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Review Article

Humanization and Childhood Cancer

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Abstract

This paper seeks to address the complexity and importance of the appropriate management of children and adolescent oncology patients, for a broad perception of the humanized way that should be adopted in the relationship between doctor versus patient and doctor versus family. With this, it is aimed to understand the practical importance of the humanized approach, both for the family members and patients to face the disease in a lighter way, as well as for better adherence to treatment and an eventual more positive outcome. The analysis of the social consequences of facing a terminal disease is essential to understand the mitigation of these factors through a humanized approach. Above all, in relation to those responsible for the child under treatment, who suffer together and are the first to be notified about the evolution of the patient's clinical picture. Daily conduct is established to facilitate the patients' routine, such as activities that stimulate the children's creativity and promote their social interaction. Although it is not an escape from reality, it can be considered a less aggressive way of experiencing it. Following the discussion, the difficulties observed by childhood oncology patients, who face invasive procedures, as well as the constant presence of the possibility of death, are addressed. Therefore, this reality leads us to understand the need for a closer relationship between the physician and the patient and family members, to a humanized approach with the aim of alleviating suffering throughout the treatment.

Keywords: Pediatric oncology; Children's hospitalization; Humanization.

Introduction

Cancer in pediatrics is defined as any malignant neoplasm that affects people under fifteen years of age and, although rare in absolute terms, is of paramount importance due to the complexity of treatment and, especially, the fact that it triggers great psychological and social distress of the patient and family [1]. Acute lymphoid leukemia is the most common type of cancer in the pediatric age group and is

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characterized as a malignant tumor of the hematopoietic system that causes changes in the growth and proliferation of lymphoid cells in the bone marrow, leading to an accumulation of blasts, which are young undifferentiated cells. Its main clinical manifestations are fever, adenomegaly, hemorrhages, pallor, hepatomegaly, splenomegaly, fatigue, and bone pain, and the definitive diagnosis is made through a myelogram [2].

The hospitalization in limited support environments makes this experience a very negative one; thus, the multidisciplinary team has the role of developing, together with the cancer patient, holistic care, focused on the biopsychosocial being, thus covering their own perceptions about the disease. Therefore, the challenge for health professionals is not to stick to the hospital-centric model, mastering the necessary techniques, but based on humanistic precepts. The family is considered the primary care in pediatric patients, thus, the interpersonal relationship between professionals and family members is of fundamental importance for the process of humanization in health services [3,4].

In a study conducted by [3], it was observed, however, that there are limiting factors regarding the integral care of the patient, such as the lack of understanding by family members regarding the treatment, the result of inefficient communication between professionals and family, which leads to decreased collaboration. In addition, a hospital environment that is not very welcoming to children makes them less receptive to care [3]. Thus, humanized care is of fundamental importance for the treatment, so that the link established between the entire multidisciplinary team together with the patient and family facilitates assistance and provides a more dignified and welcoming treatment for these children. The objective of the study is to explore the importance of humanized means for children with cancer and their families, in the face of circumstances that demonstrate limitations and/or factors that maximize this integral care. Additionally, it intends to establish a reflection about the excessive distance between doctor and patient that, as a consequence, can lead to a weak adherence to treatment due to the lack of knowledge of the anxieties and anguishes of the patient and the family.

Methods

This literature review aims to highlight the humanization in the oncologic process in children and adolescents, by analyzing the scientific knowledge already produced on the subject investigated, in a systematic and orderly manner. Thus, active searches for papers in PubMed, Latin American Literature in Health Sciences (LILACS), and Scientific Electronic Library Online (SciELO) platforms were carried out. The search for articles was limited to the Portuguese, English, and Spanish languages and was not limited to a time period. The following keywords were used: pediatric oncology; child hospitalization; humanization, with the terms and/or combining the words.

Pediatric oncology

The humanization of health care is a dialogue that involves the promotion of care actions

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and policies based on respect, ethics, empathy, and solidarity. This implies the thought of the limitation of full knowledge, that is, there is always a necessary exchange in the relationship between doctor and patient that provides a greater understanding of both and allows for a more integral dimension of care [5]. Thus, the hospitalization of pediatric patients addresses the need for a humanized look, since it reflects a difficult experience and stimulates fear and anxiety facing stressful environments and, in many cases, with limited sources of help for the satisfactory coping of these feelings [3]. Moreover, the high financial costs of the process of diagnosis and treatment along with the information of a disease that points to death, for most individuals, brings psychological and social wear, which affects the temperament of many family members [6,7].

Among the facilitating factors of the humanized treatment of these children, the act of playing stands out, which generates the development of creativity, through imagination, and strengthens social interaction. This contributes to the construction of scenarios transcending the hospital reality and creates bonds with patients in similar conditions [8]. In contrast, Vieira & Carneiro (2006) realized through the implementation of a playful project for children with cancer that many of the themes of games were related to the oncological process experienced, whether hair loss or chemotherapy treatment, contributing to their own understanding and coping with the current context of hospitalization [9].

Another project of playfulness carried out is the "Chemo library", which is a strategic space of chemotherapy integrated with toys, colorful illustrations on the walls, games, books, and music, where it was possible to notice the distraction of the painful sensations and help the child about the time that remains in the hospital [10].

When playing, it is necessary to identify their individual characteristics and their performance in intergroup relations, which contributes to the appreciation and growth of the individual as a human being. In this way, the child starts to feel participant, embraced, and respected by his playmates, since it is occurring the possibility to develop his potential and work on his feelings [11,12].

Children's hospitalization

Several situations in the child's life represent moments of loss or frustration even before the hospital admission itself. These situations can occur both individually, such as a broken or broken toy, which reinforces the importance of play in childhood, and in interpersonal relationships, such as separation from parents or disagreements with friends. Thus, the feeling of death already exists for the child and, therefore, it is important that the adult does not reinforce the denial of death, so that the child can experience all phases of mourning [13].

The child with cancer, in turn, experiences the continuous sensation of facing death, especially during the period of hospitalization, because the treatment is prolonged and involved several invasive and painful procedures. Moreover, the child may also witness the death of colleagues in the

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ward, perceiving this whole process of clinical worsening and suffering in other people as well [13].

The disintegration of identity and the compromising of self-esteem, due to the several physical alterations caused by the disease and treatment is something that the child also faces during this period. Thus, the disease interferes in several areas in the growth and development of the pediatric patient [13].

Another great facilitating factor of treatment in a humanized way is the closer relationship between the interdisciplinary team and the family nucleus, which is considered the main source of care, the primordial vehicle that can facilitate the whole process of attending to the patient, with the fact of having a vision far beyond the technical bias. It is a fact that the family is faced with numerous conflicts, doubts, and feelings since the diagnostic suspicion and, especially, at the time of hospitalization, in which, often, they do not see the opportunity to express their emotions when faced with their own human powerlessness [3].

Palliative care in pediatric oncology

Intensive and medical care at the end of life has been associated with significant suffering. Interventions such as mechanical ventilation and invasive medical procedures, as well as the intensive care unit environment, can contribute to the distressing physical and psychosocial experience of children with cancer and their families. The most common symptoms encountered in the last month of life included pain, fatigue, and edema, all of which were reported in more than 75% of the patients evaluated. Adolescents and young adults who had palliative care involved were less likely to die in the intensive care unit or be on a mechanical ventilator at the time of death [14,15].

The cornerstone of Pediatric Palliative Care is the relief of suffering through appropriate management of the physical symptoms and emotional distress of patients and families. The International Association for the Study of Pain defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue injury or described in terms of tissue damage. The proper management of pain is fundamental to care, being the starting point for any subsequent approach [16].

In the investigation of pain parameters, it is important to identify its characteristics (location, intensity, quality, duration, frequency, and associated symptoms); relief and aggravating factors; use and effect of pharmacological and non-pharmacological measures; ways of communicating/expressing pain; previous traumatic experiences and fears; coping skills and strategies; child's behaviors in the family environment; effects of pain on daily life; emotional and socioeconomic impact approach [16].

Pain assessment must be performed regularly, with the use of appropriate scales for each age group and clinical situation. It must be emphasized that the scales can be difficult to use in some clinical situations, such as in children who are sedated, have restricted

movement, or are submitted to tracheal intubation [16].

Symptom management should include both non-pharmacological and pharmacological approaches. Pharmacological pain management includes non-opiate analgesic drugs, opioids, and adjuvants (antidepressants, anticonvulsants, corticosteroids). The WHO revised the pain analgesic scale for the pediatric population in 2012, giving preference to small doses of strong opioids over the use of weak opioids such as codeine and tramadol when non-opioid analgesics are insufficient for pain relief [16,17].

The WHO recommends for children: i) Paracetamol and ibuprofen are the drugs of choice in mild pain. Both should be available for this first phase of treatment. In those younger than 3 months, use only paracetamol; ii) Opioids are the drugs of choice in moderate to severe pain. The first choice is morphine, but other options should be considered when side effects are intolerable. The selection of opioid analgesics as alternatives to morphine should be guided by considerations of safety, availability, cost, and appropriateness; iii) Opioid treatment should be individualized and adjusted progressively; iv) When pain is constant, the drug should be administered at regular intervals rather than on a "demand" basis, watching for side effects. Intermittent and intercurrent pain can be treated with rescue doses; v) The route of administration should be the simplest, most effective, and least painful, usually the oral route. When the oral route is not available, the choice of alternative routes of administration (IV, SC, rectal, or transdermal) should be based on clinical judgment, availability, feasibility, and patient preferences. Avoid the intramuscular route; vi) Switching opioids and/or route of administration is recommended when there is an insufficient analgesic effect with intolerable side effects. Systematic rotation of opioids is not recommended [16,17].

The non-pharmacological aspect of symptom management includes integrative interventions, such as psychotherapeutic/behavioral techniques (relaxation, hypnosis, therapeutic imagination, meditation, music therapy, art therapy, yoga), physical (massage, transcutaneous electrical nerve stimulation - TENS, positioning, heat/cold), and energy therapies (acupuncture, Reiki, therapeutic touch), among others [16].

The therapeutic choice should follow individual clinical criteria. It is essential to maintain a proactive attitude toward the treatment of symptoms and side effects of medications, anticipating them as much as possible, and ensuring good communication with the child and his family [16].

Humanization of healthcare

One of the main paternal feelings with the diagnosis is the fear of death and the feeling of inversion of the natural order of facts as if upon discovering the disease they had already lost their child immediately [18,19]. Thus, there is an incessant search to discover the origin of the case, and, in many situations, those responsible take upon themselves the feeling of guilt facing a void not filled by any medical information [2].

Thus, it becomes important planning of intervention actions of health professionals intertwined with family members, to ensure the monitoring of their needs and consent [4]. For, through attitudes that bring loved ones together, it is possible to establish bonds of trust and credibility, especially when there are difficulties in accepting scientific-technical treatment [20,3]. To eliminate the hospital-centric idea, the practice of making known and knowing the patient himself, as in calling him by name and not by pathology or bed, should be exercised daily [21,3].

In this bias, a limiting perspective comes into question, since it is possible to observe the customers' difficulties regarding access to the doctor. The hospital routine of health professionals tends to be of intense emotional exhaustion due to the high continuous workload in a short period of time, with great emphasis on oncologists [22-24]. Organizational issues, limited physical structure, and extreme turnover among professionals occurs an intense impact on the relationship of care, causing a distancing between the hospitalized child, the family, and the doctor [25].

In a survey carried out, it was seen that initially there is an empathic link with the patient, but that concomitant problems are adhered to, such as the lack of a clear explanation of the problem or the inexistence of a check on the understanding of those responsible for the diagnosis and therapeutic interventions [26]. Moreover, many physicians end up shortening their visiting times, where it has already been understood that a long time tends to designate a better anamnesis and a wider view of verbal and non-verbal language, which should act together as facilitators of this process [25]. Therefore, poor communication makes the path more painful, with conflicts that directly affect the child, making it impossible to achieve holistic care [3]. However, if the attention to the family member was a priority, as a desire of health employees and as an institutional foundation, new ways of directing the service would open, despite any pre-existing or imposed limitation [27]. After all, as exposed by Dixon & Sweeny, the importance of the therapeutic relationship explains why adherence to the therapeutic process depends more on the physician than on the patient's personal characteristics, in particular, the patient is much more inclined to comply with the prescription if he thinks he knows well the physician who is prescribing [28].

On the other hand, in a complementary way, the low reception environment implies the treatment approach to the child. After it is shown that a playful place brings a successful return to the individual, the excessive representation of seriousness and an unwelcoming aspect automatically contradicts itself, as it prevents the perception of warmth, in a world far from their childhood [3]. In the face of constant readmissions during the course of the illness, the entire family role is reorganized, household chores become the last plan, the focus is turned almost completely to the sick child and the mobilization as a family is permeated by the affective vector [29]. In this, the relevance of the treatment unit being an empathic and child space to experience a representation of dwelling each day is highlighted.

Final considerations

Objectively, it was observed the complexity and variety of feelings that affect children patients and their families during the oncologic treatment. Although cancer patients as a whole go through painful procedures and prolonged periods of pain and discomfort, children patients carry with them characteristics and peculiarities that must be dealt with in detail.

In this sense, in order not to traumatize the child and to help him/her to face the disease and the treatment, several initiatives are important and effective, especially regarding the incessant search for relaxation, and social interaction, and by stimulating creativity and helping this patient to understand their situation.

Transparency integrated with affection, the search for closeness and connection with the patient and his family, make facing the difficult situation in which they find themselves less stressful, as well as helping and stimulating the patient and his family members to adhere to the treatment, transmitting their confidence and promoting encouragement.

Thus, the humanized approach of the physician with children oncology patients and their families becomes not only an option but a working tool for those medical professionals who seek better outcomes for their patients, as well as a less painful end for those who are in irreversible conditions.

Certainly, medicine is a profession that deals with pain and, of course, death. Notwithstanding this fact, it is necessary to remember that, in all cases, it deals with the people, not just numbers. With this in mind, the importance of healing, when possible, of ending physical pain when possible, and, when none of this is possible, of promoting some comfort, of making it more manageable to live with suffering and the path to an inevitable end of life, remains clear.

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