better companions face this. As we receive information on the disease and treatment, become more calm, away from the fear of death.

When I arrived here I was lay on the subject ... Then there was the information that I've been more soothing. (A9).

I learned that it's not like people I spoke ... if he died there ... Now I learned to deal better with the disease (A1).

The difficulty in understanding cancer at diagnosis produces stress reactions to the family, causing fears of death and even the denial of the disease (Valle, 2001). The fear in the face of an unknown situation is an unsettling feeling. This occurs with any human being facing a health crisis that could cause you grief. But, before the cancer the fear is even greater, feelings of anguish and despair (Heidegger, 2006).

In most cases, the patient's family hides his emotions, the parents usually panic at the possibility of death and often have feelings of guilt. The family needs help, so you can separate the irrational fears of the real fears (Maia, 2005).

The spectators, after the information, felt more secure about the treatment and care for the child, reporting feelings of faith that strengthened in dealing with the disease and also hope for cure.

I have been much more peaceful after all that I saw and heard ... despite being a little difficult, I am faced with great faith and great strength (A7)

Family members, to receive a diagnosis of cancer of a loved one, seeking divine help, putting into practice their religion and having more faith in God, which becomes an important refuge (Smith, 2008). It is important that the team sees the need for the patient and family, while respecting individual beliefs and values. Spirituality put into practice by the patient, family and the team itself has collaborated with the coping of patients with cancer as a disease and its treatment (Campbell, 2007).

Subcategory 1 - Understanding of the companion on the illness and treatment.

In depositions, we find that the companions understood that leukemia is a serious disease and the risk that the child needs special care and are aware of their responsibilities, accepting and cooperating with treatment.

It is a cancer. The doctor told me all the care, the risk that the disease has (A3).

I am mother, the more I become aware that this is her best pro ... (A2).

When the family has a good understanding of the pathology that affects the child and has effective strategies to cope with problems, increases the likelihood of compliance (Crepaldi, 2006).

The leukemias are malignant neoplasm of hematopoietic tissue in the stem-cell starts to produce abnormal blood cells nonfunctional. They are classified as the cell line affected in myeloid and lymphoid in acute and chronic.

Clinical manifestations include fatigue, anorexia, weight loss, bleeding, infections, headaches or visual disturbances, lymphadenopathy, splenomegaly and hepatomegaly. The investigation to confirm the diagnosis is made through the bone marrow with immunophenotype and karyotype, which will define the line in complex cases. Treatment involves chemotherapy and bone marrow transplantation. Chemotherapy is administered for induction of remission, where the purpose is to induce a complete response means that a bone marrow aspirate with less than 5% lymphoblasts and elimination of extramedullary disease (Mohallem, 2007)

The spectators are aware of the complications that can occur and the effects of drugs that interfere with the well being of children, the immune system and even the quality of life. The understanding of this process also contributes to adherence of treatment.

This treatment ta [sic] doing well, she's accepting, she does not have those bouts of sickness ... understand you're doing well for her (A8).

Then we will fall in real and accepting little by little ... (A6)

"The more the patient is informed about the side effects of chemotherapy and how to control them better able to predict them and know better cope with the child" (Smeltzer, 2002).

Information on the effects of chemotherapy should be given since the beginning of treatment for parents to feel safe and able to clarify the child, reinforcing its role as the child trusts the parents more than the team itself (Verissimo, 1991).

Feelings of anger are more apparent when chemotherapy is started and the family feels the suffering of children, since the toxic effects of drugs are devastating. The team should provide information about the disease and the side effects and toxicity of drugs, to help in coping with the disease and for the family to realize the importance of continued treatment (Souza, 2007).

Subcategory 2 - Perception of Accompanying The Case of Treatment

The accompanying notice that the process of treatment of leukemia is complicated, that the reactions in children are a result of side effects of drugs.

Some medications could not understand today ... I have more information about the reactions that will give (A2).

The treatment process is lengthy involving several steps, use of drugs with complicated names and toxic compromising. "The knowledge of side effects and toxicities of chemotherapy drugs is essential for the management of the patient" (Bonassa, 2005).

The spectators can not understand why the child needs hospital treatment, knowing what is best for them, mainly due to reactions of chemotherapy.

I do QT he admitted it is much better for me, so in that sense of not having that run in the middle of the night to go out with him, bleeding (A2).

As always gives him a fever and then he needs to stay in the antibiotic (A6).

Side effects such as nausea, pain Emens and interfere with the well being of children and are usually reasons for hospital admissions for this course of action to be feasible and safe for the child, although traumatic because of the painful procedures that are necessary (Souza, 2007)

Another reason for hospitalization is more frequent neutropenia the risk of infection due to immunosuppression, bone marrow (Bonassa, 2005).

Accompanying reported painful processes as a normal reaction of the disease and treatment. Feel feelings of helplessness before the child's suffering with pain, knowing that cancer pain is intense and that the drugs are palliative.

A pain that I do not know if the remedy, even if the disease (A3).

According to the National Cancer Institute, the pain is a debilitating factor for a patient with cancer, a disease whose incidence of pain affects 80% of patients.

Be the toxic effects of drugs or disease, moderate or severe pain occurs in 30% of cancer patients receiving treatment and 60% to 90% of patients with advanced cancer. The prevalence of pain increases with disease progression. 46% to 92% of pain in cancer patients comes from the cancer itself (tumor invasion), 12% to 29% are related to cancer (muscle spasm, lymphedema, pressure ulcers, constipation, etc.), 5% to 20% associated with tumor therapy (post-operative, post-chemotherapy, radiotherapy, mucositis), 8% to 22% concomitant disorders - osteoarthritis, among others (Inca, 2006).

Accompanying realize that changes in the behavior of children are a result of treatment and the pain felt by the child.

However learn to deal with it.

When it comes to chemotherapy, is sad, down to isolate (A6).

When you give this pain ... he does not want to talk ... is boring but okay when a boy is very obedient (A3).

The pain is a very stressful for the child, which limits the activities, preventing them from playing. The pain in children is influenced by emotional factors, family environment. The understanding of pain and its description by the children depend on age and cognitive level. Children learn to support pain or live with it for their own painful experiences and express pain through language and behavior (Whaley and Wong, 1999).

CONCLUSION

It is important to keep your companions well informed about the disease and treatment. This helps to cope and contribute to treatment adherence. Accompanying demonstrated through their statements follow the guidelines, learning to cope with changes in the behavior of children and being more patient and aware of their responsibilities, also felt more secure with the care of the child and confident in the treatment, coping with more resignation and faith.

REFERENCES

- BARDIN, L. **Análise de Conteúdo**. Lisboa: Edições 70, 2007.
- BECK, A. R. M.; LOPES, M. H. B. M. Tensão devido ao papel de cuidador entre cuidadores de crianças com câncer. **Revista Brasileira de Enfermagem**, Brasília; 2007. 60 (5): 513-8.
- BELTRÃO, M. R.; VASCONCELOS, M. G.; ALBUQUERQUE, M. C. Childhood cancer: maternal perceptions and strategies for coping with diagnosis. **J Pediatr (Rio J)**. 2007; 83(6) 562-566.
- BONASSA, E. M. A.; SANTANA R. T. E **Enfermagem em terapêutica oncológica**. 3ª edição São Paulo: Editora Atheneu; 2005.
- CAMARGO, b.; Kurashima. **Cuidados Paliativos em Oncologia Pediátrica: o cuidar Além do curar**. São Paulo: Lemar, 2007
- COSTA, CA.; LUNAEDI filho, W.D.; SOARES, N.V. Assistência de Enfermagem ao cliente oncológico: reflexões junto à equipe, **Rev Bras Enfem**; 56(3): 310-314, maio -jun. 2003. 2003
- CREPALDI, M. A.; LINHARES, M. B. M. et al. (org.) **Temas em Psicologia Pediátricas**. São Paulo: Casa do Psicólogo; 2006
- HEIDEGGER M. **Ser e tempo**. Rio de Janeiro: Editora Vozes: Editora Universitária São Francisco; 2006
- MAIA, S. A. F. **Câncer e Morte. O impacto sobre o Paciente e a Família**. Especialização em psicooncologia. Hospital Erasto Gaertner, Curitiba, 2005.
- MINISTÉRIO DA SAÚDE-INSTITUTO NACIONAL DO CÂNCER. **Epidemiologia dos tumores da criança e do adolescente**. Rio de Janeiro: inca; 2006.
- MINISTÉRIO DA SAÚDE-INSTITUTO NACIONAL DO CÂNCER. **Particularidade do câncer infantil**. Rio de Janeiro: inca; 2008.
- MOHALLEM, A. G. C.; RODRIGUES, A. B. **Enfermagem oncológica**. São Paulo: Manole; 2007.
- SILVA, C. C.; Ribeiro, N. R. R. Percepções da criança acerca do cuidado recebido durante a hospitalização. **Ver. Brás Enferm, Brasília**, v. 53. n 2, p. 311-323, abr/jun 2000.
- SILVA, M. R. B. et al. O câncer entrou em meu lar: Sentimentos expressos por familiares de Clientes. **Ver Enferm UERJ**, Rio de Janeiro, 16(1):70-5, jan/mar 2008.
- SMELTZER S.C.; BARE B.G. **Tratado de enfermagem médico-cirúrgica**. 9a ed. Rio de Janeiro: Guanabara-Koogan; 2002
- SOUZA, M. G.; ESPIRITO SANTO, F. H. Olhar que olha o outro...Um estudo com familiares de pessoa em quimioterapia antineoplásica. **Rev Brasileira de cancerologia**, 54 (1): 31-41. 2008 2007.
- VALLE, E, R, M. (org.). **Psico-oncologia pediátrica**. São Paulo: Casa do Psicólogo; 2001.
- VERISSIMO, M. de La Ó. R. A Experiência de Hospitalização explicada pela própria criança, **Ver. Esc. Enf. USP**, v. 25, n.2, p. 153-68, ago. 1991
- WHALEY, L. F.; WONG, D. L. **Enfermagem pediátrica elementos essenciais à interação efetiva**. 5ª Ed. Rio de Janeiro: Guanabara Koogan S. A; 1999.

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PERCEPTION OF COMPANION OF CHILDREN WITH LEUKEMIA ON CHEMOTHERAPY: THE INFLUENCE OF A GROUP OF INFORMATION SUMMARY

Objective: To analyze the perception of relatives of children with leukemia, concerning the disease and chemotherapy treatment after participation in the group information. **Method:** A descriptive study of a qualitative study conducted in Ophir Loyola Hospital in Belém - PA. The participants were 10 relatives of children with leukemia undergoing chemotherapy. Data collection occurred in two phases: in the first round talks were held weekly from October 2008 to January 2009, in the second round were interviewed (10) who participated in the accompanying information group in Round 1. The data were analyzed using the technique of content analysis according to Bardin (2007). **Results and Discussion:** the contents were analyzed in a single core meaning, awareness about leukemia and its treatment with chemotherapy, emerging in one category: the perception of the companions on the information received and two Sub-categories: understanding of the companion on the illness and treatment and the perception of the on the treatment process. **Conclusion:** The information in the multidisciplinary team contributed much to the attendants understand the disease, treatment and better care of children. Helped in coping and contribute to treatment adherence. In this sense it is important to keep well informed companions, reporting the group information.

KEYWORDS: cancer, childhood, perception.

LA PERCEPTION DE L'ACCOMPAGNATEUR D' ENFANTS AVEC LA LEUCÉMIE EN CHIMIOTHÉRAPIE: L'INFLUENCE D'UN GROUPE D'INFORMATION

RESUMÉ

Objectif: analyser La perception des accompagnateurs d'enfants avec la Leucémie, concernant la maladie et la chimiothérapie après la participation dans le groupe d'information. Méthode: Étude descriptif de nature qualitative faite à l'Hôpital Ophir Loyola dans la ville de Belém à l'État du Pará. Ont participé de cette recherche 10 accompagnateurs d'enfants avec leucémie en chimiothérapie. La collecte de données a été faite en deux phases: dans la première phase des discours ont été réalisés une fois par semaine pendant la période d' octobre 2008 à janvier 2009; dans la deuxième phase 10 accompagnateurs qui ont participé du groupe d'information de la première phase ont été interviewés. Les données ont été analysées en utilisant la technique d'analyse du contenu selon Bardin (2007). Résultats et Discussions: les contenus ont été analysés dans un seul noyau de sens, la perception sur la leucémie et sa chimiothérapie, émergent dans une catégorie: la perception des accompagnateurs quant aux informations reçues et en deux sous-catégories la compréhension de l'accompagnateur de la maladie et son traitement; la perception de l'accompagnateur quant au procédé du traitement. Conclusion: les informations de l'équipe multiprofessionnelle ont bien contribué pour que les accompagnateurs comprennent la maladie, le traitement et comment mieux s'occuper des enfants. A aidé sur l'affrontement et a contribué pour l'adhésion au traitement. Dans ce sens c'est important maintenir les accompagnateurs bien informés, en effectuant le groupe d'information.

DESCRIPTIFS: cancer, enfantin, perception

PERCEPCIÓN DE COMPAÑEROS DE LOS NIÑOS CON LEUCEMIA EN LA QUIMIOTERAPIA: LA INFLUENCIA DE UN GRUPO DE INFORMACIÓN

RESUMEN

Objetivo: Analizar la percepción de los familiares de niños con leucemia, sobre la enfermedad y el tratamiento de quimioterapia después de la participación en la información del grupo. Método: Estudio descriptivo de un estudio cualitativo realizado en el Hospital Ophir Loyola en Belém - PA. Los participantes fueron 10 familiares de niños con leucemia sometidos a quimioterapia. La recopilación de los datos se produjo en dos fases: en la primera ronda de conversaciones se realizaron semanalmente desde octubre 2008 a enero 2009, en la segunda ronda fueron entrevistados (10) que participaron en el grupo de información que acompaña en la Ronda 1. Los datos fueron analizados utilizando la técnica de análisis de contenido según Bardin (2007). Resultados y Discusión: Se analizó el contenido en un solo núcleo sentido, la sensibilización acerca de la leucemia y su tratamiento con quimioterapia, que surgen en una categoría: la percepción de los compañeros en la información recibida y dos sub-categorías: la comprensión de la compañía sobre la enfermedad y el tratamiento y la percepción de ellos en el proceso de tratamiento. Conclusión: La información en el equipo multidisciplinar contribuyó mucho a los asistentes comprender la enfermedad, el tratamiento y el mejor cuidado de los niños. Ayudó a afrontar y contribuir a la adherencia al tratamiento. En este sentido, es importante mantener bien informados compañeros, la información la información del grupo.

PALABRAS CLAVE: cáncer, la infancia, la percepción

A PERCEÇÃO DO ACOMPANHANTE DE CRIANÇAS COM LEUCEMIA SOBRE TRATAMENTO QUIMIOTERÁPICO: A INFLUÊNCIA DE UM GRUPO DE INFORMAÇÃO

RESUMO

Objetivo: analisar a percepção dos acompanhantes de crianças com leucemia, concernente a doença e o tratamento quimioterápico após participação no grupo de informação. Método: Estudo descritivo de natureza qualitativa realizado no Hospital Ophir Loyola na cidade de Belém - PA. Participaram da pesquisa 10 acompanhantes de crianças com leucemia em tratamento quimioterápico. A coleta dos dados ocorreu em duas fases: na primeira fase foram realizadas palestras semanais no período de outubro 2008 a janeiro 2009; na segunda fase foram entrevistados 10 (dez) acompanhantes que participaram do grupo de informação na 1ª fase. Os dados foram analisados utilizando-se a técnica de análise de conteúdo de acordo com Bardin (2007). Resultados e Discussões: os conteúdos foram analisados em um só núcleo de sentido, a percepção sobre a leucemia e o seu tratamento quimioterápico, emergindo em uma categoria: a percepção dos acompanhantes quanto às informações recebidas e em duas Subcategorias: entendimento do acompanhante quanto à doença e o tratamento; a percepção do acompanhante quanto ao processo do tratamento. Conclusão: as informações da equipe multiprofissional contribuíram muito para os acompanhantes entenderem a doença, o tratamento e a cuidar melhor das crianças. Ajudou no enfrentamento e contribui para a adesão ao tratamento. Neste sentido é importante manter os acompanhantes bem informados, efetivando o grupo de informação.

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