

ESTRATÉGIAS DE AUXÍLIO A FAMÍLIAS NO ENFRENTAMENTO DO PÓS-DIAGNÓSTICO DE CÂNCER INFANTIL

Strategies for aid to families in the course of post-diagnosis of child cancer

Estrategias de ayuda a familias en el enfrentamiento del post-diagnóstico de cáncer infantil

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ABSTRACT

Objective: to analyze the scientific production of nursing about the strategies used by nurses to assist family members in coping with post-diagnosis of childhood cancer. **Methods:** The productions were located in the Latin American and Caribbean Literature in Health Sciences (LILACS), National Library of Medicine/ National Institutes of Health (PubMed) and SciVerse Scopus (SCOPUS) databases. Of the 460 articles analyzed, 11 answered the guiding question: what strategies were used by nurses to assist families in the post-diagnosis of childhood cancer. **Results:** the most commonly used nursing strategies: the use of love, caring and respect for the care of family and children; communication for information exchange, emotional support and encouragement for faith and hope. **Conclusion:** it was concluded that there are good strategies used by nurses to help their families in the post-diagnosis of childhood cancer.

Descriptors: Nursing care; Nursing; Family; Neoplasms; Child.

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RESUMO

Objetivo: analisar a produção científica de enfermagem acerca das estratégias utilizadas pelos enfermeiros para auxiliar familiares no enfrentamento do pós-diagnóstico de câncer infantil. **Métodos:** as produções foram localizadas nas bases de dados Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), National Library of Medicine/ National Institutes of Health (PubMed) e SciVerse Scopus (SCOPUS). Dos 460 artigos analisados, 11 respondiam à questão norteadora: quais as estratégias utilizadas pelos enfermeiros para auxiliar famílias no pós-diagnóstico de câncer infantil. **Resultados:** as estratégias de auxílio mais utilizadas pelos enfermeiros: o uso de amor, carinho e respeito para o cuidado de familiares e crianças; a comunicação para troca de informações, apoio emocional e encorajamento para a fé e a esperança. **Conclusão:** concluiu-se que existem boas estratégias utilizadas pelos enfermeiros para auxiliar os familiares no pós-diagnóstico do câncer infantil.

Descritores: Cuidados de enfermagem; Enfermagem; Família; Neoplasias; Criança.

RESUMEN

Objetivo: analizar la producción científica de enfermería acerca de las estrategias utilizadas por los enfermeros para auxiliar a familiares en el enfrentamiento del post diagnóstico de cáncer infantil. **Métodos:** las producciones fueron localizadas en las bases de datos Literatura Latinoamericana y del Caribe en Ciencias de la Salud (LILACS), National Library of Medicine / National Institutes of Health (PubMed) y SciVerse Scopus (SCOPUS). De los 460 artículos analizados, 11 respondían a la cuestión orientadora: cuáles son las estrategias utilizadas por los enfermeros para auxiliar a las familias en el post diagnóstico de cáncer infantil. **Resultados:** las estrategias de ayuda más utilizadas por los enfermeros: el uso de amor, cariño y respeto para el cuidado de familiares y niños; la comunicación para el intercambio de información, el apoyo emocional y el fomento de la fe y la esperanza. **Conclusión:** concluyó que existen buenas estrategias utilizadas por los enfermeros para auxiliar a los familiares en el post diagnóstico del cáncer infantil.

Descriptorios: Atención de enfermería; Enfermería; Familia; Neoplasias; Niño.

INTRODUCTION

In Brazil, as well as in developed countries, childhood cancer is already the leading cause of death from disease among adolescents and children from one to 19 years old. This comprises a group of various diseases that have in common the uncontrolled development of abnormal cells and can occur anywhere in the body. The most common types of neoplasms in childhood and adolescence are leukemias (which affect white blood cells), lymphomas (lymphatic system) and tumors of the central nervous system.¹

Childhood cancer stands out for the repercussions it brings to the life of the child and family. Family members' affective experience with the disease, the moment of diagnosis and the beginning of treatment are the most difficult phases.^{2,3} The impact on the family is usually related to extensive and frequent periods of hospitalization, aggressive therapy, limitations in understanding the diagnosis, suffering, anguish, and pain. Thus, the nurse, as well as the entire health team

needs to emotionally assist these families by enabling them so that they can orient themselves along the path of the disease, reduce the stress of hospitalization and maintain hope about the reality imposed on them.²

The interest in researching this theme came from observations made during experiences in the blood-cancer area of a University Hospital in the interior of *Rio Grande do Sul* State. The contact of the researcher with the situation of childhood cancer led to the reflection that the family is always present in this disease process and that the moment of receiving a diagnosis can be a strong shock, because in most cases feelings such as anguish, helplessness, and even despair become evident. In this framework, the study intends to contribute through the actions that have been employed by nursing professionals to assist family members after receiving the diagnosis of childhood cancer.

Families, although they have as a common feeling the shock caused by the bad news, they may experience this process differently. Hence, it is important that nurses systematize knowledge in order to obtain subsidies for their professional performance. Given this, the following research problem was elaborated: what are the strategies used by nurses to assist families in the post-diagnosis of childhood cancer? Strategies are all actions that nurses can develop in their work environment to assist in the post-diagnosis of cancer. Considering the aforesaid, this study aimed to identify in the publications the coping strategies used by nurses to assist family members with post-diagnosis of childhood cancer.

METHODS

This is an integrative literature review with a qualitative approach, where the analysis was performed in existing publications identifying which coping strategies nurses use to assist with families of children with cancer in the post-diagnosis. It is worth mentioning that the integrative review aims to gather and synthesize the studies already carried out on a given subject and from the results evidenced in each of them, build a conclusion. This form of revision enables the creation of a current source of studies, as well as the determination of the validity of transferring knowledge to practice.⁴ The following addresses the research question: what are the strategies used by nurses to assist families in the diagnosis of childhood cancer?

The productions were located in May 2017 in the *Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS)* [Latin-American and Caribbean Literature in Health Sciences], National Library of Medicine/National Institutes of Health (PubMed) and SciVerse Scopus (SCOPUS) databases, through different strategies in each base, using the descriptors “nursing care” “family” “neoplasms” “child” and their mesh terms. Regarding the time period considered during the selection process of the productions, it is noteworthy that there was no temporal cut. The different search strategies and the non-use of temporal cut allowed the

expansion of the possibility of finding evidence that answered the research question.

Inclusion criteria were as follows: research articles that answered the guiding question, in English, Portuguese or Spanish. 460 productions were located, of which 11 comprised the corpus of the present study (Table 1). It should be noted that the productions that were repeated were considered only once.

Table 1 – Representation of the 1st stage: Reading of titles and abstracts. Santa Maria City, Rio Grande do Sul State, 2017

Abbreviation	Motive	Description	No.
NA	Not an article	Theses, dissertations, manuals, book chapters, review articles, etc. will be excluded.	45
NIL	Not in the language	Productions that do not have texts in the established languages (eg Portuguese, English or Spanish) will be excluded.	0
NR	Not a research	Reflections, reviews, reports, etc. will be excluded.	283
NT	Not in the theme	Articles that are not of the theme of the study will be excluded.	65
NQ	Do not answer the question (revision question)	Articles that do not answer the review question will be excluded.	
NA	Not available	Articles that are not fully available will be excluded.	0

Considering the 460 articles found from the search strategy, (45) were excluded because they were theses or dissertations, (283) because they were not research articles. Furthermore, (65) of the findings did not fit the theme.

This resulted in 67 productions selected for the second stage, which was the full reading of the selected articles, represented in Table 2.

Table 2 – Representation of the 2nd stage: Full reading. Santa Maria City, Rio Grande do Sul State, 2017

Abbreviation	Motive	Description	No.
NA	Not an article	Theses, dissertations, manuals, book chapters, review articles, etc. will be excluded.	45
NIL	Not in the language	Productions that do not have texts in the established languages (eg Portuguese, English or Spanish) will be excluded.	0
NR	Not a research	Reflections, reviews, reports, and similar works will be excluded.	283
NT	Not in the theme	Articles that are not of the theme of the study will be excluded.	65
NQ	Do not answer the question (revision question)	Articles that do not answer the review question will be excluded.	56
NA	Not available	Articles that are not fully available will be excluded.	0
Total		460 – 449 = 11 selected productions	

After the selection of articles, a synoptic table was prepared (Chart 1) with a mapping of the selected scientific productions to gather and synthesize the information to be extracted from the texts, containing the following questions: title; objectives of the study; study methodology; main results; and level of evidence. Regarding the ethical aspects, the writings of the articles and the copyright were respected, with no modification of the content found for the benefit of the study proposed by the authors.

Chart 1 – Distribution of articles found after the literature review by analysis variable. Santa Maria City, Rio Grande do Sul State, 2017

Author	Period/Year	Study Type/Approach	Database	Level of evidence
Durte, M.L.C.; Zanini, L.N; Nedel M.N.B.	2012	Descriptive-exploratory research with a qualitative approach	LILACS	6
Sales, C.A. et. al.	2012	Qualitative	LILACS	6
Salles, S.P; Castro, R.C.B.R.	2010	Field research, cross-sectional, applied, with a quantitative approach	LILACS, PubMed	1
Santos, M.R. et al.	2013	Descriptive-exploratory research with a qualitative approach	LILACS	6
Silva, F.A.C. et al.	2009	Field research with both quantitative and quantitative approaches	LILACS PubMed	6
Carvalho AS, Depianti JRB, Silva LF, Aguiar RCB, Monteiro ACM	2014	Descriptive field research	LILACS	6
Alves, DA. et al	2016	Descriptive-exploratory research with a qualitative approach	LILACS	6
Rocha, MCP. et al.	2015	Qualitative research	LILACS	6
Harper, F. et al	2016	Cross-sectional study with a quantitative approach	PubMed SCOPUS	1
Almico T, Faro A	2015	Quantitative study, clinical studies	PubMed SCOPUS	1

RESULTS

Table 3 – Characterization of the analyzed productions, LILACS/PubMed/SCOPUS. Santa Maria City, Rio Grande do Sul State, Brazil, 2017.

Study approach	
Qualitative	10
Quantitative	1
Origin	
US	3
Brazil	6
Europe	2
Temporal distribution	
2009-2012	4
2013-2017	7

The characterization (Table 3) of the included productions (N=11) revealed that the majority (10) consisted of qualitative research. There was a predominance of studies conducted in Brazil. Concerning the temporal distribution, the five-year arrangement pointed to the growing publication of studies related to the research theme between 2013 and 2017.

The articles were evaluated according to their strength of evidence, taking into consideration the type of clinical issue of the primary study, according to the different classification types for the studies⁶. Among the studies related to the meaning of feelings about the effects of a health intervention, most presented evidence level 6 (8), and only 3, evidence level 1. To contribute to the progress and quality of production from scientific knowledge the technical standards of the prism instrument were also used.

Targeting to facilitate the achievement of the study's purpose, the articles found were analyzed in order to categorize, interpret, and gather similar data. This grouping allowed the synthesis of the knowledge contemplated in the literature. It was possible to identify the strategies used by nurses to help relatives in the post-diagnosis of childhood cancer, emerging three categories: communication as a vehicle for guidance and emotional support; emotional support as a form of humanization; existence of beliefs as a way to encourage and support families. These categories aim to group the strategies found and better identify them. As shown in Figure 1.

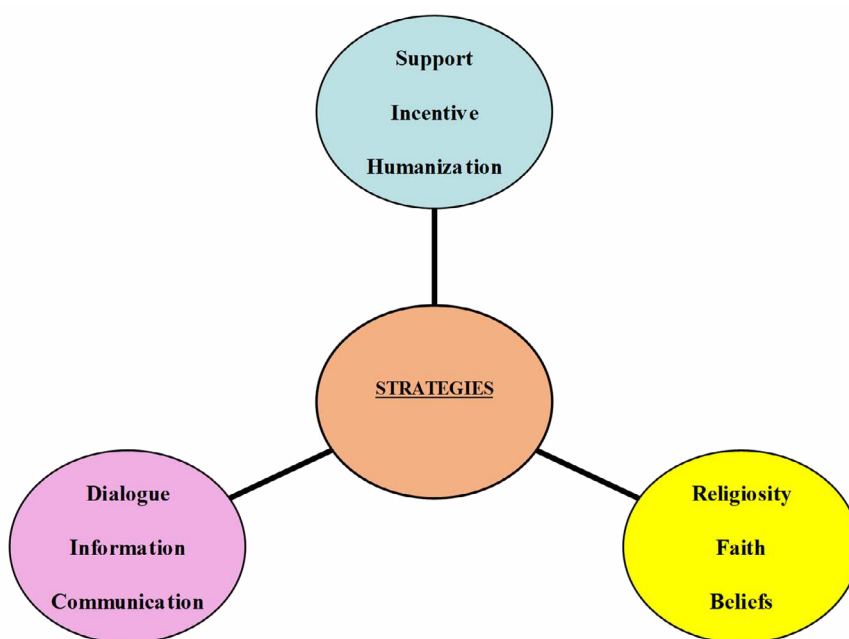


Figure 1 – Strategies used by nurses to assist family members. Santa Maria City, Rio Grande do Sul State, 2017.

DISCUSSION

Communication as a mean for guidance and emotional support

Communication is an essential element in the nurse-patient relationship. This in its various forms, concerning nursing, aims to humanize care and, therefore, the team needs to be willing and involved to establish this relationship. Narrowing

the communication ties favors the bond, besides bringing the necessary information for the understanding of the disease.¹³

Of the studies analyzed 70% report communication as a way of helping relatives of children with cancer. This demonstrates that the use of communication through dialogue, listening or writing is one of the ways of help that most professionals use in their daily lives in pediatric oncology.

Knowledge about the disease, treatment and what will happen from that moment is of paramount importance to parents, as with a good tool for explaining the disease, feelings such as insecurity, anxiety, and stress can be minimized. The nurse needs to clarify to the family everything that can happen during the child's treatment, explain issues such as hair loss or lack of appetite and all possible organic reactions from their treatment.^{9,12-21}

When communication is used as a mean for exchanging information, it becomes extremely important for parents, a good conversation between nurse and family includes the way the news is given, the clarity of the treatment and the clarification of doubts peculiar to parents.²⁻⁹

An effective communication tool is writing, one of the studies¹¹ reported the creation of an institutional teaching material written in a booklet format containing information explaining cancer treatment as well as its side effects and tips on what should be done when undergoing chemotherapy treatment. This instrument was considered satisfactory by the families and patients who received the booklet as a good way to understand the disease, especially when it is at the beginning of treatment, in which much new information that is completely unknown by parents comes out. So, the written health education mode supports family members in memorizing the contents to be learned and helps to standardize verbal orientations.¹¹

Dialogue is very important to promote the bond between nurse and family. The nurse feels, through the feeling of attachment to the family member, more comforted and more energetic to work in these situations, because they realize that if a bond has been created, there is a sign that with dedication and patience, they can receive the trust of this relative. For the family, the nurse becomes a friend with whom they can talk, cry and trust.^{12,20}

The nurse and their team should, therefore, create strategies for the family to have security in the care provided, turning their negative feelings into hope for recovery so that they can transmit comfort and stability to the child, making them more collaborative and thus facilitating the work. In this way, it reinforces the parents' participation as a positive presence, which corroborates the care provided, since it is clear that both have the same goal of reestablishing the child's health and that the presence of the accompanying family member benefits the care provided to the child.¹⁴⁻¹⁸

Hence, the presence of the family member/guardian should be transformed into a pleasant stay, in addition to preparing the team in front of the family for better flexibility and care organization, bringing back the autonomy for welcoming and open dialogue between both, in order to minimize difficulties and favor the child's recovery.¹²⁻¹⁶ The nurses' conduct should always facilitate the dialogue and understanding, then meeting the assumptions of humanization.

Emotional support as a principle for humanization

The analyzed articles⁸⁻¹² brought some kind of emotional support as a way that nurses use to assist family members dealing with the post-diagnosis of childhood cancer. Nursing¹³, with its multiple functions in care, must always be attentive to humanization. Therefore, care should be based on a composite of humanized feelings, where nurses should treat patients and families in the best possible way, respecting both the psychological, spiritual and biopsychosocial aspects, observing them as a whole, not as a sick part. Always practicing love, affection, and respect. The feelings reveal thoughts and behaviors, so nursing should be aware of the patient's feelings and the family's response to the disease situation, as a way of deep binding of the caregiver towards those who take care of others.

One of the forms of emotional support identified in the studies is the frequent presence of the nurse professional with patients and their families. Studies^{8,9-12} conducted with parents of children with cancer show that nursing is present during treatment, being available when necessary talking, listening, encouraging, and dedicating. This devotion when constant provides feelings of comfort, affection, and attention. This reflects on families and caregivers as a form of safety regarding a possible positive result in the child's treatment, as they observe that there is a competent professional who is committed to the lives of their children. For this reason, it is very important to establish bonds between the family and the nursing staff, since the beginning of the hospitalization, to alleviate the stress caused by hospitalization.¹³

The act of welcoming⁸⁻¹⁴ was presented in the studies as a way to assist in facing the diagnosis of childhood cancer. It is necessary for nursing to welcome patients and family members at the beginning of treatment, when hospitalization occurs, at this moment they are weakened and frightened by the result of the diagnosis. Family members describe the hospital as a pleasant environment where they feel welcome and safe during treatment. The family is the welcoming center, because currently they do experience hospitalization more intensely.⁹⁻¹⁰

The nurse's action to work out feelings with patients and family members was revealed in the studies analyzed. This highlights the importance of showing feelings such as: love, affection, and respect; Family members also reported that they had the perception of good feelings coming from the nursing staff. The nurses in the studies show constant concern to enable positive feelings to be able to perform a humanized work. Trust and respect between professionals and families create this possibility of transforming the hospital environment into a more humanized and welcoming place.⁸⁻¹² Humanized work comprises treating others with affection, love and respect, and dedication that are essential to receive the nursing service.¹⁵

Respecting the child and family when they are expressing feelings of anguish or anger is very important to support them emotionally, as this represents the nurse's effort to understand and help them at this time. We should also value feelings and expressions of joy, celebrating together with parents and children with each victory achieved in the treatment of the child.^{11,20}

It has been realized that acting honestly and openly is also a way of building a true relationship with family and children. Establishing a relationship with sincerity to have confidence makes the professional exercise congruence with the patient, especially when it comes to children, so the nurse will be moving beyond a productive work, because it can transcend the rigidity of expectations of their function, gaining the trust of the familiar.^{9,12}

Empathy for the nurse can be defined as the nurse's ability to experience the other's private universe, and to communicate to them some significant degree of understanding. This ability to recognize the feelings of the other or to put oneself in the other's place, which is empathy, makes the nurse more sensitive to the feelings of children and family members. Even though no one can go through the experience of the other completely, some degree of pain, anger, sadness, guilt, and anguish may already have been felt at some point in life, this is a reference for developing sensitivity, respect, and esteem.¹²

A differentiated form of support is the encouragement given by nurses to the creation of bonding networks. Encouraging the establishment of a network of bonds is characterized by encouraging family members who are beginning their child's treatment to exchange experiences with other family members who are in treatment for a longer period. This stimulation to the bond between family members will help in coping with the daily hospitalization. This is because parents, when interacting with other families, show sensitivity and willingness to give and receive help.⁹

However, the professional nurse will be emotionally supporting the family member when they are present, being available whenever necessary, when they welcome the family member, treating them with hospitality, when showing feelings of love, affection, and respect, when they are honest and sincere professionals, when they use empathy to understand what is going on with a patient or family member and when it encourages the family to create a bonding network. This way, the nurse will make their work more humane.

Beliefs as a way to encourage and support families

Religiosity^{8,9,12} was found as a way in which the family member seeks to continue the constant fight against the cancer of their children, inserting moments of faith, belief in divine strength or searching for the church in its results. For families, faith plays a significant role in the emotional balance and acceptance of illness, giving conformity and strength to continue the child's treatment firmly. In the search for spiritual definition⁹ many loved ones believe in death as divine will

and passage to a new world, a new life. Thinking like this brings conformation to support the fear and uncertainty about the child's recovery.

On the one hand, religiosity appears as a coping strategy for family members, on the other, someone should encourage them to believe in treatment, to believe in a positive future for the child, in other words, to believe in the existence of healing. The nurse, being one of the professionals who is constantly present in hospitalizations, is the one who can encourage the family member to believe so that they can better support their fears and uncertainties. The use of this encouragement on the part of the nurse was evident in the studies analyzed, and in some speeches, the professional said that they perceived using words of faith to give strength to these families.

Many people need some kind of spiritual help to cope with the disease. In one study⁸, a small portion of the subjects involved stated that they did not feel the need to attend church, while most sought this kind of help at some point. Thus, it became evident that many people need some kind of spiritual help to cope with the disease. Nurses¹² find themselves encouraging families to have faith and hope in treatment, maintaining faith and respecting each other's beliefs are essential elements for establishing a nurse-family relationship.

Faith in God is a feeling that is rooted in our culture and is as important as other modes of coping.⁸ An experience marked by suffering establishes a connection with spirituality when the family caregiver, in seeking to extract meaning for their suffering, begins to reflect on how much their human condition is permeated with limitation and fragility and acts to transcend it.⁹

When the nurse encourages a family member to seek divine help, they are spiritually supporting the familiar, helping them to be welcomed by the protection of a higher being, which each one believes, so they felt less alone in times of sadness and despair. The belief that there is a higher entity assisting in the recovery of the sick is a way to keep the hope of family members and often it is up to the nurse to encourage this, emphasizing that the professional should have the common sense to know if family members have any divine belief before intervening.

Spirituality is mentioned by families as a form of support of great value in all circumstances of life. Family members of a religious community report feeling more supportive.²²

It is clear that the search for religion and the use of spirituality was quite evident in the face of cancer in children, and therefore it is appropriate that these elements receive attention from health professionals, who, in turn, should work towards offer emotional support for the free expression of religiosity and spirituality during the treatment of children with cancer.

FINAL CONSIDERATIONS

Cancer is a disease that affects all ages, including children. When a child is stricken with cancer, the fear, fear of death, and uncertainty about the child's future on the part of the family are great. Families go through several reactions after

confirmation of the diagnosis, where feelings such as denial, anger, guilt, and sadness are easily identified.

The nurse, being the professional who most experiences these reactions to the diagnosis and is present throughout the hospitalization, must be prepared to know how to help these family members in any way. To be helpful, it is first necessary to identify what happens in their thoughts, to identify their feelings and their needs, thus, it becomes easier to create strategies to give the necessary support, leaving them calmer, minimizing their reactions and bad feelings.

The analysis of the studies led to the reflection that some nurses have been using coping strategies to assist family members in the post-diagnosis of childhood cancer. However, there are few publications on the subject, considering that the relevant articles found were from Brazilian authors.

Given the analyzed articles, it is possible to observe several actions performed by nurses, considering the strategies to obtain a better hospital environment and the assistance to both patients and their families, it was possible to ponder the most relevant ones. Communication, emotional support, and belief were the strategies used for nurses to help these family members at the time of post-diagnosis of childhood cancer. Hence, it is clear that there are still other strategies that can be developed, such as the use of recreational activities (individual and/or collective) with families to help them cope with the post-diagnosis of childhood cancer, these activities can help participants reduce their anxieties and fears regarding childcare, diagnosis, and treatment. Play activities can also be used as a way of health education for them.

It can be concluded the importance of the nurse's role in discussing, seeking, and developing together with the multidisciplinary team strategies to help relatives in coping with the post-diagnosis of childhood cancer. Aware of the comprehensiveness and complexity of this theme, this study did not intend to exhaust the subject, but to collaborate in the deepening and stimulation of new research, besides provoking questions from health professionals, especially nurses, in their work with families.

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