RESUMO
Objetivo: identificar os indicadores científicos sobre a vivência familiar da criança hospitalizada com câncer. Métodos: 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; 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 embrace 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: sentimentos del familiar del niño con cáncer; necesidades del familiar del niño con cáncer; enfermería y familia en el enfrentamiento de la enfermedad. Conclusion: se encontró evidencia científica sobre el tema familiar de los niños hospitalizados con cáncer, destacando el rol relevante de la enfermería, contribuyendo a las 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.
Descritores: Niño Hospitalizado; Familia; Neoplasias; Enfermería.

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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).

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 family-patient 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 (19,20).

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 synthesizing 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.

Figure 1- Search strategy.

<table>
<thead>
<tr>
<th>Database</th>
<th>Search strategy</th>
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<tbody>
<tr>
<td>BVSLILICS/BDENF</td>
<td>(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:(&quot;Nursing care&quot; OR &quot;Cuidados de Enfermagem&quot; OR &quot;Cuidado de Enfermería&quot; OR Nurs* OR Enfermeria OR Enfermagem)) AND (instance:&quot;regional&quot;) AND (db:&quot;LILACS&quot;) AND year_cluster:(&quot;2013&quot; OR &quot;2014&quot; OR &quot;2015&quot; OR &quot;2016&quot; OR &quot;2017&quot; OR &quot;2018&quot;))</td>
</tr>
<tr>
<td>CINAHL</td>
<td>((((((Children OR Adolescents OR Teenager) AND (Neoplasms OR Tumor* OR Tumour* OR Cancer OR Carcinoma OR Oncology)) AND (Family OR Parents)) AND (&quot;Nursing care&quot; OR &quot;Nursing&quot;))</td>
</tr>
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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, well-designed cohort and case-control study; level 5, systematic reviews of descriptive and qualitative studies; level 6, descriptive and qualitative studies and level 7, opinion of respectable authorities, based on clinical competence or opinion of expert committees.

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. 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).

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. 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.
Figure 2 - Flowchart used in the process of selection of articles based on the PRISMA model(22).

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 non-experimental 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.

Figure 3 – Characterization of selected articles, according to title, author, year of publication, place of study, database and level of scientific evidence.
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 (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 stronger before 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.(48,50-51)

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 research 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.

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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.