

SYSTEMATIC OR INTEGRATIVE REVIEW

CHILDHOOD CANCER IN THE FAMILY ENVIRONMENT: AN INTEGRATIVE REVIEW

O CÂNCER INFANTIL NO ÂMBITO FAMILIAR: REVISÃO INTEGRATIVA

ÂNCER INFANTIL EN EL ÁMBITO FAMILIAR: REVISIÓN INTEGRADORA

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ABSTRACT

Objectives: characterize the scientific output in online articles regarding the impact of childhood cancer on the family. This is an integrative literature review conducted by means of a search in LILACS, MEDLINE, BDNF, and the SCIELO virtual library, using the descriptors family, children, cancer, and oncology nursing, for articles published between 2008-2014, which led to the identification of 26 articles. For data analysis, the following themes were established: changes and feelings of family members due to the discovery of cancer in children, challenges in the treatment of children with cancer, family relationships and the nursing staff during the hospitalization of children with cancer. It was therefore concluded that the process of childhood illnesses and hospitalization causes changes in the family and requires nursing care for both the child and their family, which are critical factors in the patient's recovery and treatment when faced with a diagnosis of cancer.

Keywords: Family; Child; Neoplasms; Oncology Nursing; Child Health.

RESUMO

Objetivos: caracterizar a produção científica em artigos on-line acerca das repercussões do câncer infantil no âmbito familiar. Trata-se de revisão integrativa da literatura, realizada mediante busca na base de dados LILACS, MEDLINE, BDNF e na biblioteca virtual SCIELO, com os descritores família, criança, câncer, enfermagem oncológica, publicados entre 2008 e 2014, que possibilitou a identificação de 26 artigos. Para análise dos dados, foram estabelecidas as seguintes categorias temáticas: alterações e sentimentos de familiares frente à descoberta do câncer na criança; desafios no tratamento do filho com câncer; relacionamento família e equipe de enfermagem durante a hospitalização da criança com câncer. Concluiu-se que o processo de adoecimento infantil e a hospitalização provocam alterações no âmbito familiar e demanda atenção da enfermagem, tanto a criança quanto a sua família, o que é fundamental no processo de recuperação e tratamento frente ao diagnóstico de câncer.

Palavras-chave: Família; Criança; Neoplasias; Enfermagem Oncológica; Saúde da Criança.

RESUMEN

El objetivo del presente estudio fue caracterizar la producción científica de artículos en Internet sobre el impacto del cáncer infantil en la familia. Se trata de una revisión de la literatura realizada por la búsqueda en las bases de datos LILACS, MEDLINE, BDNF y en la biblioteca virtual SciELO con los siguientes descriptores: familia, niño, cáncer, enfermería oncológica, de artículos publicados entre 2008 y 2014. Se identificaron 26 artículos. Para el análisis de datos se establecieron los siguientes temas: cambios y sentimientos de los familiares ante el descubrimiento del cáncer en el niño; retos en el tratamiento del hijo con cáncer; relación familiar y personal de enfermería durante la internación del niño. Llegamos a la conclusión que el proceso de enfermedad y hospitalización infantil causa cambios en la familia y que tanto el niño como su familia requieren atención de enfermería, fundamental en la recuperación y en el tratamiento ante el diagnóstico de cáncer.

Palabras clave: Familia; Niño; Neoplasias; Enfermería Oncológica; Salud del Niño.

INTRODUCTION

Cancer is a disease that causes numerous repercussions both in the life of a person who contracts this disease and the family that accompanies the entire process from diagnosis, through treatment and recovery, requiring a multidisciplinary healthcare team as regards the evaluation and support provided to the person and his/her family members.

An oncologic disease is considered a fully treatable chronic disease and, in many cases, can even be cured, especially when diagnosed early.¹

Cancer is a chronic degenerative disease that affects a large number of people worldwide. The number of new cases has increased in recent years and is therefore considered a public health problem.² In children, cancer is defined as any malignant neoplasm affecting individuals under 19 years of age.

However, childhood cancer (under 19 years of age) is considered rare when compared to tumors in adults, accounting for only 2-3% of all malignant tumors. It is the second leading cause of death among children and adolescents, and it is estimated that approximately 11,840 new cases of cancer in this age group will occur in 2014.^{3,4}

As all disease causes suffering and instability in family dynamics, cancer itself generates doubts, fears, and uncertainties about its discovery, treatment, and control as it is a disease with a bleak prognosis, especially when related to children, implying the need to understand the impact of the disease from the family members' perspective, as everyone is affected by it.⁵

Accordingly, reflection and adaptations are important to the new reality that the family must face, requiring numerous adjustments, organizations, and redefining of roles to preserve the family balance⁶ through continuous monitoring through a multidisciplinary healthcare team.

For the family of a child with cancer, the time spent formulating the diagnosis instills feelings of fear and insecurity, and the formal discussion concerning diagnosis and treatment normally come after a long period of uncertainty during which the child may have gone through a series of painful tests and procedures. When the team finally sits down to discuss the diagnosis and treatment, fear of the news, along with future uncertainties, induces a sense of anxiety that makes it difficult for the family to cope with the situation.

Thus, childhood cancer presents itself as something frightening, capable of producing changes, disorder, and manifestations never before experienced, not only in the child's life, but also in the lives of their families, and can give rise to a range of feelings characterized by strong emotional shock, hopelessness, uncertainty, bewilderment, and consternation.⁸

The experience of having a child with cancer produces many effects on family life, some of which include the need for personal contact, financial hardship, sacrifice, pain, and emo-

tional distress. The feeling is that of experiencing a struggle in which the parents ask why this disease is in their lives. Its impact lead to the need for the family to develop new skills and tasks in its daily life to resolve the conflicts arising from hospitalization as well as the strain the disease places on the physical, psychosocial, and financial aspects.⁹

Incorporating the family into the hospital setting to accompany the child and the teenager is guaranteed by the Brazilian Child and Adolescent Statute, which states: the right of a guardian to stay during hospitalization¹⁰ is guaranteed, in accordance with Article 12 of the Child and Adolescent Statute (ECA), Act 8069, enacted in 1990. The article states that hospitals must provide conditions for a parent or guardian to stay full-time in cases in which a child or adolescent is hospitalized.¹⁰

The family is fundamental in the care-giving process, as it is the reference of love, trust, and often the reason for its existence. It is therefore necessary that the professional knows the family, its values, beliefs, and worldview, as they influence its ways of offering care. The nurse plays an important role in a multidisciplinary healthcare team by providing information to the family regarding the healthcare system, helping to define preferences and priorities in the treatment plan.¹¹

Hence, the present study aims to characterize the scientific production of online articles concerning the impact of childhood cancer on the family.

METHOD

This is an integrative literature review that aims to gather and synthesize research findings on a particular subject and provide a deeper understanding of it.¹²

The steps recommended in the literature were followed while developing this review: outlining the subject and formulating the guiding question; establishing the criteria for the selection of publications; defining the information to be extracted from selected studies and subsequent categorization; assessing studies included in the review; interpreting the findings; and, finally, disseminating the synthesized and evaluated knowledge.¹²

The guiding question proposed for this study was: What are the implications of childhood cancer on the family?

Inclusion criteria were as follows: the publication should contain, as the study's theme, questions about families or relatives of children with cancer who were outpatients, hospitalized, or in control; publications with full texts in Portuguese, English, and Spanish from July 2008 to January 2014, by researchers in the healthcare field, and that provide contextualization regarding the investigated matter.

The search was made in the Virtual Health Library (VHL), and used the following databases: Latin America and the Caribbean Literature in Health Sciences (LILACS), Medical Liter-

ature Analysis and Retrieval System Online (MEDLINE), Electronic Library Brazil (SCIELO), and Nursing Database (BDENF). The exclusion criteria consisted of: publications whose research subjects were adults; texts published within 10 years prior to those proposed here, which addressed the child's family, but did not directly treat the issue of cancer; texts that were repeated in the databases, dissertations, and theses. The following descriptors were used alone or in combination in the selection of articles: "Family", "Child," "Cancer/Neoplasia", and "Oncology Nursing". To restrict the sample, the *boolean* and operator was used, along with the selected terms: family and children and cancer, family and cancer and oncology nursing, and family and child and oncology nursing.

After, a check was conducted to see which studies would fit the proposed subject. The article abstracts were read, and 26 articles were selected, as they matched the proposed inclusion criteria, thus allowing a more thorough check of the data. Articles that were not published in full and those that did not meet the inclusion criteria were excluded. To organize the obtained content, after the data had been collected, a table was developed to show the information on each study, including: authors, year, title, database, method, and periodicals. The final sample of this integrative review consisted of 26 articles, which presented a greater adherence to the proposed objective.

RESULTS

Of the 26 selected articles, 23 were prepared by researchers in the field of Nursing and four in the field of Psychology. Five articles were published in 2013, nine in 2012, five in 2011, three in 2010, one in 2009, and three in 2008. Twenty-three were published in Portuguese and three in English.

Regarding the characteristics related to the types of study, two used the qualitative and quantitative approach based on descriptive and explanatory studies, 20 used a qualitative approach, one adopted Winnicott's contribution, and three were integrative reviews. Twenty-three were original papers and three were reviews. All research was conducted with family members/caregivers of children with cancer undergoing hospi-

tal treatment, those being treated as outpatients, or those who were in control of the disease.

Three themes were identified by reading and examining the selected papers: changes and feelings of family members in the face of the discovery of cancer in children; challenges in treating the child with cancer; and the family's relationship with the nursing staff during the child's hospitalization.

CHANGES AND FEELINGS OF FAMILY MEMBERS IN THE FACE OF THE DISCOVERY OF CANCER

The child's illness and hospitalization alter the entire family dynamic, since, in addition to having to deal with the issue of the disease, the parents also need to know how to deal with the economic issue. Because many families must leave their jobs to accompany the child throughout the disease process, they accrue expenses in transportation and lodging and, in some cases, have nowhere to get this money. Nevertheless, they try to be as close to their child as possible, because they are afraid that something might happen if they leave. Therefore, the family must take on new roles structured towards providing the conditions for the child to maintain and develop his/her existential potential.¹³

The experience of families with hospitalized children leads to a disruption in their routines and suffering, experiencing a breakdown in family life, especially in the home, where they still have obligations and responsibilities, plus the activities and financial demands related to the hospitalization.¹⁴

Accordingly, the family's day-to-day life undergoes a series of changes, and feelings, such as fear and anxiety surrounding the illness and hospitalization, become part of this new routine. The effects of hospitalization transcend the disease and bring about changes in the daily life and family structure.¹⁵

Following the discovery of cancer, families are overwhelmed by feelings of fear, dread, panic, worry, insecurity, anxiety, and nervousness. Initial contact with the disease creates fear through ignorance, and parents feel guilty for what is happening to their child; they come to think of it as being a kind of punishment.

Table 1 - Distribution of bibliographic references obtained from the LILACS, SCIELO, MEDLINE, and BDENF databases in accordance with the established keywords

Descriptors	Family and child and cancer / neoplasia	Family and child and oncology nursing	Family and cancer neoplasia and oncology nursing	Selected
LILACS	62	14	35	13
SCIELO	28	3	3	8
MEDLINE	423	17	73	3
BDENF	23	8	19	2
Total	536	42	130	26

Table 2 - Characterization of selected articles

Authors	Year	Title	Database	Method	Periodical
Barbeiro FMS	2013	Feelings evidenced by the parents and family facing the diagnosis of cancer in children	LILACS	Explorative and descriptive survey with a qualitative approach	R Pes Cuid Fundam Online
Alves DFS <i>et al.</i>	2013	Stress related to care: the impact of childhood cancer on the lives of parents	SCIELO	Integrative literature review	Rev. Latino-Am Enfermagem
Amador <i>et al.</i>	2013	Perceptions of the care and feelings of the caregiver of children with cancer	LILACS	Explorative and descriptive study with a qualitative approach	Acta Paul Enferm
Motta e Diefenbach	2013	Dimensions of the vulnerability of the families of children with cancer pain in a hospital setting	BDENF	Explorative and descriptive survey with a qualitative approach	Esc Anna Nery RevEnferm
Amador <i>et al.</i>	2013	Implications of childhood cancer for family caregivers: an integrative review	SCIELO	Integrative literature review	Rev Bras Enfermagem
Duarte <i>et al.</i>	2012	The daily life of parents of children hospitalized with cancer	LILACS	Explorative and descriptive study with a qualitative approach	Rev Gaúcha Enferm
Sales <i>et al.</i>	2012	The impact of the diagnosis of childhood cancer on the family environment and the care received	LILACS	Qualitative and Heidegger's existential phenomenological study	Rev Elet. Enf
Dupas <i>et al.</i>	2012	Childhood cancer: knowing the father's experience	BDENF	Qualitative study with symbolic interactionism, using George Herbert Mead's theory of human relations	Reme
Couto e Oliveira	2012	"Family's relationship with schoolchildren with cancer: perspectives for pediatric nursing"	LILACS	Qualitative case study research	Revista Bras Cancerologia
Mary <i>et al.</i>	2012	Parental perceptions in caring for a child at the end of life	MEDLINE	Qualitative study	American Journal of Hospice & Palliative Medicine®
Gomes <i>et al.</i>	2012	The presence of family in the pediatric chemotherapy room	SCIELO	Qualitative, descriptive, and exploratory study conducted at a teaching hospital in the city of Rio de Janeiro, Brazil	Rev Bras Enfermagem
Kohlsdorf M, Junior ÁLC	2012	Psychosocial impact of pediatric cancer on parents: literature review	SCIELO	Literature review between 1996 and 2009 on psychosocial processes associated with treatment	Paideia
Rigner <i>et al.</i>	2012	Talking through the child: an interactive and creative discussion between parents and healthcare professionals in a pediatric oncology ward	MEDLINE	Qualitative study guided by the steps of discursive psychology	Journal of Family Nursing
Zornig e Miceli	2012	Childhood cancer: the siblings' trauma	LILACS	Winnicott's contribution to the discontinuity associated with traumatic experience is resumed in the text	Tempo psicanalítico
Silveira e Oliveira	2011	The day-to-day life of the family member/companion with the child with cancer during hospitalization	BDENF	Qualitative, descriptive, and exploratory study conducted in a hospital in the city of Rio de Janeiro, Brazil	Rene
Silva <i>et al.</i>	2011	Experience of being a family caregiver in childhood cancer	LILACS	Qualitative study	Rene
Silva <i>et al.</i>	2011	Family of the child with cancer in palliative care	LILACS	Qualitative, exploratory, and descriptive study	Ciência Cuidado Saúde
Santos <i>et al.</i>	2011	Being the mother of a child with cancer: a phenomenological investigation	LILACS	Quality study inspired by Phenomenology in the light of Martins e Bicudo	Rev Enferm UERJ
Quintana <i>et al.</i>	2011	Grief and struggles: family structure before the cancer in a child/adolescent	SCIELO	Explorative and descriptive study with a qualitative approach	Psicol Argum
Angelo <i>et al.</i>	2010	Uncertainties facing childhood cancer: understanding mothers' needs	LILACS	Qualitative study with reference to interpretive interactionism	Esc Anna Nery RevEnferm
Silva <i>et al.</i>	2010	Cancer's impact on childhood parental relationships: an integrative review	MEDLINE	Integrative literature review	Journal of Nursing Scholarship
Castro	2010	The experience of childhood cancer: family, personal, and social implications	SCIELO	Qualitative, retrospective, and exploratory study, employed with a phenomenological inspiration	Revista Mal-estar e Subjetividade

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Table 2 - Characterization of selected articles

Authors	Year	Title	Database	Method	Periodical
Silva <i>et al.</i>	2009	Representation of the disease process in children and adolescents with cancer together with the family	LILACS	Qualitative and quantitative research, based on a descriptive and explanatory study	Esc Anna Nery RevEnferm
Klassmann <i>et al.</i>	2008	Experience of mothers of children with leukemia: feelings about home care	SCIELO	Descriptive study, guided by the qualitative and quantitative method with respect to its interpretive scheme	Rev Esc Enferm USP
Comarub e Monteiro	2008	Home care for children on chemotherapy from the family's perspective	LILACS	Qualitative study	Rev Gaúcha Enferm
Moreira e Angelo	2008	Becoming a mother of a child with cancer: building motherhood	SCIELO	Qualitative study with reference to interpretive Interactionism	Rev Latino-am Enfermagem

They must also face the fear of the unknown. Often, they verbally deny the diagnosis of cancer, and the fear of losing their child sets in almost immediately.¹⁶ Fear is also characterized by a feeling of insecurity in light of the change in routine and consequences caused by the treatment.¹⁷

In some cases, parents need to use antidepressants to minimize the effects of blame and the physical and mental strain it can cause. Many parents have symptoms of depression, predominantly feelings of hopelessness, helplessness, and despair.¹⁶ Antidepressant medications are widely used by parents, especially mothers.¹⁷

Upon learning about the illness, parents undergo a series of adjustments to better fit in their child's hospitalization, which commonly leads to family breakdown. That is when nurses must adopt a different way of seeing this family, as the diagnosis of neoplasia destabilizes family structures and perturbs their emotions.¹⁸

The siblings of children with cancer also undergo a series of transformations. It was observed that older healthy siblings show more caring, supportive, and protective attitudes towards the sick brother or sister; however, there are also cases of jealousy on the part of some siblings because of the extra attention parents give to the sick child and this, too, creates a degree of emotional instability.

In this sense, the focus is on the sick child and doing whatever is necessary to treat him or her. In considering the siblings without cancer as being healthy, both the families and the healthcare team fail to realize that they also need help to prepare for the physical and emotional absence of their parents and how to cope with feelings that could be aroused, such as anxiety, fear, envy, anger, jealousy, guilt, resentment, and remorse, as well as their fantasies about having somehow contributed to their sibling's illness and/or the absence of their parents.¹⁹

CHALLENGES IN TREATING THE CHILD WITH CANCER

Cancer treatment is highly aggressive and creates a high level of distress in the child's life, causing suffering in the fam-

ily in question due to the adverse effects from chemotherapy, starting with hair loss, weight loss, lack of appetite, and nausea. The family is invited to fully participate in their child's treatment, but they are not psychologically prepared to face the changes resulting from such an aggressive treatment.

In the process of adapting to and coping with the disease, family members of children with cancer go through well-defined stages, namely looking for ways to cope with the treatment, maintaining the integrity of the family and its emotional well-being, establishing mutual support, and searching for spiritual meaning.²⁰

It is in this moment of confusion and conflict that the parents bond closer together, as they are already in the maintenance phase and have started treatment, forming a supportive relationship, in which the older ones comfort the younger ones. This support network contributes to overcoming the obstacles experienced in the daily lives of children hospitalized with cancer.¹⁷ In addition to the mutual support, nursing care can alleviate some of the difficulties and provide support and information pertinent to treatment, further stimulating this family support bond.

FAMILY RELATIONSHIP AND THE NURSING TEAM DURING THE HOSPITALIZATION OF A CHILD WITH CANCER

Considering all the suffering experienced by the family of the child with cancer, it is essential that the nursing staff provide comprehensive care to the child and the family during hospitalization, enabling them to become active in caring for the child. Therefore, it is vital to establish a relationship of trust and respect between the families and hospital professionals, creating the possibility of turning the hospital into a more humane and welcoming place.²¹

By listening, providing emotional support, being clear and objective when asked about the cancer treatment, providing time for relaxation, encouraging the search for spiritual comfort, and involving the family in caring for the child care, the

nursing team contributes, to a certain extent, to fighting the disease, even in the face of an uncertain cure. Thus, the families find meaning and extra support to remain firm and strong during all steps involved in the disease process.

Thus, the nurses, through their intersubjective relationship with the child's family, can help alleviate some of the difficulties the families face with regard to the disease and treatment, enhancing comfort strategies and encouraging networking and links that help in their daily coping with hospitalization.²²

Thus, dialogue and information sharing can be important allies in demystifying cancer and the constructing new representations by caregivers, but it is crucial that healthcare professionals remain aware of the fact that more important than the amount of information is its quality, accessibility, and level of understanding.²³

Therefore, nursing plays an important role in the care given to the hospitalized child and especially in receiving the family. The importance of the relationship between the patient, nursing staff, and family in the care process includes how news is given, the clarity with which treatment is addressed, and making sure questions are clearly answered.

The nurse's role, which translates into attention, objectivity, and concern, has significant meaning for pediatric patients and their families, as it makes them feel welcomed and respected. Thus, it can be concluded that nursing care, guided by humanization during treatment of such patients and extended to their families, is of utmost importance.¹⁵

DISCUSSION

The data revealed that there were few articles addressing the topic of families and children with cancer in hospitals or out-patient clinics, but there was an increase in publications, beginning in 2011. It was apparent in the reviewed articles that both the researchers in Nursing, as well as those from Psychology, agreed that a family breakdown takes place when faced with the diagnosis of cancer in a child. Afterwards, family life undergoes many changes, starting with the fear that arises from the initial contact with the disease up to the changes that affect the child due to aggressive treatment.

Another issue that deserves attention is that the family member (mother) that accompanies the child during hospitalization usually leaves the other children, employment, and social life behind; in short, she becomes fully dedicated to the sick child. The other siblings feel abandoned, which may trigger feelings of anger, lack of protection, and insecurity, as they realize that the sick brother or sister is the focus of everyone's attention. In addition, the financial issue also suffers, since now only one family member is responsible for financial maintenance. These issues were well-developed in the articles written by researchers in the field of Psychology.

It should be noted that, in addition to the vast majority of articles written by researchers in Nursing, these professionals are the ones that remain with the child and the accompanying family member on a full-time basis, so it is understandable that a strong relationship would develop the child, the family, and the nursing staff alike.

When speaking of the child with cancer, the family, and the nursing staff triad, priority should be given to training the nursing staff to provide them with the proper psychological support so that there is an emotional involvement that functions not as an overload for the professional, but rather as a facilitator for giving care to children with cancer. This kind of emotional support may be transmitted in various ways to the families: unity during conversation, active listening, encouragement, expressions of support and understanding by putting one's self in another person's place, and effective bonding.¹⁵

Therefore, the family is of fundamental importance to the success of such initiatives. Nurses and other healthcare professionals themselves share the responsibility and commitment to make this possible by developing the necessary healthcare skills. If such initiatives are to succeed, the guidelines must be clearly understood by the caregiver and patient alike, whenever possible. Therefore, the child's routine and that of the family is completely transformed by the advent of a chronic disease like cancer. In this case, the nurse should be able to assess the cognitive and emotional condition of the caregiver, using clear language and appropriate methods to facilitate the understanding of these specific contents.²⁴

The nursing staff was the focus of the reviewed articles as regards the care provided to the family. Thus, it is understood that nursing plays an important role for both the child and the family during hospitalization, as it is through these professionals that the family feels supported, listened to, and has their questions answered. It should be noted that, in addition to nursing professionals, monitoring by a multidisciplinary healthcare team is also vital.

FINAL CONSIDERATIONS

Based on the data presented in this study, it can be concluded that the child's disease process and hospitalization cause changes in the family. However, as the people involved begin to adapt to this disease, there is a movement towards family reorganization in terms of physical, psychosocial, and financial resources so that all members are prepared to face the processes arising from the disease.

Nursing stands out in the context of hospitalization as regards its performance with respect to listening, being attentive and objective with the family, and especially their receiving of family members. As such, it is important for the professionals

in question to find a way to unify humanized care and the care arising from the use of technologies to minimize the impact that a child's hospitalization has on these families. Therefore, it should be emphasized that nursing care, based on the humanized care of both the sick child and the family, is of great relevance to this study.

The results of this research strive to update the topic and recommend further studies in the field of pediatric oncology, including approaches geared towards multidisciplinary teams. Moreover, the results emphasize that the role of nursing must transcend the semiotics of knowledge acquired in undergraduate and specialization courses and that the providing of care should be developed in a comprehensive and holistic manner for both the child and the family.

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