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PALLIATIVE CARE IN CHILDHOOD LEUKEMIA: A HUMANIZED AND CHILD-CENTERED APPROACH

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ABSTRACT

Leukemia, especially Acute Lymphoblastic Leukemia (ALL), is the most common hematological cancer in childhood and poses significant challenges due to the intensity of treatment and the impact on the life of the child and family. In advanced or refractory cases, palliative care becomes essential, aiming not only at symptom control but also at promoting dignity, comfort, and quality of life. This approach seeks to prevent and alleviate physical, emotional, social, and spiritual suffering, respecting the specificities of child development and considering the child as an active subject in the care process. The study presents the following guiding question: How is palliative care provided in childhood leukemia with a humanized and child-centered approach? Its objectives are: To analyze the importance of a humanized and child-centered approach in providing palliative care to pediatric patients with leukemia, considering physical, emotional, social, and spiritual aspects; This study aims to describe multidisciplinary strategies used to promote quality of life and comfort for children in the palliative care phase, as well as to identify the challenges faced by the nursing team and the impact of empathetic communication and family support on the experience of palliative treatment. It is a narrative literature review, a method that aims to provide an overview of a topic, exploring and discussing existing literature comprehensively, without the need to follow rigid search and selection criteria. The review was conducted in six interconnected stages, following a specific sequence: formulating the research question, literature search, data collection, critical analysis of included studies, and discussion of results. The review revealed that physical management includes controlling pain, fatigue, nausea, dyspnea, and other symptoms, using pharmacological and non-pharmacological strategies, with a multidisciplinary approach. In the emotional sphere, children face fears, uncertainties, and changes in self-image; interventions such as play therapy, art therapy, and music therapy help in the expression of feelings and strengthening resilience. Socially, it is fundamental to maintain family ties, school continuity, and inclusion in activities compatible with the clinical condition, avoiding isolation. The spiritual dimension should also be considered, respecting beliefs and values as coping resources. Psychosocial needs involve family support, clear communication and active listening, as well as humanizing the hospital environment through play, which contributes to treatment adherence, anxiety reduction, and improved quality of life. The multidisciplinary team works in an integrated manner to ensure continuous and personalized care. Finally, strategies such as rigorous symptom control, complementary therapies, effective communication, and family involvement are fundamental to ensuring comfort and dignity for the child with leukemia in the palliative phase, promoting humanized and comprehensive care.

Keywords: Palliative care. Pain relief. Terminal patient care. Psychosocial support. Spirituality.

1. Introduction

Leukemia is a type of cancer that affects the white blood cells. Among the most common types in childhood are Acute Lymphoblastic Leukemia (ALL) and Acute Myeloid Leukemia (AML). Treatment generally involves chemotherapy, radiotherapy, and, in some cases, bone marrow transplantation. According to the National Cancer Institute (INCA), ALL accounts for about 80% of leukemia cases in children and has cure rates exceeding 80% when diagnosed early and the child receives appropriate treatment (INCA, 2022).

In children, leukemia is one of the most common hematological neoplasms in this age group, with acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML) being particularly noteworthy, with the latter accounting for about 15% of hematological neoplasms in childhood. Diagnosis generally involves a complete blood count, bone marrow examination, and, in some cases, additional tests such as immunophenotyping, cytogenetic analysis, and molecular tests. The blood count may reveal a decrease in red blood cells, white blood cells, and platelets, and the presence of blasts (immature cells). Bone marrow examination is essential to confirm the diagnosis and identify the percentage of blasts. Therefore, a thorough clinical evaluation by the physician is necessary, who assesses the patient's clinical history, including symptoms, risk factors, and family history, among others (Stone RM et al, 2017).

The diagnosis of cancer in childhood is a public health challenge. The estimated incidence of leukemia is 3 to 4 cases per 100,000 children under 15 years of age, corresponding to 25% of childhood cancer diagnoses (Vidal; Hui; Bruera, 2018; BRAZIL, 2020). Despite continuous advances in oncology, cancer remains the leading cause of death from disease among children in Brazil and the second leading cause of death overall, according to INCA. Among the most frequent types, leukemias stand out, affecting the hematopoietic system. Leukemia is a malignant neoplasm of the hematopoietic system, with several subdivisions, such as Acute Myeloid Leukemia (AML) and Acute Lymphocytic Leukemia (ALL). (INCA, 2024).

Acute myeloid leukemia, in terms of signs and symptoms, can manifest with the most common initial symptoms resulting from altered hematopoiesis, followed by anemia, thrombocytopenia, and granulocytopenia. Anemia can manifest as fatigue, weakness, pallor, malaise, dyspnea on exertion, tachycardia, and chest pain on exertion. Thrombocytopenia can cause easy bruising, petechiae/purpura, mucosal bleeding, epistaxis, gingival bleeding, among others. Pediatric patients may present with spontaneous bleeding, including intracranial or intra-abdominal hematomas. Granulocytopenia (neutropenia) can lead to a high risk of infections, including those of bacterial, fungal, and viral etiology. Patients may also present with fever and severe or recurrent infection (Ashkan Emadi; Law Jennie York, 2023).

Treatment of childhood leukemia is generally aggressive and complex, lasting months or years, and involves prolonged hospitalizations, invasive procedures, and chemotherapy. This process causes significant damage to the quality of life of the child and their family, with the onset of side effects and social prejudice. Although a cure is the main goal in most cases, it is not always achieved, making palliative care (PC) a fundamental need.

Palliative care comprises a comprehensive care approach aimed at patients and families facing life-threatening illnesses, that is, the terminal phase, aiming at the prevention and relief of suffering through early identification, correct assessment and treatment of pain and other problems of a physical, psychosocial and spiritual nature (World Health Organization [WHO], 2020).

Initially, palliative care was restricted to patients in the terminal phase, but currently it is indicated from the diagnosis of chronic or progressive diseases, and can be applied simultaneously with disease-modifying treatments. This expansion is due to the recognition that early intervention contributes to improving quality of life, reducing symptoms and providing emotional support to patients and families (Kavalieratos et al., 2016).

In Brazil, Resolution No. 41, of October 31, 2018, from the Ministry of Health, establishes that palliative care must be offered equitably and comprehensively within the Unified Health System (SUS), guaranteeing respect for the dignity, autonomy, and rights of the patient (Ministry of Health, 2018).

Care is part of the essence of being human, especially concerning a welcoming, empathetic, sensitive, and loving relationship. With the advent of humanization processes, care has come to be considered a new paradigm, represented by the symbol of the hand that caresses, protects, and supports. In this way, it fosters a complete involvement with those most deprived, through the desire to devote oneself with empathy and promote healing (Rankings, 2023).

The rationale for conducting this study considers the importance of investigating and understanding palliative care practices in childhood leukemia from a humanized and child-centered perspective, with the aim of contributing to improving care protocols, expanding support for families, and strengthening humanization in pediatric oncology.

The study has the following objectives: To analyze the importance of a humanized and child-centered approach in providing palliative care to pediatric patients with leukemia, considering physical, emotional, social, and spiritual aspects; to describe multidisciplinary strategies used to promote quality of life and comfort for children in the palliative phase, as well as to identify the challenges faced by the nursing team and investigate the impact of empathetic communication and family support on the experience of palliative treatment.

2. Methods

This is a narrative literature review study that allows data to be collected from bibliographic sources and analyzed in order to deduce possible similarities or differences in elements. The narrative literature review is a research method that aims to provide an overview of a topic, exploring and discussing the existing literature comprehensively, without the need to follow rigid search and study selection criteria. It is a more flexible approach, which allows the researcher to interpret and contextualize information from various sources, identifying theoretical debates, trends, and gaps in the area. It consists of gathering results from primary studies, so that the literature review is embedded in evidence-based practice (EBP), an approach that uses scientific evidence to support clinical practice.

The study was conducted in six stages, which are connected and follow a specific sequence: formulation of the research question, literature search, data collection, critical analysis of the included studies, discussion of the results, and presentation of the narrative review. The delimited research question is: How is palliative care carried out in childhood leukemia with a humanized and child-centered approach?

For the selection of articles, a search was conducted in the following databases: PubMed, Medical Literature Analysis and Retrieval System online (Medline), Latin American and Caribbean Literature in Health Sciences (Lilacs) and Virtual Health Library Nursing (BVS) via Virtual Health Library Brazil (BVS), using a combination of controlled, structured and organized descriptors to facilitate access to the knowledge contained in the Health Sciences Descriptors (DeCS).

The following descriptors were used, in English, Portuguese and Spanish: Children AND Palliative care AND humanized AND Pain relief, together with the Boolean operator OR. Articles related to the proposed theme, published in Portuguese, English, and Spanish, and within the last five years were selected, given the need to encompass the largest possible amount of evidence. Duplicate articles in the selected databases or articles that did not relate to the study's theme were excluded.

3. Results and Discussion

3.1 A HUMANIZED AND CHILD-CENTERED APPROACH TO PROVIDING PALLIATIVE CARE TO PEDIATRIC PATIENTS WITH LEUKEMIA

Leukemia is the most frequent hematological cancer in the pediatric population, especially in the form of Acute Lymphoblastic Leukemia (ALL), which represents a significant challenge due to the intensity of treatments and the comprehensive impact on the life of the child and family members (INCA, 2022). In advanced stages or in situations that do not respond adequately to therapeutic treatment, palliative care emerges as an essential component of care, aiming not only at symptom control, but also at promoting dignity, comfort and quality of life.

Palliative care is an approach that aims to improve the quality of life of patients and families facing life-threatening illnesses, through the prevention and relief of suffering, using early identification, assessment and treatment of pain and other situations of a physical, psychosocial and spiritual nature. In the pediatric context, this practice takes on an even more compassionate dimension, considering the specificities of child development, the fragility of the child, and the emotional impact on caregivers (Turbano et al, 2025).

Regarding the humanized and child-centered approach in pediatric palliative care, it requires considering the child as an active subject in the care process, respecting their needs, priorities, and values (Brazil, 2018). This perspective expands the focus beyond the disease, encompassing physical, emotional, social, and spiritual aspects.

Considering the physical aspect, the effective management of symptoms such as pain, fatigue, nausea, dyspnea, among others that may arise, is essential to minimize suffering (World Health Organization, 2018). Pharmacological and non-pharmacological strategies should be combined, involving a multidisciplinary team to ensure an individualized and humanized approach.

From an emotional perspective, children with leukemia face situations of fear, uncertainty, and changes in self-image due to the side effects of treatment. Interventions such as play therapy, art therapy, and music therapy can promote the expression of feelings, reduce anxiety, and strengthen resilience (Miranda et al., 2020).

Regarding social aspects, these include support for the continuity of school studies, the preservation of family ties, and inclusion in activities compatible with the child's clinical condition. The multidisciplinary participation of the social worker and hospital educators is essential to avoid social isolation and preserve the child's identity and routine (Oliveira, 2019).

As for the spiritual dimension, it is necessary to offer support that respects the beliefs and values of the child and their family, recognizing spirituality as a coping resource. Thus, the spiritual approach, when aligned with the child's needs, contributes to greater comfort and acceptance of the illness process (Santos; Cardoso, 2016).

Therefore, humanized and child-centered pediatric palliative care suggests integration between medicine, nursing, psychology, physiotherapy, dentistry, social work, education, and hospital chaplaincy, creating a welcoming environment that recognizes the uniqueness of each patient. This practice promotes symptom relief, prevents the incidence of discomfort, and also strengthens the child's sense of dignity and right to live fully, even in the face of serious illness.

3.2 PHYSICAL, EMOTIONAL, AND PSYCHOSOCIAL NEEDS OF CHILDREN WITH LEUKEMIA IN PALLIATIVE CARE

Palliative care for children with leukemia is multifaceted, encompassing a range of needs that go beyond treating the disease itself, profoundly impacting the child and their family.

Physical Needs

Children with leukemia in palliative care face a number of physical challenges imposed by both the disease and the treatment. Pain is a prevalent and complex symptom in pediatric oncology, occurring in more than 50% of cases. Pain management involves both pharmacotherapy (analgesics, anti-inflammatories, and strong opioids such as morphine) and non-pharmacological interventions, such as changes in position, immersion baths, diet control, relaxation, therapeutic listening, and acupuncture, which can be performed by trained nurses. The dosage of strong opioids is determined by the balance between analgesia and side effects. (Labudde et al., 2021).

In addition to pain, other physical symptoms are common. Nausea, vomiting, diarrhea, mucositis, apathy, and bleeding are frequent side effects of chemotherapy. Fatigue, constipation, delirium, and dyspnea are also important manifestations that require attention. Fatigue can be treated with progestogens, corticosteroids, methylphenidate, and modafinil. Nausea and vomiting are addressed with metoclopramide, serotonins, phenothiazines, steroids, and anticholinergics. Constipation, often caused by opioids, requires hydration, fiber intake, and laxatives. Delirium, which can result from radiotherapy and chemotherapy, is treated with neuroleptics and benzodiazepines. Dyspnea, more common in near-death cases, is relieved with opioids, benzodiazepines, and bronchodilators. The nursing team is essential to alleviate these discomforts, using their knowledge to provide comfort and relief (Labudde et al, 2021).

Protein-energy malnutrition (PEM) is another serious problem affecting many children with high-grade malignant cancer, directly impacting their development and quality of life. Leukemia treatment is prolonged and aggressive, involving frequent hospitalizations and invasive procedures, which impairs quality of life and can lead to constant re-hospitalizations.

Emotional Needs

The emotional impact on children with leukemia and in palliative care, as well as on their families and the nursing staff, is profound. Anxiety and fear are predominant feelings. Young children (up to 8 years old) and their parents frequently report anxiety, especially regarding unfamiliar procedures. Cancer in general induces a high level of anxiety and uncertainty, being perceived as more devastating than other diseases.

Suffering and anguish are experienced daily, both by the seriously ill child, who is conditioned by the hospital situation, and by their family members. Nursing professionals are also exposed to high levels of stress and experience suffering and anguish, especially when dealing with frequent situations of death and grief in pediatric ICUs.

The possibility of the child's death generates feelings of helplessness, frustration, sadness, denial, and grief for nursing professionals, who feel psychologically unprepared to deal with these emotions. In addition, professionals may feel an ambivalence between "feeling" and "acting" due to the bonds established with patients. Children in hospitals may also experience feelings of loneliness and boredom due to the long length of their stay.

Concern about physical appearance is more pronounced in children aged 8 to 12 and their caregivers, due to the beginning of social life and group interactions, which can affect self-esteem. Adolescents, in turn, face physical and cognitive changes, and the transformations in their bodies can lead them to feel incapable, invalid, strange, and tired, impacting their self-perception.

To cope with these emotional challenges, children and professionals develop coping mechanisms. Studies indicate that spirituality can offer psychological comfort, especially during the dying process. Social support from friends, family, and colleagues is also crucial. Strategies such as problem-solving, positive reappraisal, and seeking social support are the most used by nurses. However, failure to develop effective coping strategies can lead professionals to emotional burnout and Burnout Syndrome, characterized by emotional exhaustion, depersonalization, and decreased personal accomplishment (Barros, 2019).

Psychosocial Needs

Pediatric palliative care adopts a family-centered approach, recognizing the family as the primary unit of care and a key element in facilitating the entire process. The emotional, social, and spiritual needs of the family must be met, in addition to the pathophysiological needs of the patient. The family needs to be informed about the progression of the disease and have support to cope with their feelings, as the family member may also suffer from anxiety, depression, and fear.

Social isolation is a reality for many children with cancer, who are separated from their daily lives, home, school, friends, and leisure activities. Hospitalization is an unfamiliar and frightening environment, and the child may feel fear and distress. It is the nurse's responsibility to humanize the hospital environment and use playful care (playing, reading, music) to alleviate suffering and promote the biopsychosocial well-being of the child. Play is a universal right and an essential tool for socialization, adherence to treatment, reduction of irritability and anxiety, and improvement of quality of life. Therapeutic play facilitates communication and adaptation of the child to the "new normal". Cognitive development and the child's potential are enabled by play, allowing them to express their feelings, improve their ability to concentrate and be creative, stimulate their imagination, and discover themselves, which can contribute to improving the pathological condition (Dal'Bosco et al, 2018).

Table 1 – Benefits of play in promoting the well-being of children in palliative care

Playing helps children cope with and process their emotions.	Therapeutic play sessions in the hospital facilitate emotional expression, allowing children to process their thoughts and feelings and find comfort through play, providing the resilience essential to persevere through procedures and treatments.
Play helps children understand their diagnosis and treatment path.	Children can understand each step of the procedure and feel prepared for something that previously seemed frightening and unknown to them.
Play creates a safe space for children to interact with their peers.	Children can play with peers who are going through similar illness and treatment experiences and truly understand what others are going through, helping them feel less alone and more emotionally supported.
Play provides an environment for patients to build confidence.	Children can feel safe asking questions about future procedures, clarifying misconceptions while building confidence.

Fonte: Allie Jones; Emily Capron. organizado pela autoria – 2025. (https://www.starlight.org/stories/five-ways-cancer-patients-cope-with-play).

Effective communication is a basic and indispensable tool in care, establishing a relationship of trust and security between the child, the family, and the nursing team. Healthcare professionals must provide clear, objective, and didactic information, respecting the individuality and limits of understanding of each person. Active listening is fundamental to understanding the needs of the family, which is often overwhelmed and in need of care.

Humanized care implies building affective bonds with the patient and family, ensuring ethics, respect, and human dignity. Multiprofessional teamwork is essential, as the demands encompass various specialties. Dialogue and the sharing of experiences among members of the multidisciplinary team strengthen interpersonal relationships and contribute to well-being and safety.

Nursing plays a crucial role as a health educator, especially in the transition from hospital care to home care. It is the nurse's responsibility to instruct and answer caregivers' questions, respecting the reality of each family and encouraging understanding of the health-disease process. Furthermore, the nurse must assist in the transition from the pediatric world to the adult world, encouraging self-care (Santos, 2024).

There are significant challenges for the nursing team, as these professionals often feel psychologically unprepared to deal with the emotions and stressful situations aroused in pediatric palliative care. The lack of focus on the subject during professional training is a contributing factor. There are also organizational challenges, such as the need for adequate spaces for rest and privacy for the team and family members, and the scarcity of psychologists to meet the needs. Ineffective communication in the unit is also a problem. These challenges highlight the need for psychological support for the nursing team, continuous professional training, and the standardization of conduct to ensure more qualified and safe care.

3.3 MULTIDISCIPLINARY STRATEGIES USED TO PROMOTE QUALITY OF LIFE AND COMFORT FOR CHILDREN WITH LEUKEMIA IN THE PALLIATIVE PHASE

The quality of life and comfort of children with leukemia in the palliative phase should be ensured through a multidisciplinary approach centered on the child and their family, prioritizing pain relief, control of physical and emotional symptoms, as well as spiritual and psychosocial support. Attention should be directed not only to clinical treatment, but also to preserving dignity, respecting the preferences of the child and family members, and promoting moments of well-being and emotional bonding (Nascimento et al., 2013).

The multidisciplinary team, composed of nurses, physiotherapists, doctors, psychologists, occupational therapists, social workers, pharmacists, and complementary therapy professionals, works in an integrated way to manage physical symptoms and offer support. This articulation favors personalized interventions, respecting constant communication between professionals, which ensures continuous and coherent care throughout the entire process (Guimarães et al., 2016).

The team approach allows for a broader and more sensitive assessment of the patient's needs. Care strategies are constantly adjusted, ensuring greater effectiveness in treatment. The bond built with the child and their family strengthens the therapeutic process and promotes a more humanized environment. In addition, the exchange of knowledge between professionals from different areas enriches interventions and reduces gaps in care. The support offered contributes to alleviating physical and emotional suffering, valuing dignity and well-being. In this way, care becomes more comprehensive (Felix et al., 2024).

Effective communication also strengthens the bond with the child, promoting trust and tranquility. Clear dialogue with the family is equally essential, allowing doubts to be clarified and decisions to be shared. Strategies such as the use of playful language and visual resources facilitate the child's understanding of their own care process. Thus, communication becomes a fundamental therapeutic tool in the pediatric environment (Guimarães et al., 2016).

Family involvement is encouraged at all stages, promoting an environment of trust and acceptance. Thus, comprehensive care contributes to improving the quality of life and well-being of the pediatric patient (Guimarães et al., 2016).

The nurse plays a central role, planning rehabilitation interventions, offering health education, providing emotional support, and ensuring that care protocols are followed safely, including infection prevention and management of symptoms such as nausea, pain, and nutritional status. In addition, they actively listen, promoting more humanized and patient-centered care. They actively participate in interdisciplinary discussions, contributing their clinical vision and sensitivity to daily monitoring. Their attentive observation allows for the early detection of changes in the clinical picture, favoring rapid and effective interventions (Felix et al., 2024).

Symptom control is one of the pillars of palliative care. In addition to the use of medications, non-pharmacological interventions such as physical exercise are employed, which improve fatigue, self-esteem, and sense of well-being. Play and moments of privacy are also promoted to provide feelings of normalcy and emotional comfort. Relaxation techniques, music therapy, and aromatherapy can also be used to alleviate anxiety and promote tranquility (Gomes and Othero, 2016).

The impact of the disease on families is profound, involving shock at the diagnosis, emotional difficulties, reorganization of the family routine, and dependence on support networks. In addition, the transition process from curative treatment to palliative care was marked by frustrations, conflicts, and the need for clear and humanized communication between the health team, the patient, and family members (Silva, 2018).

Understanding the experiences of families allows nursing and other health professionals to expand clinical practice in pediatric palliative care. The team's care reinforces the importance of communication, interdisciplinary support, and respect for the cultural, social, and spiritual needs of families, contributing to more humanized care centered on the patient and their support network (Silva, 2018).

Final Considerations

Palliative care for children with leukemia is a comprehensive and essential approach that extends far beyond the terminal phase, seeking to optimize the quality of life of the patient and their family from diagnosis onwards. This study demonstrated the complexity of the needs faced by these children, which encompass physical aspects such as pain and other debilitating symptoms; emotional aspects such as fear, anxiety, suffering, and grief; and psychosocial aspects such as social isolation, the need for effective communication, and family support.

The nursing team emerges as a fundamental pillar in this care, given its continuous presence and ability to establish bonds with the child and family. Their role goes beyond the execution of technical procedures, including providing comfort, emotional support, the use of playful tools, and acting as a health educator for home care.

However, the work of these professionals is permeated by considerable challenges, such as emotional overload, a feeling of unpreparedness, ineffective communication, and the need for improved training and psychological support. Overcoming these challenges is crucial for nursing to offer holistic, humane, and quality care, ensuring dignity for the child and support for the family at a time of extreme vulnerability.

This study reinforces the importance of new research, training, and the implementation of protocols aimed at systematizing and strengthening pediatric palliative care, filling the gaps in knowledge and practice that currently exist. By focusing on the wholeness of the individual, nursing contributes significantly to enabling the child and their family to experience the process of illness and, if applicable, the end of life, with the maximum possible well-being and dignity.

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