Understanding the Process of Illness in Childhood: Exploring Meanings for Health Promotion

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ABSTRACT

The diagnosis of childhood cancer changes the lives of children and their families. Hospitalization in pediatric oncology presents challenges for the health team, which seeks to promote an environment in which children feel safe and their biopsychosocial needs are met. Thus, the objective was to understand, in the specialized literature, the meanings of the disease process for the child and, based on this, to seek ways to improve this process through health promotion. This is an integrative literature review, using the Lilacs and Medline databases, with the Health Sciences Descriptors: "child", "neoplasia" and "health promotion". As inclusion criteria, the study focused on articles involving the research theme, available in full in full, published between 2006 and 2016, in Portuguese, English and Spanish. Those in the form of monographs, theses, dissertations and annals of papers presented at events were excluded. The search for the analysis material resulted in a total of 214 articles, and ten articles were selected according to the inclusion criteria. Of the ten articles, eight focused on health promotion actions and of these eight, five addressed humanization in health as the main strategy. The diagnosis provokes several emotional reactions in the parents, in the child and in all those inserted in their context. Another action for health promotion is to work with play, which brings benefits to the child and to the treatment, serving as a strategy to cope with hospitalization. With regard to the family, the literature has indicated priorities for research in the area on experiences with the disease. After the review, it can be seen that the literature is still scarce regarding the child, because the child's perspective in relation to the disease and diagnosis is little addressed. The synthesis of the knowledge produced by the present study provides a framework of empirical evidence that allows us to affirm that the effort to understand the experiences and challenges experienced by pediatric patients and their family caregivers can help in the organization of comprehensive care in this delicate stage of treatment.

Keywords: Health Promotion, Child, Cancer, Public health.

1 INTRODUCTION

Childhood cancer is a group of several diseases that have in common the uncontrolled proliferation of abnormal cells and that can occur anywhere in the body. Unlike adult cancer, childhood cancer usually affects the cells of the blood system and the supporting tissues. Pediatric cancer represents only a small percentage (approximately 3%) of adult cancer. Because they are predominantly embryonic in nature, tumors in children and adolescents are made up of undifferentiated cells, which generally provides a better response to current treatments. The causes of pediatric cancer are unknown, however, a small number of cancer cases in children and adolescents (about 10%) are due to genetic or hereditary abnormalities (BRASIL, 2023).

Childhood cancer is relatively uncommon and generally has a good prognosis, with 5-year survival rates of approximately 80% in high-income countries (NAKATA et al., 2018*) and 60-72% in low- and middle-income countries (ZHENG* et al., 2015). It is believed that 70% to 80% of children diagnosed with neoplasms can be cured, as long as it is early (BRASIL, 2016).

The diagnosis of childhood cancer completely changes the lives of children and their families, as they are suddenly inserted into the hospital context - an unfamiliar environment - surrounded by strangers and subjected to invasive and painful exams (MENEZES *et al*., 2007). The authors also mention that, no matter the age of the child and their degree of understanding of the world around them, it is common for them to be able to recognize when something serious is occurring. Therefore, the torment of children with cancer may be associated not only with the disease, but also with separation from their routine and family environment.

That is why, despite all the advances that have taken place in medicine, having a higher cure rate than many other types of cancer, the diagnosis of cancer in children generates a series of feelings, anguish, depression, fear, shame and panic, because the disease is still very stigmatized, mainly related to death (ARRUDA-COLLI; SANTOS, 2015).

Hospitalization in pediatric oncology presents challenges for the health team itself, which seeks to promote an environment in which children feel safe and in which their physical and psychosocial needs are met (SILAVUTKAN, 2012). According to Bradding and Horstman (1999), they emphasize that health professionals are constantly looking for approaches that enable children to communicate their demands, so that their perspectives are taken into account when they are ill, thus allowing them to play an active role as facilitators during the therapeutic process.

According to Anders and Souza (2009), throughout their existence, human beings go through phases of adjustment and, when confronted with an illness, the process of illness can be seen as a rupture in their routine and way of being. In the same way, the child, when experiencing the pathological process, needs to develop control to deal with the consequences of the disease.

Thus, the objective was to understand, in the specialized literature, the meanings of the disease process for the child and, based on this, to seek – through health promotion – ways to improve this process for the child.

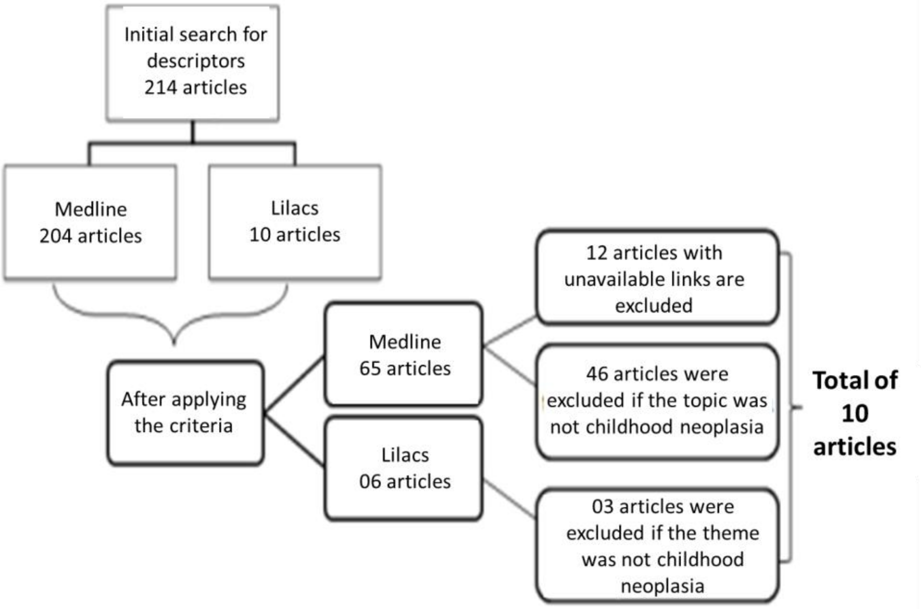
2 METHODOLOGY

This is an integrative literature review, whose guiding question was: "What is the meaning of the disease process for children with cancer? How could I study the significance of cancer for children under the age of seven?"

For the construction of this research, a literature review was carried out, searching the Lilacs and Medline databases, through the descriptors selected from the Health Sciences Descriptors (DECS) "child", "neoplasia" and "health promotion". As inclusion criteria, the study focused on scientific articles that involved the research theme, that were fully available electronically, that were published between 2006 and 2016, in Portuguese, English and Spanish. Works that did not fit the aforementioned criteria were excluded, as well as monographs, theses, dissertations and annals of papers presented at events.

The search for the analysis material resulted in a total of 214 articles. Applying the inclusion and exclusion criteria, a total of 61 articles were obtained, which, after reading the abstracts, resulted in a total of ten articles. These were read for the elaboration of the review of the present research project.

Figure 01 - Flow of selection, inclusion and exclusion of available scientific articles.



Source: The authors (2023).

During the search, it was possible to notice that the scientific articles dealt more specifically with the suffering and perception of the parents about the child's disease or the professionals responsible for the child's care, that is, the articles sought to promote the health of the caregiver and the family, but few addressed the sick child as the focus of health promotion.

Of the ten articles, eight focused on health promotion actions and of these eight, five addressed humanization in health as the main strategy. When the disease is confirmed, the first impact is felt by family members. The diagnosis provokes several emotional reactions in the parents, in the child and in all those inserted in their context. Cancer poses a threat to the child and his/her family, affecting the family unit and causing an imbalance (FERMO et al, 2014). According to Maranhão *et al.* (2011) The work of the nursing team with pediatric cancer patients and their families should consist not only of care that involves the planning of interventions, application of technical knowledge, but also of care that involves the entire biopsychosocial context of the child, seeing him as an integral being, who at that moment goes through contradictory feelings.

Once again, the training of the professional is observed because, according to Malta and Shall (2012), the training of health professionals has been based on the use of conservative (or traditional) methodologies, in which the body is separated from the mind, the reason from the feeling, that is, because of this, questions arise about the profile and essence of the trained professional, focused on the disease, so the need for a Health Humanization Policy was seen.

Another action for health promotion is to work with play, as it is an instrument widely used with oncological children, which brings benefits to the child and to the treatment, serving as a strategy to cope with hospitalization. Toys in the hospital should represent everyday life, such as toys for role-play, for construction, for artistic expression and games, as long as they are safe, accessible and functional. For health professionals, this type of activity allows them to observe the way the child copes with the stressful situation, processes information about the medical context and seeks to understand their diagnosis (HOSTERT; ENUMO; LOSS, 2014). And this is important for health promotion, because the child needs to be aware of the diagnosis and what its treatments are, with this he will be able to elaborate the fears and fantasies of being sick. By knowing about the disease, they will be able to put themselves in the position of an active subject and thus become more participative in its treatment (FERMO *et al.*, 2014).

The area of Child Health is a field with several aspects, from physiology to child psychology, through development, anatomical immaturity, among many other topics. However, childhood cancer has emerged as a topic due to the difficulty of finding professionals who want to work, or even study, about children with cancer. It is possible to perceive, through professional experience, that children experience the entire disease process differently from an adult, and that many health professionals focus more on the disease, forgetting that there is a child there, who needs differentiated care, and that it is essential to work with health promotion to improve the quality of life of these children.

After the review, it can be seen that the literature is still scarce regarding the child, because the child's perspective in relation to the disease and diagnosis is little addressed. There is a gap in the national literature, and there are no Brazilian studies that seek to understand child coping, as well as few international studies on the subject.

3 THEORETICAL FRAMEWORK

3.1 CHILDHOOD CANCER, DIAGNOSIS AND TREATMENT

According to the National Cancer Institute (INCA) (BRASIL, 2014) for childhood cancer, there is little scientific evidence that there is a relationship between the development of the neoplasm and environmental causes. In general, etiologic factors are associated with intrauterine exposures. Regarding the main types of childhood cancers, leukemias correspond to 25% to 35% of diagnosed cases. The most common type in children is Acute Lymphoblastic Leukemia (ALL). Tumors of the nervous system affect 8% to 15% of the child population, and are considered the most frequent solid tumor among pediatric neoplasms, belonging to the second position among the most common neoplasms in Brazilian children. In developing countries, lymphomas occupy the second place, but in Brazil and most developed countries they are in the third position.

Kohlsdorf and Costa Junior (2011) refer to six types of therapies used in the treatment of cancer: chemotherapy, radiotherapy, immunotherapy, surgical treatment, hormone therapy and bone marrow transplantation. These can be chosen on an individual basis or we can use a combination (one or more therapies). The selection of the appropriate intervention should be carried out together with the attending physician, the family and the patient, taking into account the type of treatment, whether it will be curative or palliative. In addition, we consider the location, size, degree of aggressiveness of the tumor, as well as the child's age and stage of the disease.

Chemotherapy is the most widely used therapy because childhood cancer is more sensitive to it, both for palliation and cure. Chemotherapy indiscriminately affects all cells of the organisms, producing many adverse effects, causing a series of physical, emotional and social consequences, generating a period of crisis and sudden changes in feelings, lifestyle habits and daily life (ALEXANDER *et al*., 2015).

A study conducted by Soares *et al*. (2014) with cancer patients showed that adverse effects are considered one of the main limitations of treatment and that one of the main effects was psychosocial damage and self-image problems. Leading us to understand that cancer is a complex disease, which manages to unbalance all aspects of the human being and that does not distinguish race, age, color or social class.

From the diagnosis to the end of treatment, it is common for people to suffer physical and emotional damage as a result of invasive procedures and changes in their routine. According to Cohen and Melo (2010), for the child everything is more intense, because he is still developing and building his life story. The way they will experience the disease is different from adults, since the child has a unique way of placing himself in the world. In this way, children diagnosed with cancer will face new and threatening situations.

When the disease is confirmed, the first impact is felt by family members. At this time, reactions of stress and psychological distress are observed both in patients and in their families and in all those inserted in their context (ALVES *et al.*, 2016). According to Silva and Cabral (2015), the child's reaction to the diagnosis can be amplified by disease and treatment stressors, such as being away from home and their routine, since, in general, it is in the hospital that the process of diagnosis and initiation of treatment takes place. Cancer begins to pose a threat to the child and his family, affecting the family unit and causing an imbalance (FERMO *et al.*, 2014).

This impact is perceived by the child who can see the worried family members, observes them through their facial expressions, speech and even in their silence. The fact is that the child's life will change rapidly and intensely. The way in which each person copes with the disease will depend on the personal and social resources available to them. However, regardless of age and cognitive ability, children realize that something bad is happening around them (DIAS *et al*. 2013).

With regard to the family, the literature has indicated priorities for research in the area, with emphasis on the need to identify families who are at risk at the time of diagnosis, their perception and experience of cancer (KAZAK *et al.*, 2011). One of the reasons for this need is the finding that good family dynamics at diagnosis is a predictor of later adjustment (RODRIGUEZ *et al.*, 2012).

It is important that the child knows what is happening to him/herself, that he/she receives guidance and support from the family, as well as from the health team, because it is up to these professionals to inform, clarify and provide support to the family members so that they can be able to understand and help the child, both at this stage and throughout the treatment. All of this should be said respecting the child's age, in an accessible way and avoiding medical jargon (MALTA; SHALL; MODENA, 2009).

Therefore, it is important that the child is aware of the diagnosis and what their treatments are, so that they will be able to elaborate on the fears and fantasies of being sick. By knowing about the disease, they will be able to put themselves in the position of an active subject and thus become more participative in its treatment (FERMO *et al.*, 2014).

Chemotherapies, which are the most widely used therapies, are divided into cycles and the duration of treatment varies depending on the stage of the disease. The first moment is the induction phase, when the patient needs to be admitted to the hospital to receive the necessary care. After induction, comes the maintenance phase and the patient continues to be treated periodically in outpatient clinics (BRASIL, 2014).

Children on antineoplastic treatment are exposed to contexts of repeated medical procedures, side effects, interruption of school and social routine, suspension of leisure activities, changes in diet, changes in self-image, feelings of uncertainty about the evolution of treatment, periodic hospitalizations, pain, losses that impair their socialization and adversely interfere with the maintenance of their daily relationships (KARS *et al.*, 2008; ALEXANDER *et al.*, 2015). Becoming ambiguous, chemotherapy is necessary for both curative and palliative treatment; However, it is destructive to have to undergo such aggressive treatment.

Another therapy is radiotherapy, where radiation is used to destroy or reduce the size of the tumor, and it is possible to carry out treatment concomitantly with chemotherapy. And it causes side effects, such as: tiredness, weight loss, difficulty ingesting food, and skin reactions at the site that receives the radiation (BRASIL, 2014).

In some cases, usually of more extensive tumors, surgical treatment is indicated, but the size of the surgery will depend on the development of the disease and the condition of the child. According to Maranhão et al. (2011), it is because there are so many treatment possibilities that the way the child will experience the disease process will be directly related to the procedure used and its characteristics.

Despite the consequences of the treatment, Lanza and Valle (2014) point out that children are also able to understand the treatment process as a positive experience, as they relate it to coping and triumphing in the face of a very difficult battle against cancer. Therefore, even with all the adversities imposed by the disease, the child can develop a resilient way of dealing with the aspects that involve the disease.

3.2 HEALTH PROMOTION AND CHILDHOOD CANCER

The concept of traditional health promotion was initially defined based on the model of Leavell and Clark (1978), in the 40's, in the scheme of the Natural History of the disease, as one of the elements of the primary level of care in preventive medicine.

The modern health promotion movement emerged in Canada in May 1974, with the publication of the well-known "Lalonde Report", which had political, technical and economic motivation to face the increases in the cost of health (LALONDE, 1974). This study was conducted against the backdrop of the increasing costs of health care and the questioning of the physician-centered model in the management of chronic diseases, since the results presented were of little significance (BUSS; CARVALHO, 2009).

Through the Lalonde Report, it was identified that human biology, environment, and lifestyle were related to the main causes of morbidity and mortality in Canada; However, most of the direct health expenditures were concentrated on the organization of care. Therefore, five strategies were proposed to address the problems of the health field: health promotion, regulation, efficiency of medical care, research and goal setting. This Report favored the holding of the First International Conference on Primary Health Care, in 1978, in Alma-Ata, with great repercussions in almost all health systems in the world (MALTA et al., 2016).

Brasil (2002) describes that in 1986, the First International Conference on Health Promotion took place, which gave rise to the Ottawa Charter, according to this document:

> Health promotion is the name given to the process of training the community to act to improve their quality of life and health, including greater participation in the control of this process. To attain a state of complete physical, mental, and social well-being [...] in this sense, health is a positive concept, which emphasizes social and personal resources as well as physical capabilities. Thus, health promotion is not the exclusive responsibility of the health sector, and goes beyond a healthy lifestyle, towards global well-being (BRASIL, 2002, p. 19).

Subsequently, other international conferences on Health Promotion were held, which reaffirmed the precepts established at the First Conference and added new issues and action strategies focused on priority areas, in order to generate healthy public policies.

According to Vassal et al (2014), the challenge is to review the primary care protocol, traditionally focused on the control of infectious diseases and malnutrition. Because childhood cancer has a great potential for cure, if the diagnosis of cancer is made in the early stages, that is, it is important to invest in early detection. It is estimated that the cure rates of tumors in childhood and adolescence reach 70% if the patient is diagnosed early and receives treatment in specialized centers (BRASIL, 2014).

Therefore, the prevention of childhood cancer is still a challenge for the future and the current emphasis in the approach to this cancer should be given to its early diagnosis and referral to quality treatment, which allows higher cure rates. It is also important to promote health throughout the disease process, from diagnosis to cure.

According to Malta and Shall (2012), childhood cancer is a public health problem and, as the survival of children affected by it increases, it is essential to direct efforts and resources to guide care for this patient and his family, at all levels of action, such as health promotion, aiming at the well-being of these children.

The work of the health team with pediatric cancer patients and their families should consist not only of care that involves the planning of interventions and the application of technical-scientific knowledge, but also of how to provide care for pediatric cancer patients and their families. (2007) reports that in addition to this knowledge, we must involve the entire biopsychosocial context of the client in order to perceive him as an integral being, full of an infinite range of contradictory feelings, we must seek to promote his health through humanized care.

In addition to the child, we have to understand that behind it, we have a family, which takes time and has difficulty accepting the diagnosis of one of their own, especially when we are dealing with cancer. And according to Avanci *et al.* (2010) From the knowledge about the disease that the family begins to accept the diagnosis, because it is with this knowledge that they will learn to take care of the child and know how he can react. This provides security, as family members feel that they are providing good care, especially when there are visible results, that is, with an improvement in the patient's clinical condition. By working on the empowerment of this family, we will promote the health of both the child and the family members, who are in need as much as the patient.

According to Frota *et al.* (2007), a differentiated and empathetic care favors the improvement of the mood and mental and emotional well-being of hospitalized children, leading to satisfactory evolutions in their health condition. From this perspective, the humanization of care represents a vital tool for the patient's recovery, minimizing the damage and trauma of hospitalization or invasive treatments.

The constant trips to the treatment center for hospitalization, or even for outpatient care, the child is vulnerable to pain and suffering, in addition to removing him from his living environment, schools, routine and friends. This causes the child to withdraw from social and family life, which can interfere with their desire to play or talk (SILVA; CABRAL; CHRISTOFFEL, 2010). Thus, the professional should seek other methods to get closer to that child, in order to promote humanized care and health promotion.

3.3 CHILDREN'S DRAWING

In order to broaden the view of the theoretical foundation of the theme under study and to strengthen the real meaning of falling ill for children with cancer, an approach to non-verbal communication was also used, with a focus on children's drawing.

For Mèredieu (2004), children's drawing is like a language with its own vocabulary and syntax. As early as 1981, Hammer pointed out that, through drawing, children convey things that they would not be able to express with words. Even if they were aware of the feelings that mobilize them, the author understands drawing as a phenomenon that should be seen not only as a projection of something repressed, but, above all, as a way of placing the internal experience in the external world.

To interpret a child's drawing is to explain what is obscure, translating it into an understandable language, extracting from the drawing a meaning hidden both to the child's understanding and to the adults around him, transcribing this latent meaning into a verbal language. Drawing is the most eloquent, immediate, and simplest method to investigate a child's humorous, behavioral, and character traits, as well as their intrapsychic conflicts, thus overcoming their difficulty in talking about themselves and exposing their problems (ARFOUILLOUX, 1983).

The availability to share the feelings and doubts of sick children seems to be a great challenge for health professionals and family members. It can be assumed that the great concern of the adult is to face and deal with his own feelings aroused by this situation, which can lead to a vacuum between the sick child and the adults, leading the minor not to share his fears and doubts about his disease and hospitalization (KOHLSDORF; COSTA JUNIOR, 2011).

In an attempt to understand the feelings of children who are going through a process of becoming ill, Freitas (2008) conducted a research, whose main objective was to verify cognitive and emotional aspects in children through the drawing of the human person and the drawing of the hospitalized person, in order to verify which of the two forms of drawing the child was able to express himself better. The research concluded that the design of the hospitalized person made it possible to obtain better data regarding the child's understanding of his clinical condition, as well as the emotions that emerge from it.

Another example of research developed was the one carried out by Gabarra (2005) with children in a situation of hospitalization, which used free drawings. The objective of this study was to investigate children's understanding of their disease in general and its specific aspects, such as treatment, hospitalization and medication. It was found that the children understood the diseases in general, and their own disease, based on their experiences with becoming ill, with hospitalization and from other events in their lives.

As it was possible to perceive, children's drawing and its use in the hospital or outpatient environment are already considered relevant by several authors, being an instrument used in research that aims, in general, to understand the representations constructed by the child and his feelings.

According to Piaget (2011), there are two meanings for the term "representation", in a broader sense, which he called conceptual representation, it is confused with thought, that is, with all intelligence that is based on a system of concepts and, in a stricter sense, he called symbolic representation that refers to mental images, that is, to the symbolic memories of absent reality. They are related to each other, because while the image is a concrete symbol, the concept is more abstract.

Piaget distinguished five representative conducts, which he called the development of the symbolic function. According to the author, they appear at about the same time, but he has enumerated them in ascending order of complexity. The first of these is deferred imitation, in which the child imitates a person's behavior when the person is no longer present. It is the beginning of the appearance of a differentiated signifier. Secondly, there is the symbolic game, in which the child plays make-believe, using imitative gestures with objects, which become symbolic because they are given some meaning. Thirdly, there is the drawing or the graphic image, which is initially a bridge between the symbolic game and the mental image. Up to about eight or nine years old, children draw what they know and not what they see. Fourthly, there are mental images, which are internalized representations. They are different from both perceptions and mental operations, for images do not deal with concepts, but with objects as such, and with all perceptual experience passed on to the subject. Finally, there is the verbal evocation of past actions through language. Then comes the ability to verbalize events.

Drawing, a semiotic manifestation that emerges in the symbolic period, evolves together with the development of cognition. On the one hand, it shares more intimately the phases of the evolution of perception and mental image, subordinating itself to the laws of conceptualization and perception. (PIAGET, 1975).

According to Piaget (1975), children's drawing goes through phases, according to the child's development. For him, drawing is preceded by doodling, the initial phase of graphics. Similarly to playing, it is initially characterized by the exercise of action. It is part of the sensory-motor phase (zero to two years) and part of the pre-operational phase (two to seven years), going approximately up to three or four years. At this stage, the child says what he is going to draw, but there is no fixed relationship between the object and its representation. So she can say that a square is a heart, and before she finishes the drawing, say that it's a dog.

Doodle can be divided into: Doodle Clutter and Doodle. The disordered movements are wide and disordered, there is no concern with the preservation of the features. On the other hand, the Ordinate Ordinate, longitudinal and circular lines appear, and there is a beginning to be an interest in shapes.

Soon after, there is the phase called pre-schematism, which occurs in the middle of the pre-operational phase, usually going until the age of seven when the relationship between drawing, thought and reality is discovered. It is observed that the elements are dispersed and are not related to each other.

Next comes the schematism phase, which is part of the concrete operations phase (seven to ten years). It begins to construct different shapes for each category of object. At this stage, two major changes emerge: the use of the baseline and the discovery of the color-object relationship. It already has a defined concept regarding the human figure, however some changes may arise, such as: exaggerations, omissions, among others.

The next phase is realism, which usually arises at the end of concrete operations, having a greater awareness of sex and begins a pronounced self-criticism. In space, it discovers the plane and the superposition, but abandons the baseline. Geometric shapes appear, along with greater rigidity and formalism.

Pseudo-naturalism comes next, it is part of the phase of abstract operations (ten years onwards). It is the end of art as a spontaneous activity and many give up drawing at this stage of development. He begins the investigation of his own personality, transferring to paper his anxieties and anxieties, characteristic of the beginning of adolescence. Realism, objectivity, depth, subjective space and the conscious use of color appear a lot in the drawings.

It is possible to see that in the continuity of the development process, the movement of accommodation prevails, that is, there is more and more approximation to the real and concern with the similarity of the object represented. For this reason, according to Piaget (1975), the child draws less what he sees and more what he knows. When drawing, she conceptually elaborates objects and events. Hence the importance of studying the process of construction of the drawing together with the verbal utterance given to us by the researched.

4 FINAL THOUGHTS

As final recommendations, this research points to the need for more studies on the subject, with the inclusion of more participants, from different contexts and health services. Updating hospital data and public health databases would make it easier to recruit participants. Above all, the findings of the present study reinforce the need for health services to offer follow-up of family members in the postmortem period, following the recommendations of the palliative care guidelines recommended by the World Health Organization.

In view of the guiding question assumed in this review, the present study allowed us to explore the knowledge produced on this theme in the national and international context. In general, the analyzed studies offered a panoramic view of the topics investigated in the context of recurrence in Pediatric Oncology, with regard to the psychosocial repercussions of the experience of the patient and their families.

Considering the low number of publications selected in this review, it is clear that further research is still needed to shed light on the theme. Some studies have pointed out the difficulties of parents in sharing their experience in a moment of pain, apprehension and emotional unavailability as a justification for not participating in research, suggesting barriers that permeate the study of the theme. On the other hand, the opportunity for emotional expression was also pointed out as a potential benefit of participating in studies of this nature. Providing family members with a safe and comfortable environment can be important to favor the development of investigations during the crisis situation experienced by the family that has a child with cancer recurrence.

A limitation to be highlighted in the literature reviewed concerns the quality of the evidence provided. The studies found are descriptive (not experimental) or with a qualitative approach. Another limitation that can be pointed out is that the limited number of studies originating in Latin American countries may have led to little exploration of regional aspects. However, studies developed in eight countries were included, which allowed for a global look at the subject. Future studies should explore in more depth the experience of pediatric patients in the face of cancer recurrence, as well as the interaction of the patient-caregiver dyad, dimensions that are still little explored in the literature, in order to favor the understanding of the psychosocial aspects involved and to better define the care strategies to be implemented.

The systematization of the findings favored the delimitation of an overview of the knowledge already produced about the psychosocial impact, emotional reactions and feelings experienced by children and their families in the face of the diagnosis and treatment of cancer recurrence, focusing on the stressors and their implications for quality of life and coping. It is believed that the synthesis of the knowledge produced by this integrative review provides a framework of empirical evidence that allows us to affirm that the effort to understand the experiences, difficulties and challenges experienced by pediatric patients and their family caregivers can help in the organization of comprehensive care in this delicate stage of treatment.

REFERENCES

ANDERS, J. C.; SOUZA, A. I. J. Crianças e adolescentes sobreviventes ao câncer: Desafios e possibilidades. Ciência Cuidado e Saúde, [*s. l.*], v. 8, n. 1, p. 131-137, 2009. DOI: https://doi.org/10.4025/cienccuidsaude.v8i1.7788. Disponível em: https://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/7788. Acesso em: 12 jul. 2023.

ARFOUILLOUX, J. C. A entrevista com a criança: a abordagem da criança através do diálogo, do brinquedo e do desenho. 3. ed. Rio de Janeiro: Zahar, 1983.

ALEXANDER, S. *et al*. Classification of treatment-related mortality in children with cancer: a systematic assessment. The Lancet Oncology, [*s. l.*] v. 16, n. 16, p. 604-610, 2015. DOI: https://doi.org/10.1016/S1470-2045(15)00197-7. Disponível em: https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(15)00197-7/fulltext. Acesso em: 29 jun. 2023.

ALVES, K. de M. C. *et al*. A vivência dos pais da criança com câncer na condição de impossibilidade terapêutica. Texto e Contexto Enfermagem, [*s. l.*], v. 25, n. 2, p. 01-09, 2016. DOI: https://doi.org/10.1590/0104-07072016002120014. Disponível em: https://www.scielo.br/j/tce/a/sbvdvXChgtDXTw9yG43GRFD/?format=pdf&lang=pt. Acesso em: 29 jun. 2023.

ARRUDA-COLLI, M. N. F.; SANTOS, M. Aspectos psicológicos da recidiva em Oncologia Pediátrica: uma revisão integrativa. Arquivos Brasileiros de Psicologia, [*s. l.*], v. 67, n. 3, p. 75-93, 2015. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1809-52672015000300007. Acesso em: 29 jun. 2023.

AVANCI, B. S. *et al*. Nursing care for children submitted to chemotherapy. Revista de Pesquisa Cuidado é Fundamental Online, [*s. l.*], v. 2, n. 2, p. 787-796, 2010. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/520. Acesso em: 29 jun. 2023.

BRADDING, A.; HORSTMAN, M. Using the write and draw technique with children. European Journal of Oncology Nursing, [*s. l.*], v. 3, n. 3, p. 170-175, 1999. DOI: https://doi.org/10.1016/S1462-3889(99)80801-1. Disponível em: https://www.ejoncologynursing.com/article/S1462-3889(99)80801-1/pdf. Acesso em: 12 jul. 2023.

BRASIL. Ministério da Saúde. Instituto Nacional de Câncer. Câncer da criança e adolescente no Brasil: dados dos registros de base populacional e de mortalidade. Rio de Janeiro: INCA, 2008. *E-book*. Disponível em: http://bvsms.saude.gov.br/bvs/publicacoes/cancer_crianca_adolescente_brasil.pdf. Acesso em: 25 jun. 2023.

BRASIL. Ministério da Saúde. Instituto Nacional de Câncer. Diagnóstico precoce do câncer na criança e no adolescente. Rio de Janeiro: INCA, 2014. *E-book*. Disponível em: https://www.inca.gov.br/sites/ufu.sti.inca.local/files/media/document/diagnostico-precoce-na-crianca-e-no-adolescente.pdf. Acesso em: 25 jun. 2023.

BRASIL. Ministério da Saúde. Instituto Nacional de Câncer. Incidência, mortalidade e morbidade hospitalar por câncer em crianças, adolescentes e adultos jovens no Brasil: informações dos registros de câncer e do sistema de mortalidade. Rio de Janeiro: INCA, 2016. *E-book*. Disponível em: https://www.inca.gov.br/sites/ufu.sti.inca.local/files/media/document/incidencia_mortalidade_morbidade.pdf. Acesso em: 25 jun. 2023.

BRASIL. Instituto Nacional do Câncer. Tipos de câncer: Câncer infantojuvenil. Gov BR, 2023. Disponível em: https://www.gov.br/inca/pt-br/assuntos/cancer/tipos/infantojuvenil. Acesso em: 11 jul. 2023.

BUSS, P. M.; CARVALHO, A. I. Desenvolvimento da Promoção da Saúde no Brasil últimos vinte anos (1988-2008). Ciência e Saúde Coletiva, [*s. l.*], v. 14, n. 6, p. 2305-2316, 2009. DOI: https://doi.org/10.1590/S1413-81232009000600039. Disponível em: https://www.scielo.br/j/csc/a/D65mRPV5fD5yGcMswW4dszQ/?lang=pt. Acesso em: 29 jun. 2023.

BRASIL. Ministério da Saúde. Secretaria de Políticas de Saúde. Projeto Promoção da Saúde. As Cartas da Promoção da Saúde. Brasília: Ministério da Saúde, 2002. *E-book*. Disponível em: https://bvsms.saude.gov.br/bvs/publicacoes/cartas_promocao.pdf. Acesso em: 11 jul. 2023.

COHEN, R. H. P; MELO, A. G. S. Entre o hospital e a escola: o câncer em crianças. Estilos da Clínica, São Paulo, v. 15, n. 2, p. 306-325, 2010. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1415-71282010000200003. Acesso em: 29 jun. 2023.

DIAS, J. de J. *et al*. A experiência de crianças com câncer no processo de hospitalização e no brincar. Revista Mineira de Enfermagem, Belo Horizonte, v. 17, n. 3, p. 608-613, 2013. Disponível em: http://www.revenf.bvs.br/pdf/reme/v17n3/v17n3a10.pdf. Acesso em: 29 jun. 2023.

FERMO, V. C. *et al*. O diagnóstico precoce do câncer infanto-juvenil: o caminho percorrido pelas famílias. Escola Ana Nery Revista de Enfermagem, Rio de Janeiro, v. 18, n. 1, p. 54-59, 2014. DOI: https://doi.org/10.5935/1414-8145.20140008. Disponível em: https://www.scielo.br/j/ean/a/95kDKGxKb5K6dHD8stmDFkH/?format=pdf&lang=pt. Acesso em: 29 jun. 2023.

FREITAS, P. G. O desenho da figura humana e o desenho da pessoa doente na avaliação psicologia de crianças hospitalizadas. 2008. Dissertação (Mestrado em Psicologia) - Universidade de São Paulo, São Paulo, 2008.

FROTA, M. A. *et al*. O lúdico como instrumento facilitador na humanização do cuidado de crianças hospitalizadas. Cogitare Enfermagem, [s. l.], v. 12, n. 1, p. 69-75, 2007. DOI: http://dx.doi.org/10.5380/ce.v12i1.8270. Disponível em: https://revistas.ufpr.br/cogitare/article/view/8270/5781. Acesso em: 29 jun. 2023.

GABARRA, L. M. Crianças hospitalizadas com doenças crônicas: a compreensão da doença. 2005. Dissertação (Mestrado em Psicologia) – Universidade Federal de Santa Catarina, Florianópolis, 2005.

HAMMER, E. F. Aplicações clínicas dos desenhos projetivos. Rio de Janeiro: Interamericana, 1981.

HOSTERT, P. C. C; ENUMO, S. R. F; LOSS, A. B. M. Brincar e problemas de comportamento de crianças com câncer de classes hospitalares. Revista Psicologia: Teoria e Prática, São Paulo, v. 16, n. 1, p. 127- 140, 2014. DOI: http://dx.doi.org/10.15348/1980-6906/psicologia.v16n1p127-140. Disponível em: http://pepsic.bvsalud.org/pdf/ptp/v16n1/11.pdf. Acesso em: 29 jun. 2023.

KOHLSDORF, M; COSTA JUNIOR, A. L. Cuidadores de crianças com leucemia: exigências do tratamento e aprendizagem de novos comportamentos. Estudos de Psicologia, [*s. l.*], v. 16, n. 3, p. 227-234, 2011. DOI: https://doi.org/10.1590/S1413-294X2011000300004. Disponível em: https://www.scielo.br/j/epsic/a/xJzR7T6DjGypFtDmTwmbLvC/?format=pdf&lang=pt. Acesso em: 29 jun. 2023.

KARS, M. C. *et al*. Being there: parenting the child with acute lymphoblastic leukemia. Journal of Clinical Nursing, [s. l.], v. 17, n. 12, p. 1553-1562, 2008. DOI: https://doi.org/10.1111/j.1365-2702.2007.02235.x. Disponível em: https://pubmed.ncbi.nlm.nih.gov/18482117/. Acesso em: 29 jun. 2023.

KAZAK, A. E. *et al*. Association of psychosocial risk screening in pediatric cancer with psychosocial services provide. Psycho-Oncology, [*s. l.*], v. 20, n. 7, p. 715-723, 2011. DOI: https://doi.org/10.1002/pon.1972. Disponível em: https://onlinelibrary.wiley.com/doi/10.1002/pon.1972. Acesso em: 29 jun. 2023.

LALONDE, M. A new perspective on the health of Canadians: a working document. Ottawa: Government of Canada, 1974.

LANZA, L. F.; VALLE, E. R. M. V. Criança no tratamento final do câncer e seu olhar para o futuro. Estudos de Psicologia, [*s. l.*], v. 31, n. 2, p. 289-297, 2014. DOI: https://doi.org/10.1590/0103-166X2014000200013. Disponível em: https://www.scielo.br/j/estpsi/a/rkpDx59Mdzr3kWWtRBmcbPm/?lang=pt. Acesso em: 29 jun. 2023.

LEAVELL, H.; CLARK, G. G. Medicina preventiva. Rio de Janeiro: Mcgraw-Hill do Brasil, 1978.

MALTA, D. C. *et al*. Política Nacional de Promoção da Saúde (PNPS): capítulos de uma caminhada ainda em construção. Ciência & Saúde Coletiva, [*s. l.*], v. 21, n. 6, p. 1683-1694, 2016. DOI: https://doi.org/10.1590/1413-81232015216.0757201. Disponível em: https://www.scielo.br/j/csc/a/pWG9W7grqFzzQGszmDKzvrb/abstract/?lang=pt. Acesso em: 29 jun. 2023.

MALTA, J. D.; SHALL, V. T. Instrumento para a humanização do cuidado do câncer infanto juvenil. Pediatria moderna, [*s. l.*], v. 48, n. 2, p. 74-78, 2012. Disponível em: https://www.arca.fiocruz.br/handle/icict/7723. Acesso em: 29 jun. 2023.

MALTA, J. D.; SHALL, V. T.; MODENA, C. M. O momento do diagnóstico e as dificuldades encontradas pelos oncologistas pediátricos no tratamento do Câncer em Belo Horizonte. Revista Brasileira de Cancerologia, [*s. l.*], v. 55, n. 1, p. 33-39, 2009. Disponível em: https://rbc.inca.gov.br/index.php/revista/article/view/1674. Acesso em: 29 jun. 2023.

MALTA, D. C. *et al.* Política Nacional de Promoção da Saúde (PNPS): capítulos de uma caminhada ainda em construção. Ciência & Saúde Coletiva, [*s. l.*], v. 21, n. 6, p. 1683-1694, 2016. DOI: https://doi.org/10.1590/1413-81232015216.07572016. Disponível em: https://www.scielo.br/j/csc/a/pWG9W7grqFzzQGszmDKzvrb/?format=pdf&lang=pt. Acesso em: 29 jun. 2023.

MARANHÃO, T. A. *et al*. A humanização no cuidar da criança portadora de câncer: fatores limitantes e facilitadores. Journal of the Health Sciences Institute, [*s. l.*], v. 29, n. 2, p. 106-109, 2011. Disponível em: https://repositorio.unip.br/wp-content/uploads/2020/12/V29_n2_2011_p106-109.pdf. Acesso em: 29 jun. 2023.

MENEZES, C. N. B. *et al*. Câncer infantil: Organização familiar e doença. Revista Mal-Estar e Subjetividade, [*s. l.*], v. 7, n. 1, p. 191-210, 2007. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1518-61482007000100011. Acesso em: 12 jul. 2023.

MEREDIEU, F. O desenho infantil. 10. ed. São Paulo: Cultrix, 2012.

PIAGET, J. A formação do símbolo na criança. 2. ed. Rio de Janeiro: Zahar, 1975.

PIAGET, J. Seis estudos de Psicologia. 25. ed. Rio de Janeiro: Forense Universitária, 2011.

RODRIGUEZ, E. M. *et al*. Cancer-related sources of stress for children with cancer and their parents. Journal of Pediatric Psychology, [*s. l.*], v. 37, n. 2, p. 185–197, 2012. DOI: https://doi.org/10.1093/jpepsy/jsr054. Disponível em: https://pubmed.ncbi.nlm.nih.gov/21841187/. Acesso em: 29 jun. 2023.

SILAVUTKAN, M. Children hospital design in children picture. Procedia: Social and Behavioral Sciences, [*s. l.*], v. 51, p. 110-114, 2012. DOI: https://doi.org/10.1016/j.sbspro.2012.08.127. Disponível em: https://www.sciencedirect.com/science/article/pii/S187704281203265X?via%3Dihub. Acesso em: 12 jul. 2023.

SILVA, L. F; CABRAL, I. E. O resgate do prazer de brincar da criança com câncer no espaço hospitalar. Revista Brasileira de Enfermagem, [*s. l.*], v. 68, n. 3, p. 391-397, 2015. DOI: https://doi.org/10.1590/0034-7167.2015680303i. Disponível em: https://www.scielo.br/j/reben/a/qF6yYwbyhKgQjNfbB7yftGw/?format=pdf&lang=pt. Acesso em: 29 jun. 2023.

SILVA, L. F.; CABRAL, I. E.; CHRISTOFFEL, M. M. The (im)possibilities of play for children with outpatient cancer treatment. Acta Paulista de Enfermagem, [*s. l.*], v. 23, n. 3, p. 334-340, 2010. DOI: https://doi.org/10.1590/S0103-21002010000300004. Disponível em: https://acta-ape.org/article/as-impossibilidades-de-brincar-para-o-escolar-com-cancer-em-tratamento-ambulatorial/. Acesso em: 29 jun. 2023.

SOARES, V. A. *et al*. O uso do brincar pela equipe de enfermagem no cuidado paliativo de crianças com câncer. Revista Gaúcha de Enfermagem, [*s. l.*], v. 35, n. 3, 2014. DOI: https://doi.org/10.1590/1983-1447.2014.03.43224. Disponível em: https://www.scielo.br/j/rgenf/a/5pdcScVkjbvgxty66V6CFYB/?lang=pt. Acesso em: 29 jun. 2023.

VASSAL, G. *et al*. Challenges for children and adolescents with cancer in Europe: The SIOP Europe agenda. Pediatric Blood & Cancer, [*s. l.*], v. 1, n. 9, p. 1551-1557, 2014. DOI: https://doi.org/10.1002/pbc.25044. Disponível em: https://pubmed.ncbi.nlm.nih.gov/24706509/. Acesso em: 29 jun. 2023.