

VIVÊNCIA FAMILIAR DA CRIANÇA HOSPITALIZADA COM CÂNCER

FAMILY EXPERIENCE OF HOSPITALIZED CHILDREN WITH CANCER

VIVENCIA FAMILIAR DEL NIÑO HOSPITALIZADO CON CÂNCER

Rosana Fidelis Coelho Vieira¹, Fátima Helena do Espírito Santo², Fernanda Ferreira da Silva Lima³

RESUMO

Objetivo: identificar os indicadores científicos sobre a vivência familiar da criança hospitalizada com câncer. **Método**s: revisão integrativa de literatura, nas bases de dados Literatura Latino-Americana e do Caribe em Ciências da Saúde, Medical Literature Analysis and Retrieval System On-line, Cumulative Index to Nursing and Allied Health e Base de Dados em Enfermagem. **Resultados**: dezenove artigos, selecionados dentre os 413 publicados, entre 2010 e 2019, cujos principais sintomas analisados foram categorizados em: sentimentos do familiar da criança com câncer; necessidades do familiar da criança com câncer; enfermagem e família no enfrentamento da doença. **Conclusão**: constata-se o papel relevante da enfermagem, ao contribuir com ações que atendam às dimensões clínicas, afetivas, sociais e emocionais das famílias que precisam ser amparadas e acolhidas, para resgatarem sua autonomia, construindo com elas relações de confiança, fortalecendo-as para o enfrentamento da doença. **Descritores:** Criança Hospitalizada; Família; Neoplasias; Enfermagem.

ABSTRACT

Objective: to identify the scientific evidence about the family experience of hospitalized children with cancer. **Methods**: integrative literature review, on databases Latin American and Caribbean Health Sciences Literature, Medical Literature Analysis and Retrieval System Online, Cumulative Index to Nursing and Allied Health and Nursing Database. **Results**: nineteen articles were selected from 413 publications from 2010 to 2019, in which the main analyzed types of evidence were categorized into: feelings of the family member of the child with cancer; needs of the family member of the child with cancer; needs of the family member of the child with cancer; nursing and family in coping with the disease. **Conclusion**: the relevant role of nursing was confirmed, since it contributes to actions related to the clinical, affective, social and emotional dimensions of families that need support and embracement to retrieve their autonomy, building trusting relationships and strengthening them to cope with the disease.

Descriptors: Child, Hospitalized; Family; Neoplasms; Nursing.

RESUMEN

Objetivo: identificar las evidencias científicas sobre la vivencia familiar de niños hospitalizados con cáncer. **Métodos:** revisión integradora de literatura, en las bases de datos Literatura Latinoamericana y Caribeña en Ciencias de la Salud, *Medical Literature Analysis and Retrieval System On-line, Cumulative Index to Nursing and Allied Health* y Base de Datos en Enfermería. **Resultados**: diecinueve artículos fueron seleccionados de 413 publicados entre 2010 y 2019, cuyas principales evidencias analizadas se clasificaron en: sentimientos del familiar del niño con cáncer; necesidades del familiar del niño con cáncer; enfermería y familia en el enfrentamiento de la enfermedad. **Conclusión:** se encontró evidencia científica sobre el tema familiar de los niños hospitalizados con cáncer, destacando el rol relevante de la enfermería, contribuyendo a la acciones que atienden las dimensiones clínicas, afectivas, sociales y emocionales de las familias que necesitan apoyo y recogida para rescatar su autonomía, construyendo relaciones de confianza, fortaleciéndolas para enfrentar la enfermedad.

Descriptores: Niño Hospitalizado; Familia; Neoplasias; Enfermería.

¹Mestre em Enfermagem. Enfermeira do Instituto Nacional do Câncer (INCA). ²Doutora em Enfermagem. Professora Associada do Departamento de Enfermagem Médico Cirúrgica da Escola de Enfermagem Aurora de Afonso Costa da Universidade Federal Fluminense (EEAAC/ UFF). ³Mestre em Patologia Enfermeira do Instituto Nacional do Câncer (INCA).

How to cite this article:

Vieira RFC, Santo FHE, LIMA FFS. Family experience of hospitalized children with cancer. Revista de Enfermagem do Centro Oeste Mineiro 2020;10:e 3546.[Access___]: Available in :_____.DOI: <u>http://doi.org/10.19175/recom.v10i0.3546</u>

INTRODUCTION

In Brazil, cancer represents the leading cause of death from disease among children and adolescents aged from one to 19 years and, according to data from the Mortality Information System, in the range from 0 to 4 years, it occupies the eighth position among the causes of death; from 5 to 19 years, it is the main cause⁽¹⁾.

Considering the Human Development Index (HDI), it is possible to project that, in countries with a low index of this indicator, there may be an increase in cancer by 112% and, in countries with medium HDI, the rate may increase by 86% between 2012 and 2035, revealing a proportionality of higher cases of cancer in countries with lower HDI⁽²⁾.

In fact, this worldwide problem has been raising concerns regarding prevention, early diagnosis, treatment and rehabilitation. The expectation of cancer in Brazil, published in 2019, for the triennium 2020-2022, is 450 thousand new cases, for each year, excluding non-melanoma skin cancer. For the same period, there may occur 8,460 new cases in children and adolescents aged up to 19 years⁽³⁾.

Furthermore, according to the estimate, for the year 2020, the crude incidence rate of new cases of cancer in children and adolescents will be 3690 in the Southeast and 2,190 in the Northeast. These regions will present the highest numbers of new cases⁽³⁾.

The child's illness and hospitalization lead to different feelings in the family caregiver, mainly due to unknown routines and devices, arousing fear, expectations and uncertainties and may even traumatize them⁽⁴⁻⁵⁾. The mothers, few decades ago, could not accompany their children, being distanced, at the most difficult time for the child, who was sick, far from home, in a new and strange environment, without the presence of the family⁽⁶⁾.

However, in the family, the child, during hospitalization, is supported by the search for affection, protection and support. Therefore, childcare, when shared with the nursing team and the family caregiver, may be favorable for families to experience less stressful moments in hospitalization. The encouragement with integrated actions and the family inclusion in childcare is essential, in order to better control the situation and reduce their suffering. The family is a fundamental part in the treatment due to their capacity for reorganization and action⁽⁷⁻⁹⁾.

In general, the mother most accompanies

the child, in a process of illness and hospitalization, generating, in the child and adolescent, different feelings, such as guilt, pain, shock, impotence for the impossibility of doing something, besides feeling responsible for the child. Parallel to this reality, there is an imbalance usual activities even if transiently⁽¹⁰⁻¹¹⁾. In the hospitalization of pediatric patients, the stay of the companion is necessary, and health facilities must be adapted to the presence of parents or guardians, during the hospitalization, guaranteeing them equal access, as provided for in Article 12 of the Byelaw of the Child and Adolescent⁽¹²⁾.

The presence of the accompanying family member has become increasingly frequent regardless of the patient's age group and level of dependence⁽¹³⁾. It has been awakening different reflections in professionals, especially in the nursing team, which is the one that, in the face of their activities, remains longer close to the familypatient binomial. Therefore, it has demanded new forms of organization, in the dynamics of nursing care, largely due to the new challenges faced by families ⁽¹⁴⁾.

Nevertheless, this care that encompasses the child and his/her family needs to be expanded differently, focusing on the attitudes of the teams, involving the participation of families in the care with children and not being seen by the nursing team only as co-adjuvants⁽¹⁵⁻¹⁶⁾.

Chronic diseases result in longer hospitalization length and more frequent hospital calls, increasing stress and vulnerability in families. On the other hand, they bring the family and the health team closer together, favoring the identification of the demands for support for the care with children, as well as good communication between companions and the nursing team, which, through ethical competence, optimizes the process of coping with the disease^(14,17-19).

The lack of information from professionals triggers feelings of uncertainty and doubts in the mothers, which can decrease, provided that the nursing team listens to the complaints, fears of families, including them in the care, thus improving the relationship of trust between the team and the family^(9,20).

Moreover, the growing emphasis on the family in the hospital context raises concerns about the health team's perception of the family, thinking of them as a system that cannot be dissociated in the care with hospitalized children with cancer. The child patient needs the family actively and integrated in the care, helping him/her face and adapt to this moment.

In view of the progressive incidence of childhood cancer, nursing has become increasingly significant, since its work is based on the identification of human responses, since it seeks to establish strategies that can recover the health and well-being of the sick child and his/her family.

In light of these considerations, this study aims to analyze the scientific production about the family of hospitalized children with cancer.

METHODS

This is an integrative literature review (ILR), an analysis of relevant researches that allows synthetizing results, enabling general conclusions about a particular area of study, as well as showing gaps in knowledge that need to be filled with new researches⁽²¹⁾.

The methodological path was carefully carried out, according to the following stages: formulation and identification of the problem and research question; establishment of inclusion and exclusion criteria; data collection; evaluation of the included studies; data analysis and interpretation; and presentation of results⁽²²⁾.

The elaboration of the guiding question was based on the PICO strategy, which provides information on the focus, scope and applicability in a review. Detailing the PICO strategy, the P determines the population to be studied; the I, the intervention, indication or interest of what is intended to be studied; C is the comparison and, finally, O is the outcome and the expected result⁽²³⁾. In the acronym PICO of this review, the PI question will be investigated, whose P is the relative of the hospitalized child with cancer and the I identifies the scientific indications published in the literature about the family experience of the hospitalized child with cancer. Thus, the following guiding question emerges: what is the scientific evidence about the family experience of hospitalized children with cancer?

The search was conducted from January to February 2019 on the following databases: Latin American and Caribbean Health Sciences Literature (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE), Cumulative Index to Nursing and Allied Health (CINAHL) and Nursing Database (BDENF), accessed by a single researcher. In order to expand the search field, the databases were diversified, taking into account the national and international literature.

The descriptors used in the research were identified, on the Health Sciences Descriptors (DECS), specific to LILACS databases, on the Medical Subject Headings (MeSH) and by titles, on the CINAHL database, respecting the specificities of each one. The descriptors were crossed according to the AND and OR Boolean operators specified in the table.

Figure 1- Search strategy.

Database	Search strategy
BVSLILICS/BDENF	(tw:(Child* OR Crianca OR Nino OR Adolescent* OR Teen*)) AND (tw:(Neoplas* OR Tumor* OR
	Tumour* OR Cancer OR Carcinoma* OR Onco*)) AND (tw:(Family OR Familia OR Parent*)) AND
	(tw:("Nursing care" OR "Cuidados de Enfermagem" OR "Cuidado de Enfermeria" OR Nurs* OR
	Enfermeria OR Enfermagem)) AND (instance:"regional") AND (db:("LILACS") AND
	year_cluster:("2013" OR "2014" OR "2015" OR "2016" OR "2017" OR "2018"))
PUBMED	((((Child[mj] OR Child*[tiab] OR Adolescent[mj] OR Adolescent*[tiab] OR Teen*[tiab]) AND
	(Neoplasms[mj] OR Neoplas*[tiab] OR Tumor*[tiab] OR Tumour*[tiab] OR Cancer[tiab] OR
	Carcinoma*[tiab] OR Onco*[tiab])) AND (Family[mj] OR Family[tiab] OR Parents[tiab])) AND
	(Nursing care[mj] OR Nurs*[tiab])) AND ("2013/11/29"[PDat] : "2018/11/27"[PDat] AND
	"humans"[MeSH Terms])
CINAHL	((((Children OR Adolescents OR Teenager) AND (Neoplasms OR Tumor* OR Tumour* OR Cancer O
	Carcinoma OR Oncology)) AND (Family OR Parents)) AND ("Nursing care" OR Nursing))

Created by the author.

For the selection of articles, the inclusion criteria defined were original articles, in English, Portuguese and Spanish that portrayed the family experience of children with cancer in the hospital, published between 2010 and 2019.There was exclusion of repeated articles on databases, review studies, case reports, reflections or communication and articles with no relationship with the theme, verified by reading title and abstract.

This integrative review chose the categorization of evidence based by experts from the Agency for Healthcare Research and Quality (AHRQ), namely: level 1, systematic review or meta-analysis of randomized controlled trials; level 2, evidence of a well-designed randomized controlled trial; level 3, well-described clinical trial, without randomization; level 4, welldesigned cohort and case-control study; level 5, systematic reviews of descriptive and qualitative studies; level 6, descriptive and gualitative studies and level 7, opinion of respectable authorities, based on clinical competence or opinion of expert committees⁽²⁵⁾.

Regarding the degree of recommendation of scientific evidence, this classification calls levels I and II as strong, III and IV as moderate and V through VII as weak, since level of evidence I is the most reliable and the best to answer its clinical question⁽²⁵⁾. All ethical issues were respected and, since this is an integrative review, there was no need for submission to the Research Ethics Committee (REC).

In the identification stage, 413 articles were found. After reading the titles and abstracts, 93 were removed, in the screening stage, because they did not meet the inclusion criteria of the research. For the eligibility stage, 45 pre-selected articles were retrieved, of which, in the inclusion stage, 19 composed the review, and 23 articles were removed because they were not related to the theme of study. The flow diagram, according to the meta-analysis model (PRISMA), is as follows (Figure 2)⁽²²⁾.

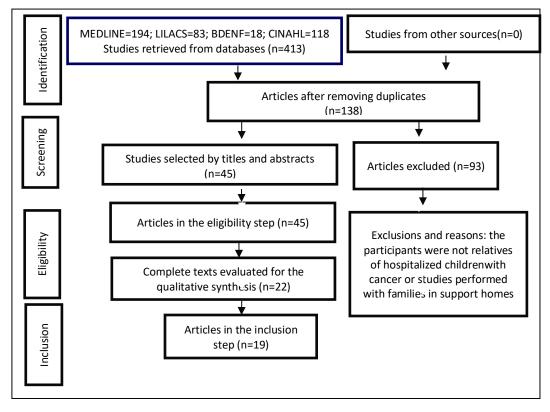
The articles of the final sample were identified with fictitious name by alphabetical letters, following the order of the list of references presented in this ILR and submitted to an exploratory reading, complete analysis, in a critical and systematized way.

To ensure methodological rigor and verify the evidence of the included publications, Figures 2 and 3 were elaborated by the author on Microsoft Word, specifying the main information of the articles used, identified by alphabetical letters, in the order of the list of references presented in this ILR, including title, authors, year, place of study, database, level of evidence and objectives, facilitating the comparison of studies about specific topics , for the analysis and writing of the text of the integrative review, discussed in the light of the specific literature.

Finally, the contents of the figures also allowed organizing the data and subsequently systematizing the search results, in order to better characterize all the collected content, following the recommendations of the PRISMA model⁽²²⁾. The studies were analyzed by two researchers, independently and interpreted aiming to achieve the research objective. The analysis allowed identifying the information and descriptions most frequent and relevant to the theme, which stood out regarding the intentionality of the guiding question of the present study. The following thematic categories were grouped: "Feelings of the family member of the child with cancer. Needs of the family member of the child with cancer. Nursing and family in coping with the disease."

After the synthesis of the data extracted from the articles, the analysis was performed descriptively, in order to gather the knowledge produced about the theme explored in the review, respecting all ethical precepts and with no conflict of interest.





Source: created by the author.

RESULTS AND DISCUSSION

According to the year of publication, of the nineteen articles selected for the study, three (15.79%) were published in 2014, 2016 and 2017; two (10.53%) in 2010, 2012, 2015 and 2018; 1(one) (5.26%) in 2011 and 2013. Regarding the study sites found, Brazil appears with the highest publication rate, fourteen (73.68%); one (5.26%) in the USA; one (5.68%) in Iran; one (5.26%) in China; one (5.26%) in Kenya and one (5.26%) in Taiwan.

Regarding the database, CINAHL stood out with 31.58% of the publications. Regarding the

research design, 100% used the qualitative approach, and 17 articles were categorized with level of evidence 6, defined as studies with a nonexperimental design, as a correlational and qualitative descriptive research; and two studies, with level of evidence 3, classified as a study with an quasi-experimental design, without randomization with a single pre- and post-test group, time series or case-control according to the classification of the Agency for Healthcare Research and Quality (AHRQ)⁽²²⁾ Therefore, scientific evidence of this theme presents level of evidence 6.

ID	TITLE	AUTHOR	YEAR	SITE	DATABAS E	LEVEL OF EVIDENCE
A	Mothers/companions of children with cancer: apprehension of the hospital culture	Vieira RFC et AL	2017	Rio de Janeiro, Brazil	LILACS	6
В	Family experience in the face of illness and treatment of children and adolescents with acute lymphoid leukemia	Monteiro CFS, Veloso LUP, Sousa PCB, Morais SCRV	2014	Teresina, Brazil	MEDLINE	6
С	Pediatric Oncology: the use of cluster analysis to examine maternal concerns	Liu YM, Yeh CH	2010	Northern Taiwan	CINAHL	3

Figure 3 – Characterization of selected articles, according to title, author, year of publication, place of study, database and level of scientific evidence.

D	Tension in the role of primary caregiver in the care provided to children with	Oliveira RAA, et AL	2015	Pernambuco Brazil	LILACS	6
E	cancer Dimensions of vulnerability for families of children with cancer pain in a	Motta MGC, Diefenbach GDF	2013	Rio Grande do Sul, Brazil	LILACS	6
F	hospital environment Uncertainties in the face of childhood cancer: understanding the mother's needs	Angelo M, et AL	2010	São Paulo, Brazil	MEDLINE	6
G	The daily lives of parents of children with cancer and hospitalized	Duarte MLC, et AL	2012	Rio Grande do Sul, Brazil	BDENF	6
Н	Social support among companions of children hospitalized in a hematopediatric unit	Kozan, L, et AL	2016	Curitiba, Brazil	LILACS	6
I	Being a mother of a child with cancer: a phenomenological investigation	Santos LF, et AL	2011	Goiás, Brazil	BDENF	6
J	Secrets and truths in the family's communication process with the child with cancer	Borges AA, Duppas G	2016	Minas Gerais, Brazil	LILACS	6
L	How Parents of Children With Cancer Learn About Their Children's Prognosis	Sisk BA et AL	2018	Boston, Massachusetts Pennsylvania	MEDLINE	3
Μ	Psychological Limbo as a Barrier to Spiritual Care for Parents of Children with Cancer: A Qualitative Study	Sheikhzakaryae e, Neda, et AL	2018	Iran	MEDLINE	6
N	Coping with the diagnosis and hospitalization of a child with childhood cancer	NoiaTC, et AL	2015	Bahia, Brazil	MEDLINE	6
0	Female caregivers accompanying children with cancer in the hospital setting	Wegner W, Pedro ENR.	2017	Rio Grande do Sul, Brazil	BDENF	6
Ρ	Psychometric Validation of an Instrument to Measure Family Coping During a Child's Hospitalization for Cancer	Liu Q, et AL	2017	China	CINAHL	6
Q	Repercussions of child cancer in the daily life of a family caregiver	Medeiros, et AL	2014	Paraíba, Brazil	CINAHL	6
R	Assessment of Parents' Perception of Quality of Pediatric Oncology Inpatient Care at Kenyatta National Hospital	Keiza EM, Chege MN, Omuga BO	2016	Kenya	CINAHL	6
S	Nursing care: family and child with cancer pain	Diefenbach GDF, Motta MGC	2012	Rio Grande do Sul, Brazil	CINAHL	6
Т	Reactions of family members of children diagnosed with cancer: a descriptive study	Carvalho AS, Depianti JRB, Silva LF, Aguiar RCB, Monteiro ACM	2014	Rio de Janeiro, Brazil	CINAHL	6

Source: Created by the author.

The studies revealed the assertion that the nursing team is a fundamental link between the family and hospitalized child, and should promote health education, while providing care, combining the understanding, technical skills, humanization and sensitivity in care.

The first thematic category was constructed, based on eighteen articles, emphasizing the feelings of fear, pain, sadness, anxiety and vulnerability, emphasized by the impact of diagnosis, the unknown, uncertainties and the possibility of loss and death^(26,29-37).

Families forget their own lives, nullify themselves when they have a child under cancer treatment. They do not project their futures for fear of loss; their routine becomes the child's routine. They come out of their own stories and immerse themselves in their children's life stories, serving them as sustenance^(26,33,39).

Different changes in the personal and professional field occur in the lives of mothers of children with cancer, such as unemployment, weakening of marital relationships, social isolation, physical and emotional exhaustion, due to a need for reorganization to care for the sick child $^{\rm (40)}.$

These feelings of fear and insecurity in family members during the hospitalization of children with cancer are caused by psychological fragility combined with the severity of the disease and treatment uncertainties, which develop anguish, destabilize families and reflect on quality of life, being directly proportional, causing tension to the caregiver^(30,42).

The cancer associated with the young person brings reflections on the possibility of the future, which can frustrate life projects, especially in the face of threat of death. Therefore, some strategies arise regarding the diagnosis, such as not wanting to talk about cancer, when assuming a posture of denial to minimize suffering⁽⁴³⁾.

Vulnerability is associated with the impact of the diagnosis; being sick and hospitalization, for children and their families with frequent hospitalizations, alter their daily lives and make them experience a new context, immersed in misunderstandings regarding care, suffering generated by treatment and oncologic pain^(30-31,39,44).

The impact of cancer diagnosis reflects in families the idea of a cureless disease still very stigmatized, causing rapid loss and inevitable death, but the way to deal with changes, hospitalization and disease is closely related to the characteristics of each family^(28,31,33,45).

On the other hand, it was also possible to identify that mothers become strongerbefore interactions, adapting to the environment, encouraging themselves during hospital procedures, managing to master their fears, even strengthening other mothers who experience the same context. Culturally, these mothers are seen as strong, warriors and have opportunities to grow with the disease, which provides an opportunity for mutual understanding^(26,39,42).

The possibility of loss, in view of the cancer diagnosis, causes in families an experience of intense feelings that permeate the phases of the disease, always with the imminent risk of an early loss making them vulnerable. For mothers, the diagnosis of cancer contributes to negative impacts, such as death sentence^(33-34,45).

Living with the unknown results in feelings of uncertainties and insecurities that are part of the universe of cancer treatment, whose success of the entire trajectory is directly linked to the way this phase will be experienced by all^(32,39). The second category deals with the needs of the relative of the child with cancer. In ten articles, the desire to be present emerged, as well as to follow the treatment, to receive a clear communication, to be heard, to be supported, to rescue spirituality to improve quality of life and to maintain bonds^(26,30,33,35-39,45-46).

The fact of being present and following the treatment of the child provides the mothers with security to establish bonds of trust with the team, which treats and cares for their child. This mother needs support and care in order not to develop the feeling of loneliness⁽³³⁾.

The mother or other female relative frequently accompanies the child in hospitalization, being responsible for maintaining a bond of trust with the health team, organizing ways of coping, aiming to heal and return to normality of family dynamics^(32,37).

The clear form of communication proved to be strongly allied to the treatment of hospitalized children and essential to care, as it is extremely efficient in nursing care with family members of children with cancer. When informed of the prognoses, they become more confident and optimistic^(27,36,45).

Through the demands of the disease and hospitalization, both children and family need to be heard and supported by the team, which must optimize embracement spaces so that mothers can express their emotions, in order to provide them with their insertion in the care with their child^(30,39).

By meeting the needs of the family members, while providing and, above all, listening to their desires and feelings, health professionals have in families a strong partner in patient care, with the ability to reformulate the information given in the hospital and add it to the daily care^(26,35).

The third category addresses nursing and family in coping with the disease. In seventeen articles, the relevance of the nursing team's performance with families in detecting possible problems was evidenced, identifying the risk of ineffective coping process of these families concerning the disease and emotional support, seeking to alleviate daily life through clear communication and rescue of autonomy^(26-33,36-46).

Another aspect shown in this category was related to the interactions between nursing and family in the hospital environment, which reduce stressors regarding the diagnosis, hospitalization and treatment of the disease. Thus, they bring comfort and close bonds, helping to cope with the disease and its difficulties, in this critical period, by offering humanized care^(34,44).

The nursing team is the first to establish contact with the initial moment of the family, in the hospital environment. Furthermore, this category stays with the family and the child during hospitalization, creating more bonds. Thus, they should be able to perceive difficulties and intervene with adequate safety, ensuring emotional support to families during this moment^(28,31).

Importantly, the more one encourages the participation of the child's family members, making them important and indispensable in care, inserting them in daily routines, in the solutions of problems and conflicts, the easier will be to transform the more solid intersubjective relationship, besides helping to rescue autonomy, quality of life and coping with the disease⁽³³⁾.

The lack of information increases the difficulty of knowing more about the disease, aggravating feelings of helplessness and sadness. The nursing professional must understand the family as a care unit, which is part of the child's treatment, because the disease is related to the interruption of the life path^(34,46).

The more information is reinforced by the nursing, the greater the support, embracement, establishment of bonds and trust, supporting the family member, which will be significant to the care process. The dialogue transmits safety and continuity of treatment at home⁽⁴⁷⁾.

One way to alleviate symptoms of anxiety, concern and fear, in the face of cancer treatment in families, is seeking spirituality, which brings tranquility and the ability to resist catastrophic problems, because faith in God reduces negative thinking and plays an important role in emotional balance, being a strategy adopted by the companions of children with cancer^(33,37,39).

Trust in God, faith and spirituality are tools that help in the process of acceptance of the disease, strengthen, encourage, improve the expectation of cure and enable means to restructure families⁽⁴⁸⁻⁴⁹⁾.

In the care with the oncologic child, professionals should consider interpersonal relationships, with zeal and technical competence, throughout the process, in order to reduce the consequences of treatment and hospitalization for the child and his/her family^(38,50-51).

Given the possibilities of this review, researches about families were developed seeking

to investigate their experiences, considering situations of suffering, physical and emotional distress, changes in routines, needs of families to be supported, heard, share thoughts, form affective bonds, be present, during treatment, before the fear, insecurity, anguish and the new context experienced in cancer diagnosis.

However, the analysis of the publications revealed that nursing has a relevant role in the care with families during hospitalization, since they represent support and aid for children with cancer, who, in a fragile moment, become vulnerable and lose their autonomy. Thus, care cannot be disconnected from the child and family dyad.

In this sense, there is need to reflect on the importance of nursing inserting family-centered care in the treatment of oncologic children, relying on nursing theories, encompassing the various interfaces that hospitalization brings to the child and his/her family member, respecting and appreciating feelings, needs and limitations individually and humanly.

CONCLUSION

The study found scientific evidence about the family of children with cancer, highlighting the difficulties in receiving the diagnosis of childhood cancer, revealing an experience of pain, despair, fears, doubts, insecurities, anxiety and much concern about the uncertain future. The relevant role of nursing in the child's hospitalization and in his/her situation stands out, as it is an unknown environment, surrounded by devices and new routines. In this scenario, nursing should contribute to actions that meet the clinical, affective, social and emotional dimensions of families, which need to be supported and embraced in order to regain their autonomy; build these relationships of trust, strengthening them to cope with the disease.

The findings in this review also reinforce the fundamental role of nursing in the care centered on children and their families regarding the diagnosis of cancer. The family should be seen as a care unit that needs to be heard, embraced and taught to continue the child's treatment. The interaction between family and nursing team builds bonds, relationships of trust and care safety.

A limitation of this article was the scarcity of publications with the theme of hospitalized children's families, specifically with cancer, even though significant increases in published articles were found, with emphasis on the family, since the promulgation of the Byelaw of the Child and Adolescent in 1990.

There is also the need for more studies, which present a better classification regarding the degree of evidence levels in relation to the theme of family of children with cancer, which indicate more accurate results of family-centered care. Likewise, they can help future researches incorporate families in the care actions, bringing better indicators and easy access to results that support nursing behaviors and decision-making in the care with children with cancer and their families in the hospital setting.

REFERENCES

1- Paixão TM, Farias SNP, Rosas AMMTF, Coropes BVAS. Early detection and child cancer approach for primary care.Rev Enferm UFPE2018;12(5):1437-43. DOI:10.5205/1981-8963-v12i5a231281p1437-1443-2018 Disponível em:https://periodicos.ufpe.br/revistas/revistaenf ermagem/article/view/231281.

2- Fidler MM, Bray F. Global cancer inequalities.Front Oncol. 2018;8:293. DOI: 10.3389/fonc.2018.00293

3- Instituto Nacional de Câncer José Alencar Gomes da Silva. Estimativa 2020: Incidência de câncer no Brasil. Rio de Janeiro: INCA; 2019.

4- Costa AR, Nobre CMG, Gomes GC, Nornberg PKO, Rosa GSM. Sentimentos gerados na família pela internação hospitalar da criança. J Nurs Health 2019;9(2):1-12. DOI: 10.15210/jonah.v9i2.14012

5- Turolla KR, Souza MC. Enfermagem Pediátrica Oncológica: Assistência na fase de terminalidade. EnsaiosCiênc,CiencBiol Agrar Saúde 2015 [citado em 7abr 2019];19(1):26-37.Available in: file:///C:/Users/FAMILIA/Downloads/3013-

Texto%20do%20artigo-12380-1-10-20151119.pdf 6- Leite AO, Medeiros CCM, Medeiros DDM, Batista DA. Ansiedade do acompanhante diante da assistência de enfermagem na ala de pediatria. Temas Saúde 2017 [citado 25 abr 2019]; 17(1):147-66. Available in: http://temasemsaude.com/wp-

content/uploads/2017/05/17110.pdf

7- Paula DPS, Silva GRC, Andrade JMO, Paraiso AF.
Câncer infanto-juvenil do âmbito familiar:
Percepções e experiências frente ao diagnóstico.
RevCuid. 2019; 10(1):1-12. DOI:
1015649/cuidarte.v10il.571

8- Gomes GC, Xavier DM, Pintanel AC, Farias DHR, Lunardi VL, Aquino DR. Significados atribuídos por familiares na pediatria acerca de suas interações com os profissionais da enfermagem. RevEscEnferm USP2015;49(6):953-9. DOI:10.1590/S0080-623420150000600011

9- Chagas MCS, Gomes GC, Pereira FW, Diel PKV, Farias DHR. Significado atribuído a família ao cuidado da criança hospitalizada. AvEnferm. 2017;35(1):7-18.DOI:

10.15446/av.enferm.v35n1.42466

10- Morais RCM, Souza TV, Oliveira ICS, Moraes RMM. A estrutura da rede social da mãe/acompanhante da criança hospitalizada.
CogitareEnferm. 2018;1(23):1-10.DOI: 10.5380/ce.v23i1.50456

11- Fernandes MA, Soares AJ, Ferraz MMM, Silva FAA, Silva JS, Carvalho RJ. Representações sociais por mães com filhos em tratamento de câncer. RevEnferm Atual. 2019 [citado 25 abr 2019]; 89(27):1-7. Available in: https://revistaenfermagematual.com.br/index.ph p/revista/article/view/418/487

12- Neutzling BRS, Barlem JGT, Barlem ELD, Hirsch CD, Pereira LA, Schallenberguer CD. Em defesa dos direitos da criança no ambiente hospitalar: O exercício da advocacia em saúde pelos enfermeiros. Esc Anna Nery Rev Enferm. 2017;21(1):1-9. DOI: 10.5935/1414-8145.20170025

13- Passos SSS, Henckemaier L, Costa JC, Pereira A, Nitschke RG. Daily care of families in hospital: What about patient safety? TextoContexto-Enferm. 2016;25(4):1-10.DOI: 10.1590/0104-07072016002980015

14- Silva TP, Leite JL, Stinson J, Laloo C, Silva IR, Jibb L. Estratégias de ação e interação para o cuidado à criança hospitalizada com dor oncológica crônica. Texto Contexto-Enferm. 2015;27(4):1-11. DOI: 10.1590/0104-07072018003990017

15- Neves L, Gondim AA, Soares SCMR, Coelho DP, Pinheiro JAM. O impacto do processo de hospitalização para o acompanhante familiar do paciente crítico crônico internado em uma unidade de terapia semi-intensiva. Esc Anna Nery 2018;22(2):1-8.DOI: 10.1590/2177-9465-EAN-2017-0304

16- Azevêdo AVS, Lançoni Júnior AC, Crepaldi MA. Interação equipe de enfermagem, família, e criança hospitalizada: Revisão integrativa. Ciênc Saúde Coletiva 2017;22(112):3653-66. DOI: 10.1590/1413-812320172211.26362015

17- Machado NA, Nóbrega VM, Silva MEA, França DBL, Reichert APS, Collet N. Doença crônica infanto-juvenil: Vínculo profissional-família para a

promoção do apoio social. RevGaúcha Enferm. 2018;39:1-8. DOI: 10.1590/1983-1447.2018.2017-0290

18- Ferreira LB, Oliveira JSA, Gonçalves RG, Elias TMN, Medeiros SM, Mororó DDS. Cuidar de Enfermagem às famílias de crianças e adolescentes hospitalizados. Rev Enferm UFPE 2019;13(1):23-31. DOI: 10.5205/1981-8963v13i01a237672p23-31-2019

19- Fontes ALC, Patricio ACFA, Lima TDS, Nascimento LBM, Silva RAR. Vulnerabilidade ao estresse: Pais cuidadores de filhos com câncer. Cuidado e Fundamental. RevFun Care 2019;11(4):857-64.DOI:10.9789/2175-

5361.2019.v11i4.857-861

20- Santos RS, Takeshita IM, Araujo CM, Jardim ASL, Cunha GR. Percepção das mães de crianças com câncer sobre o cuidado humanizado da enfermagem. RevEnfermCent-Oeste Min. 2019; 9:e2883. DOI: 10.19175/recom.v9i0.2883

21- Ercole FF, Melo LS, Alcoforado CLGC. Integrative review versus systematic review. Rev Min Enferm. 2014;18(1):9-12. DOI: 10.5935/1415-2762.20140001

22- Galvão TF, Pansani TSA. Principais itens para relatar Revisões Sistemáticas e Meta-análises: A recomendação do PRISMA. EpidemiolServ Saúde 2015;24(2):1-8. DOI:10.5123/S1679-

49742015000200017

23- The Joanna Briggs Institute. Joanna Briggs Institute Reviewers' Manual: 2015 edition. 2015[citado 15 mar 2020]. Available in: https:// https://nursing.lsuhsc.edu/JBI/docs/ReviewersM anuals/Scoping-.pdf

24- Pompeo DA, Rossi LA, Galvão CM. Revisão integrativa: Etapa inicial do processo de validação de diagnóstico de enfermagem. Acta Paul Enferm.
2009;22(4): DOI: 434-8. 10.1590/S0103-21002009000400014

25- Melnyk BM, Fineout-Overholt E. Evidence based practice in nursing & healthcare: A guide to best practice. 2nd ed. Philadelphia: Wolters Kluwer Health; 2011.

26- Vieira RF, Souza TV, Oliveira ICS, Morais RCM, Gois JR. Mothers/companions of children with cancer: Apprehension of the hospital culture.Esc Anna Nery 2017;21(1):1-7. DOI: 10.5935/1414-8145.20170019

27- Borges AA, Lima RAG, Dupas G. Segredos e verdades no processo comunicacional da família com a criança com câncer. Esc Anna Nery 2016;20(4):1-9.DOI:10.5935/1414-

8145.20160101

28- Monteiro CFS, Veloso LUP, Souza PCB, Coelho S, Morais RV. A vivência familiar diante do adoecimento e tratamento de crianças e adolescentes com leucemia linfoide aguda. CogitareEnferm2008 [citado 25 Fev2019];13(4):484-9. Available in: https://revistas.ufpr.br/cogitare/article/view/131 04/8863

29- Liu YM, Yeh CH. Pediatric Oncology: The useof cluster analysis to examine maternal concerns.OncolNursForum37(4):4-11.DOI:10.1188/10.ONF.E304-E311

30- Oliveira RAA, Moura TML, Perreli JGA, Lopes MVO, Oliveira SM. Tensão do papel do cuidador principal diante do cuidado prestado a crianças com câncer. RevCuba Enferm. 2015 [citado 20 mar 2020]; 31(2). Available in: www.revenfermeria.sld.cu/index.php/enf/article/ view/331/125

31- Motta MGC, Diefenbach GDF. Dimensions of vulnerability for the Family of the child with oncologic pain in the hospital environment. Esc Anna Nery 2013; 1(3):482-90. DOI:10.1590/S1414-81452013000300011

32- Angelo M, Moreira PL, Rodrigues LMA. Incertezas diante do câncer infantil: Compreendendo as necessidades da mãe.Esc Anna Nery 2019;14(2):301-8. DOI: 10.1590/S1414-81452010000200013

33- Duarte MLC,Zanini LN, Nede MNB.O cotidiano dos pais de criança com câncer e hospitalizadas. RevGaúchEnferm. 2012;33(3): 111-8. DOI: 10.1590/S1983-14472012000300015

34- Alves KMC, Comassetto I, Almeida TG, Treza MCSF, Silva JMO, Magalhães APN. The experience of parentes of children with cancer in treatment failure conditions. Texto Contexto-Enferm.
2016;25(2):1-9. DOI: 10.1590/0104-07072016002120014

35- Kozan L, Wanderbroocke ACNS, Polli GM. Apoio social entre acompanhantes de crianças hospitalizadas em uma unidade de hematopediatria. PsicolHosp. 2016 [citado 10 mar 2019]; 14(1):53-78. Available in: http://pepsic.bvsalud.org/scielo.php?script=sci_a bstract&pid=S1677-

74092016000100004&Ing=pt&nrm=iso

36- Santos LF, Marinho KC, Oliveira RR, Siqueira KM, Oliveira LMAC, Peixoto MKAV, et al. Ser mãe de criança com câncer: Uma investigação fenomenológica. RevEnferm UERJ2011 [citado 10 mar 2019];19(4):626-31. Available in: http://www.facenf.uerj.br/v19n4/v19n4a21.pdf

37- Sheikjzakaryaee N, Atashzadeh-Shoorideh F, Ahmadi F, Fani M. Psychological limbo as barrier to spiritual care for parentes of children with câncer: A qualitative study. Asian Pac J Cancer Prev. 2018;19(4):1063-68. DOI: 10.22034/APJCP.2018.19.4.1063

38- Noia TC, Sant'ana SER, Santos ADS, Oliveira SC, Veras SMCB, Lopes-Junior CL. Coping with the diagnosis and hospitalization of a child with childhood cancer. Invest EducEnferm. 2015;33(3):465-72. DOI:

10.17533/udea.iee.v33n3a10

39- Wegner W, Pedro ENR. Female caregivers accompanying children with cancer in the hospital setting. RevGaúcha Enferm. 2010;31(4):678-84. DOI: 10.1590/S1983-14472010000400010

40- Costa MADJ, Agra G, Souza Neto VL, Silva BCO, Laísi CBB, Mendonça AEO. Desvelando a experiência de mães de criança com câncer. 2016; 1(6):2052-65.DOI: 10.19175/recom.v0i0.965

41- Lyu QY, Kong SKF, Wong FKY, You LM, Yan J, Zhou XZ, et al. Psycometric validation of na instrument to measure Family coping during a child's hospitalization for cancer. Cancer Nurs. 2017;40(3):194-200.

DOI:10.1097/NCC.00000000000382

42- Medeiros EGMS, Leite RFB, Ramos DKR, Almeida LAL. Repercussions of child cancer in the daily life of a family caregiver. Rev Rene2014;15(2):233-9. DOI:10.15253/2175-6783.2014000200007

43- Karkow MC, Perlini NMOG, Stamm B, Camponogara S, Terra MG, Viero V. Experience of families facing the revelation of the câncer diagnosis in one of its integrants. Rev Min Enferm. 2015;19(3):747-51. DOI:0.5935/1415-

2762.20150056

44- Diefenbach GD, Motta MGC. O cuidar em enfermagem: Família e criança com dor oncológica.CogitareEnferm. 2012;17(3):458-63. DOI:10.5380/ce.v17i3.24752

45- Carvalho AS, Depianti JRB, Silva LF, Aguiar RCB, Monteiro ACM. Reações da família da criança com diagnóstico de câncer: Estudo descritivo. Braz J Nurs. 2014 [citado 31 maio 2019]; 13(3):282-91. Available in:

https://pesquisa.bvsalud.org/portal/resource/pt/ biblio875771http://www.objnursing.uff.br/index. php/nursing/article/view/4356/pdf_173

46- Sisk BA, Kang TI, Mack JW. How parents of children with cancer learn about their children's prognosis. Pediatrics2018;141(1):1-10. DOI:10.1542/peds.2017-2241

47- Rodrigues JRG, Siqueira Júnior AC, Siqueira FPC. Nursing consultation in pediatric oncology: A tool for empowering parentes. RevFun Care 2020;12:202-11. DOI: 10.9789/2175-5361.rpcfo.v12.7569

48- Vidotto PCP, Ferrari RAP, Tacla MTGM, Facio BC. Experiência materna no itinerário diagnóstico do câncer infantil. RevEnferm UFPE 2017;11(4):1565-73. DOI:10.5205/reuol.9763-85423-1-SM.1104201702

49- Alves DA, Silva LG, Delmondes GA, Lemos ICS, Kerntopf MR, Albuquerque GA. Cuidador da criança com câncer: Religiosidade e espiritualidade como mecanismos de enfrentamento. RevCuid. 2016;7(2):1318-24. DOI: 10.15649/cuidarte.v7i2.336

50- Keiza EM, Chege MN, Omuga BO. Assessment of parents' perception of quality of pediatric oncology inpatient care at keniattanational hospital. Asia Pac J OncolNurs. 2017;4(1):29-37. DOI:10.4103/2347-5625.199071

51- Hopia H, Tolonen TH. Families in paediatric oncology nursing: Critical incidents from the nurses perspective. J PediatrNurs.2019;44:28-35. DOI: 10.1016/j.pedn.2018.10.013

Note: This study is linked to the Doctoral Project of the Postgraduate Program in Health Care Sciences, a line of research in Clinical Care at the Aurora de Afonso Costa Nursing School of the University Federal Fluminense.

Received: 28/10/2019 Approved: 30/03/2020

Mailing address:

Rua Garibaldi, 225 bloco II, 1109, Tijuca, Rio de Janeiro. Brazil. CEP: 20511-330