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REVIEW

Feelings evidenced by the parents and family members before the cancer diagnosis in the child

Sentimentos evidenciados pelos pais e familiares frente ao diagnóstico de câncer na criança

Sentimientos evidenciado por SUS padres y lãs famílias que enfrentan El diagnostico de câncer em niños

Fernanda Morena dos Santos Barbeiro¹

ABSTRACT

Objective: To reveal the feelings evidenced by the family members of hospitalized children before the cancer diagnosis and highlight the main capabilities of the Nursing in assisting the confrontation of the disease. **Method:** It is a descriptive, exploratory and bibliographic research, with a qualitative approach, which was conducted through searches the in VHL, with full papers published in Portuguese in the last eight years. The used descriptors were: Child; Cancer; Diagnosis; Relationships between nurse and patient. 12 bibliographies were selected. **Results:** Three thematic categories have emerged: The imbalance in the social and family coexistence after the cancer diagnosis; Adaptation tools and coping strategies; and Holistic and humanized care from the nursing staff. **Conclusion:** The cancer requires the complete change of the life routine of the family, by bringing anguishes to the main caregiver, since it neglects the other members when taking care of the sick relative. The cancer drives the family members to feelings of fear and anxiety, also makes the faith in God and the religious belief of each of the members are maximized, thus creating greater hopes in relation to the healing. **Descriptors:** Children, Cancer, Diagnosis, Relationships between nurse and patient.

RESUMO

Objetivo: desvelar os sentimentos evidenciados pelos familiares de crianças hospitalizadas frente ao diagnóstico do câncer e evidenciar as principais capacidades da Enfermagem no auxílio ao enfrentamento da doença. **Método:** Pesquisa descritiva e exploratória do tipo bibliográfica, com abordagem qualitativa, realizado através de buscas na BVS, com artigos completos em português publicados nos últimos oito anos. Os descritores utilizados foram: Criança; Câncer; Diagnóstico; Relações enfermeiro e paciente. 12 bibliografias foram selecionadas. **Resultados:** Emergiram três categorias temáticas: O desequilíbrio no convívio familiar e social após o diagnóstico de câncer; Ferramentas de adaptação e estratégias de enfrentamento; e Assistência holística e humanizada da equipe de enfermagem. **Conclusão:** O câncer força a alteração da rotina de vida da família, trazendo angústias para o cuidador por este preterir os outros membros ao cuidar do doente. O câncer direciona os familiares aos sentimentos de medo e ansiedade, também faz com que a fé e a crença religiosa sejam aumentadas, criando maiores esperanças em relação à cura. **Descritores:** Criança, Câncer, Diagnóstico, Relações enfermeiro e paciente.

RESUMEN

Objetivo: mostrar los sentimientos mostrados por las familias de niños hospitalizados frente al diagnóstico de cáncer y poner de relieve las capacidades clave de ayuda de enfermería para hacer frente a la enfermedad. **Metodo:** Un tipo descriptivo y exploratorio de la literatura con un enfoque cualitativo, llevado a cabo mediante la búsqueda de la BVS, con artículos publicados en portugués, en los últimos ocho años. **Descriptor:** niños, las relaciones de cáncer, el diagnóstico, la enfermera y el paciente. **Bibliografía** seleccionada 12. **Resultados:** tres temas emergieron: desequilibrio en la vida familiar y social después de herramientas de diagnóstico de la adaptación, y estrategias de afrontamiento y el apoyo de enfermería humano y holístico. **Conclusión:** El cáncer se le obliga a cambiar la rutina de la vida familiar, con lo que angustia al cuidador para despedir a los otros miembros el cuidado de ese paciente. El cáncer de la familia dirige los sentimientos de miedo y ansiedad, también hace que la fe y la creencia religiosa a aumentar, creando una mayor esperanza de una cura. **Descriptor:** Niños, Câncer, El diagnóstico, La enfermera y el paciente.

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INTRODUCTION

The disease affects the human being, regardless of age group and, depending on the sick family member, and its characteristics, there might be serious damage to this institution. When this happens to a child, generates multiple feelings to parents and might be intensified by the possibility of the child's death, as occurs in cancer cases.

The childhood and youth cancer should not be regarded as a single and isolated disease, but as a set of multiple and differentiated pathologies; it has differently been studied from the adult cancer because histopathological differences and primary location.¹ It is considered rare in comparison to the neoplasms in adults, by evidencing about 2-3% of all malignant tumors.² In developing countries, it is configured as the second cause of death in the age group from 0 to 14 years, second only to external causes. Estimate indicate approximately 9.400 new cases of pediatric cancer in the 2010-2011 biennium, being that 25-30% of these cases matches to the leukemia.¹

The chronic aspect of cancer, which requires multiple hospitalizations, withdrawal from the daily and recreational activities and family disharmony causes the sick child to be differently treated, with a view to preventing further trauma to its physical integrity and family members.³

The word "family" comes from the Latin "*familia*", and means kindred people that normally live in the same household. Often, this institution is comprised of father, mother and children.⁴ The family is the first group in which the child is inserted, by constituting the main network of relationships among the individuals. Furthermore, it represents the main context of the child's behavioral learning, by decisively influencing the identity formation, as well as proper affective feelings.⁵

There is a strong relationship between the family institution and the health-disease status of its members. Thus, the family is of utmost importance in maintaining health, preventing disease and confrontation of diseases.⁶

The disease means the loss of homeostasis, by disassembling the whole family context, often because the family structure is closer to the patients' experiences.⁶ Given this, the family structure and its working habits are notoriously changed and its members need to find ways to overcome this situation.

The lifestyle changes and forced habits by the onset of the disease are directly dependent on the disease type, how it manifests itself, its evolution, and, especially, the meaning assigned to it.⁶ This meaning is formed by previous experiences with the disease, both individually and collectively, given that this meaning is crucial for determining the space that this pathology will occupy in the family's life.

In the healthcare institutions, it is clearly perceived that the family member who usually accompanies the children and the mother, both in outpatient treatments or in hospital admissions, is confronted, throughout the daily treatment, with the suffering and anguish of its child, mainly, due to the possibility of death thereof.⁷⁻⁸

Due to the inherent structuring nature of tenderness coming from the mother-son binomial during the childhood, one should admit that, throughout the hospitalization, the emotional welfare of the mother certainly favors the child, by contributing to an improved adherence to the treatment. Conversely, it is also necessary to admit that the emotional malaise of the mother influences on her child, by accentuating its state of suffering and, consequently, hindering the treatment

implementation. Thus, the care of the neoplastic child is, obligatorily, linked to the emotional care of the mother who accompanies thereof.

The cancer stigma as a disease with bad and fatal prognosis ends up causing overload the family circuit, by bringing as a result of this diagnosis a change in the relationship pattern of the father-mother couple, often resulting in decreased intimacy between them, because of the long time in which one of the parents stays with the hospitalized child. Another found consequence is related to the siblings, who might feel postponed in comparison to the child who is sick.⁹

Given the above mentioned context, this current study aims at revealing the feelings evidenced by the relatives of hospitalized children before the cancer diagnosis, besides highlighting the main capabilities of the nursing staff in helping to fight against the disease at stake. In accordance with an approach perspective focused to the psychosocial conditions related to childhood cancer treatment, we pursued to raise information that, by assisting nurses and other professionals from healthcare services, contribute to the definition and execution of actions that promote the emotional welfare of the caregiver and, consequently, of the child.

METHODOLOGY

It is a descriptive, exploratory and bibliographic research, with a qualitative approach. In this research type, the data are observed, recorded, analyzed and interpreted without the researcher directly or indirectly interfere with them. Therefore, the studied phenomenon is not manipulated by the observer.¹⁰

The descriptive research has the overriding aim of describing the characteristics of a given population or phenomenon or the establishment of relationships among the variables.¹¹ While the exploratory research aims at formulating questions or a problem with triple purpose: to develop hypotheses, increase the familiarity of the researcher with an environment, fact or phenomenon, for conducting a future and more accurate research or modify and clarify concepts.¹²

The bibliographic research aims at analyzing the same problem from different foci, through a detailed analysis of several literature sources, by allowing the researcher to have a greater coverage of the events occurred on the issue, without necessarily searching for the data in a direct manner.¹¹

The bibliographic survey was performed by using the Virtual Health Library (VHL), with full papers published in Portuguese in the last eight years (2004-2011). We have prioritized the search for materials in the LILACS, BDNF, SciELO and MEDLINE databases.

The descriptors were used according to the DeCS/MeSH, namely: Child; Cancer; Diagnosis; Relationships between nurse and patient. It should be emphasized that the survey was initially performed the descriptors in an individual form and, later, by making use of the Boolean Operator AND.

DESCRIPTOR	LILACS	BDNF	SciELO	MEDLINE
Child	6778	1953	1663	1738
Cancer	3007	551	1232	723
Diagnosis	8745	1318	5101	457
Relationships nurse and patient	60	0	2	0
Total	18590	3822	7998	2918

Table 1 - Quantitative distribution of the bibliographies found in the databases

It is noteworthy that the LILACS database covers the literature related to the Health Sciences, published in the countries of the Region, from 1982, being that is intended for the healthcare professionals. Furthermore, it constitutes the main bibliographic index of the VHL.¹³

The MEDLINE® is the English acronym for Medical Literature Analysis and Retrieval System Online, which contains bibliographic references and abstracts from over 4.000 biomedical journals published in the United States and 70 other countries. It holds approximately 11 million records in the literature, since 1966 until now, which encompass the areas of Medicine, Nursing, Dentistry, Veterinary Medicine and related sciences.

The SciELO is an electronic library that covers a selected collection of Brazilian scientific journals, by bringing a vast amount of scientific production in the Health Area and Social Sciences with full texts.

After the initial data search, due to the evidence of a very large quantity in the selected databases, it was necessary to perform a more refined search for papers in such databases, since the individual amount of works was very extensive. The new refining was performed by the search for associated descriptors, according to Table 2.

DESCRIPTORS	LILACS	BDENF	SciELO	MEDLINE
Child + Cancer	193	67	24	73
Child + Diagnosis	975	146	248	57
Child + Relationships nurse and patient	05	68	00	02
Cancer + Relationships nurse and patient	06	27	00	02
Cancer + Diagnosis	75	126	323	02
Diagnosis + Relationships nurse and patient	00	26	00	00
Total	1248	460	595	136

Table 2 - Quantitative distribution of bibliographies found by means of descriptors association

Thereafter, we performed an inspeccional reading of the quantitative with sights to identify which jobs would fit into the proposed theme, thus becoming part of the study sample. We have performed a reading of abstracts, by allowing a brief investigation, by selecting references that actually would be fitted into the theme, thus allowing a more accurate data selection. The items that were not in full version and also the ones that did not meet the goals were excluded from the study.

Given the result of the analysis of the abstracts, it has emerged a new table, with the quantitative value of the bibliographic references considered relevant to the investigation, as Table 3.

DESCRIPTORS	LILACS	BDENF	SciELO	MEDLINE
Child + Cancer	02	00	04	00
Child + Diagnosis	02	00	01	00
Cancer + Diagnosis	01	00	02	00
Total	05	00	07	00

Table 3 - Quantitative bibliography

It is worth noting that some bibliographies were repeated in the selected databases. Hence, we chose to prioritize the SciELO database, since this directory contained the papers in their full versions. Thus, after the exclusion criteria, we selected twelve (12) scientific productions.

Authors	Year	Title	Journal	Category
Beck & Lopes	2007	Caregivers of children with cancer: life aspects affected by the caregiver's activity	<i>Revista Brasileira de Enfermagem</i>	Child Cancer +
Monteiro; Veloso; Souza & Morais	2008	The family living before the illness and treatment of children and teenagers with Acute Myeloid Leukemia	<i>Cogitare</i>	Child Cancer +
Angelo; Moreira & Rodrigues	2010	Uncertainties before the childhood cancer: understanding the mother's needs	<i>Escola de Enfermagem Anna Nery</i>	Child Cancer +
Santos & Gonçalves	2008	Children with cancer: unveiling the meaning of illness assigned by their mothers	<i>Revista Enfermagem UERJ</i>	Child Diagnosis +
Oliveira; Costa & Nóbrega	2006	Performed dialogue between nurse and mothers of children with cancer	<i>Revista Eletrônica de Enfermagem</i>	Child Diagnosis +
Beck & Lopes	2007	Tension among caregivers of children with cancer due to their own role	<i>Revista Brasileira de Enfermagem</i>	Child Diagnosis +
Silva; Andrade; Barbosa; Hoffman & Macedo	2009	Representations of the illness process in children and teenagers with cancer before their relatives	<i>Escola de Enfermagem Anna Nery</i>	Child Diagnosis +
Nascimento; Rocha; Hayes & Lima	2005	Children with cancer and their families	<i>Revista da Escola de Enfermagem USP</i>	Child Cancer +
Quintana; Wottich; Camargo; Chere & Ries	2011	Bereavements and Fights: family restructuring before the cancer in a child/teenager	<i>Psicologia Argumento</i>	Child Cancer +
Beltrão; Vasconcelos / Pontes & Albuquerque	2007	Childhood cancer: maternal perceptions and coping strategies before with diagnosis	<i>Jornal de Pediatria</i>	Cancer Diagnosis +
Faria & Cardoso	2010	Psychosocial aspects of companion caregivers of children with cancer: stress and coping	<i>Estudos de Psicologia</i>	Child Cancer +
Nascimento; Monteiro; Vinhaes; Cavalcanti & Ramos	2009	Childhood cancer: meanings of some maternal livings	<i>Revista Rene Fortaleza</i>	Cancer Diagnosis +

Table 4 - distribution of selected potential bibliographies

Subsequently, we conducted an interpretive and analytical reading of the productions, the decontextualization and recontextualization of the text, in order to reveal its possible meanings: textual, contextual and inter-textual relationships, thus emerging the following thematic categories: The imbalance in the social and family coexistence after the cancer diagnosis; Adaptation tools and coping strategies; and Holistic and humanized care from the nursing staff.

RESULTS AND DISCUSSION

The imbalance in the social and family coexistence after the cancer diagnosis

Childhood cancer presents itself as a complex disease and with multiple behavioral and therapeutic implications, both for the child and for its family, by requiring an increased attention with regard to the physical and emotional needs.

Its diagnosis and treatment demand drastic and sudden changes in the life routine, by requiring multiple hospitalizations from the children and monitoring by their family members, especially from the mother, who is configured as the main caregiver of the sick child.¹⁴

Upon being notified of the child's disease, the family members tackle, firstly, feelings of denial and helplessness before the future of their child, such a context is configured as a unique and painful experience. The situation of having a child with cancer implies the generation of a break with all the expectations about the future thereof, by turning the parents' wishes in frustration and fear of death.¹⁵ The new world that is configured in the lives of these families, the multiple hospitalizations and the adaptation to the disease bring with them feelings of fear, anguish, doubts and despair in the face of the new situation.

The changes evidenced in the life routine of the mother are configured in conflicting situations, since it becomes necessary being absent of working practices, household activities and even of the married life with her husband, who usually stays at home with the other children.

The mother feels compelled to be present and participate in the disease background, as well as in the treatment and suffering of her child, in order to provide him a greater security and strength at this time. The uncertainty about the healing of the infant is added to the belief that she needs to do everything within her power to protect the child's life.¹⁶

Even knowing about the need and desire of being present at this difficult time, the treatment of their sick children, many mothers demonstrate contradictory feelings between being with the sick child and being with other children at the home. This dual need turns the mothers into frustrated subjects by the inability to meet all their family members, by believing that prefer to one over the other.¹⁴ The sense of miss becomes evident when they are questioned about the other children.

The conflicts arising from multiple roles played by the woman in the society, such as mother, wife, homemaker and professional, influence and intensify the emotional wear. Most mothers do not manage to keep their jobs, thus becoming unemployed shortly after the diagnoses of their children¹⁷; the husband-wife relationship often gets shaken due to the long periods of hospitalization, by discouraging the sexual bond between the couple. The extra-hospital rest and leisure periods are usually reprimanded, since many relatives have difficulties to accept the leisure times without showing a sense of guilt.¹⁸

Changes in mother's lifestyle and in daily activities are also highlighted. There are reports of decreased quality of sleep and wakefulness, since they sleep in unsuitable furniture within the hospital centers; in addition to the decreased quality of care of their own needs for self-care, due to the caregiver's activities prevent their personal care.¹⁹⁻²⁰

The escape and the negotiation also are configured as major factors outlined in these caregivers. Many of the mothers who accompany their children during the diagnosis and hospital treatment leave their story behind to walk in the pathway of their children; their experiences start to

be sustained in struggles, care procedures, hopes and fears. They begin to question why their children are sick instead of themselves.²¹

Adaptation tools and coping strategies

The literature describes coping, in pediatric oncology, as the actions and thoughts used by parents to deal with the wear and stress of the disease and its consequences.²²

The cancer, in itself, carries stigmas and prejudices, including becoming a synonymous with death. Because of this, many caregivers seek the religions and the beliefs with sights to minimize the pain evidenced by the course of the treatment. The spiritual support helps to endure the coexistence with the experience of illness, hospitalization and possibility of death.²⁰

The efficacy of treatment, although is likely, turns into a possibility in confrontation with its inefficiency, by leading to the experience of a permanent status of duality between the life and the death. The religiosity is placed as a mechanism that allows rationalizing the anguish before the uncertainty arising from the treatment, and at the same time helps to support it. It also allows the mother starts to prepare herself, involuntarily, for the loss of her child, in a more comfortable way, due to the belief of divine omnipotence.⁸

The parents find in the faith in God a way of strengthening and aid in coping with the disease, which gives them strength to be able to fight and keep hoping, by leading them to reformulate new life projects and thoughts on the future.¹⁵ The attachment to the divine belief, faith and spirituality tend to increase with the onset of the disease, while it will also be questioned by many family members at the time in which the children show signs of relapse.

Just as the religious attachment becomes comforting for the parents, the coexistence with other family members who are or have gone through this process also takes place as being essential for coping with the disease.

The contact with other caregivers seems to minimize the feeling of loneliness and helplessness during the long hospitalization, from the construction of imaginary spaces where the verbalization and the exchange of experiences can be shared. This relationship starts to be part of a fulcrum that provides support for them, since there is an exchange of experiences and feelings which end up minimizing anxiety, fear and powerlessness.¹⁵

The mutual support from several mothers, exchange of experiences, comfort and the self-esteem transmitted among them are means of strengthening and sharing pain and anguish, which helps in the resurgence and growth of the hope, by assisting in the continuation of the fight against the disease.

Just as the conversation welcomes the family members of children with cancer, the access to the full information and easy to understand also makes parents and other relatives feel more secure with regard to the course of the painful treatment. The search for new information and knowledge about the disease makes the mother feel more confident, especially if the quality information is provided by the multiprofessional staff.

The mother need to trust on whom cares of her child, and this bond occurs through the exchange of information and constant observation of the team's attitude towards everyone around her.¹⁶ The mother needs concrete information to support her own being and can insert the experience from the information into her life and in her family's life.

The clear and consistent information makes the mother to clarify doubts in relation to the disease and treatment of her child, thus feeling more included in the care process, by welcoming and

being welcomed by the multiprofessional staff, in addition to cooperating in the healing process of the child.

Holistic and humanized care from the nursing staff

Nursing staff is the team that is in direct contact with patients more frequently, by creating greater bonds and providing a greater set of information for the patient's relatives. This team should always be able to provide immediate emotional support, by becoming able to highlight potential problems and implement necessary interventions for the reduction of the anxiety and minimization of fears and anguishes of the family.

The nursing care needs to be an integral and holistic care, in order to meet not only the needs of very young patients as well as the needs of family members who are hospitalized with the child. The care should be full of friendliness, comprehension and devoid of prejudices and assumptions.²³

The nursing actions towards the oncological client and their family members should cover care procedures that transcend the semiotics of nursing, and they should also act to listen, comfort and share moments of pain and sadness with the family, by encouraging, constantly, the faith and the hope of all people who surround the world of the hospitalized child.

The humanization requires from nursing professionals knowledge, disposition, active interest, affectivity, flexibility, quest to improve the care, responsibility, sensitivity and ability to listen, by providing opportunities for the expression of feelings of children and family members without pre-judgments and censorship.²⁴

For the maintenance of a better family-nursing bond, it becomes necessary that this staff is present in moments such as diagnosis communication, throughout the painful process of treatment and in the discharge of the child, by turning the bond into something much larger than a professional act: a human act.

The team interaction throughout the disease process of the child will allow the identification and attendance of all needs of the mother and child, by providing spiritual comfort, body care, fondness and attention to everyone.⁷

Another factor that helps with the family-nursing interaction is the permission of the possibility to play by the part of the staff. The joking and the recreation emerge from the child's universe as the representativeness of its healthy side, by giving it a common image of most children.²⁵

Of the selected papers for this thematic category, all showed that the Nursing needs to develop methods of approach which seize the universal needs of oncological patients, but also develop particular characteristics of each case, thus avoiding stereotypes or prejudices. They also show the care related to the information provided to family members with regard to the power thereof.

CONCLUSION

The cancer stigma turns it into a fatal and incurable disease, with painful and heartbreaking evolution. When this disease strikes a child, who did little things in his short life trajectory, it soon begins to have a more fatal and painful meaning for its family, especially for the mother, who witnesses all the treatment phases together with the child.

The bibliographic review on the issue at stake has shown that the cancer requires the complete change of the life routine of the family, by bringing anguishes to the main caregiver, who

feels as if it was neglecting the other family members by caring for the patient in an exclusive manner. Just as the cancer drives the family members to feelings of fear and anxiety, also makes the faith in God and the religious belief of each of the members are maximized, thus creating greater hopes in relation to the healing.

Even showing up as a disease with fatal outcome, the cancer helps in structuring a bond of friendship among relatives of sick children, due to its contribution to the exchange of information among them and assistance in maintaining the hope of each one. It also enhances the family bond, by making the relatives more united and hopeful in the diagnosis moment and during the cancer treatment.

The Nursing as art needs to develop capacities larger than the techniques taught by the graduation courses, since the skills held by this category transcend the care implementation techniques: they are human and emotional skills that go beyond what is taught in the specialized teaching.

Given the observed results, we recommend that further studies are conducted in this field of Pediatric Oncology, by giving prominence not only to the feelings and yearnings emphasized by parents and relatives, but also to those experienced by the subjects of the care in Oncological Nursing: the cancer patients.

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