

## PERCEÇÃO DAS MÃES DE CRIANÇAS COM CÂNCER SOBRE O CUIDADO HUMANIZADO DA ENFERMAGEM

### MOTHERS OF CHILDREN WITH CANCER PERCEPTION ABOUT HUMANIZED NURSING CARE

### PERCEPCIÓN DE LAS MADRES DE NIÑOS CON CÁNCER SOBRE EL CUIDADO HUMANIZADO DE LA ENFERMERÍA

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#### RESUMO

**Objetivo:** Conhecer a percepção das mães de crianças em tratamento oncológico sobre o cuidado humanizado da enfermagem. **Método:** Estudo qualitativo, exploratório e descritivo, realizado com 16 mães de crianças em tratamento oncológico em uma casa de apoio filantrópica. Foi utilizada a entrevista semiestruturada para coleta das informações e foi empregada a análise de discurso, a partir dos depoimentos das participantes. **Resultados:** Os resultados trazem uma discrepância em relação à assistência de enfermagem: algumas mães se sentiram completamente acolhidas e apoiadas e, em contrapartida, outras se sentiram desamparadas e desrespeitadas. **Conclusão:** As mães percebem o cuidado humanizado da enfermagem no acolhimento integral da criança e família para além da doença; a enfermagem contribui na reflexão e reestruturação das ações do cuidado, elevando a qualidade da assistência.

**Descritores:** Humanização da assistência; Cuidado da criança; Cuidados de enfermagem; Enfermagem oncológica.

#### ABSTRACT

**Objective:** To know the mothers of children in oncological treatment perception on the humanized nursing care. **Method:** Qualitative, exploratory and descriptive study, carried out with 16 mothers of children in oncological treatment in a philanthropic support house. The semi-structured interview was used to collect information and the speech analysis was used, from the participants' testimonials. **Results:** The results bring some discrepancy regarding the nursing care: some mothers felt completely welcomed and supported, however, others felt helpless and disrespected. **Conclusion:** Mothers realize the humanized nursing care in the integral reception of the child and family beyond the disease; nursing contributes to the reflection and restructuring of the care actions, raising the care quality.

**Keywords:** Care humanization; Childcare; Nursing care; Oncological nursing.

#### RESUMEN

**Objetivo:** Conocer la percepción de las madres de niños en tratamiento oncológico sobre el cuidado humanizado de la enfermería. **Método:** Estudio cualitativo, exploratorio y descriptivo, realizado con 16 madres de niños en tratamiento oncológico en una casa de apoyo filantrópica. Se utilizó la entrevista semiestruturada para recopilar la información y se empleó el análisis de discurso, a partir de los testimonios de los participantes. **Resultados:** Los resultados traen una discrepancia en relación a la asistencia de enfermería: algunas madres se sintieron completamente acogidas y apoyadas, pero, en contrapartida, otras se sintieron desamparadas e no respetadas. **Conclusión:** Las mujeres perciben el cuidado humanizado de la enfermería en la acogida integral del niño y la familia más allá de la enfermedad; la enfermería contribuye en la reflexión y reestructuración de las acciones del cuidado, elevando la calidad de la asistencia.

**Descriptores:** Humanización de la asistencia; Cuidado del niño; Cuidados de enfermería; Enfermería oncológica.

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#### Como citar este artigo:

Santos RS, Takeshita IM, Araujo CM, et al. Percepção dos Pais de Crianças com Câncer sobre o Cuidado Humanizado da Enfermagem. Revista de Enfermagem do Centro Oeste Mineiro. 2019;9: e2883. [Access \_\_\_\_\_]; Available in: \_\_\_\_\_. DOI: <http://dx.doi.org/10.19175/recom.v9i0.2883>

## INTRODUCTION

The National Institute of Cancer estimates that 12,600 new cases of cancer in children and adolescents were diagnosed in Brazil in 2017<sup>(1)</sup>. The significant progression of the development of treatment in childhood cancer in the last four decades has increased the possibilities of cure and survival. It is estimated that 70% of children submitted to treatments can be cured with early diagnosis and follow up in specialized centers<sup>(2)</sup>.

Oncological children experience unpleasant experiences related to the hospital environment and treatment, which may negatively influence the disease's prognosis<sup>(3)</sup>. There are several benefits related to the interaction between the child, the companion, and the nursing team. This interaction facilitates the assistance provided and, at the same time, optimizes the work of the entire multidisciplinary team involved<sup>(4)</sup>.

The impact of the diagnosis brings suffering to the patient and the family, generates uncertainties, and stimulates the search for support to confront the disease. The family, when witnessing these difficulties closely, recognizes them as real battles and identifies their own fragility in the face of this process<sup>(2)</sup>.

Hospitalization can generate fear and anxiety not only because the disease exists, but also because of the innumerable interventions that the child undergoes in long-term treatment. When mothers are not included in the care plan, and they remain uninformed about treatment, doubts and insecurities arise regarding the assistance provided by the health team, mainly nursing, which deals with that child at all times<sup>(3)</sup>.

In 2003, the Ministry of Health created the National Humanization Policy (PNH) to ensure the valorization of users, workers, and managers throughout the health production process. From this valuation, greater autonomy is promoted, and the idea of shared responsibility and the creation of solidarity bonds are broadened. The PNH is constituted from its basic document, which establishes its method, principles, directives, and devices in order to disseminate the experiences of a "SUS that works," as well as to face its main limitations and challenges<sup>(5)</sup>.

Therefore, the establishment of a bond with mothers, who follow closely the disease process, makes the care less traumatic, being indispensable, empathic, and based on trust, establishing itself as a strategy that contributes to the needs of the children and their families,

reducing feelings of impotence and implicit fears during the care<sup>(6)</sup>.

Teamwork is fundamental in the treatment of oncological children. Communication has a relevant role, as well as empathy, awareness, care strategies, and consideration of the context experienced by the patient and his/her relatives. Respect is of fundamental importance because the practitioner deals with diverse beliefs and cultures, spirituality, and religiosity beyond the revolt generated by the diagnosis<sup>(7)</sup>.

The health team should be aware of the needs and be trained in continuous communication skills, seeing the importance of mothers finding other mothers in the same situation, increasing access to psychosocial support services and psychological care.<sup>(8)</sup> A qualified communication between nurses and mothers tends to reduce anxiety and, consequently, contributes to the processes of hospitalization and coping with the disease by the family, in addition to being essential in the definition of preferences and priorities in the treatment plan<sup>(6)</sup>.

Nurses have technical and scientific knowledge that must be allied with some aspects of humanization in order to achieve better results and benefits. One of these aspects is qualified listening, which ensures adequacy and effectiveness in services because it takes a real necessity as the basis. To make care more humanized, it is necessary to understand how nursing can help these families, what actions should be taken to reduce anxiety and distress, clarifying questions related to the clinical picture, and explaining processes during procedures<sup>(5)</sup>.

The oncological and pediatric universe is permeated by several aspects, and therefore, it is of paramount importance that nursing teams are confident and prepared to overcome the technical limitations when caring for children/adolescents. This specialty presents physical and emotional delimitations that inevitably extend over as the direct contact with mothers, and should be extended and individualized in the assistance<sup>(6)</sup>.

The complexity of this assistance demands investments in professional training and improvement in practical contexts and in the interactions that help to build models of care that value the whole context of the child and his/her relatives<sup>(6)</sup>. Humanized care comes from changes built collectively and shared. By including those involved, it is possible to create new ways of

caring and new types of care management<sup>(5)</sup>. Thus, getting to know the people who receive assistance becomes fundamental to adapt and improve the whole process.

The objective of the study was to understand the perception of mothers of children in cancer treatment about humanized nursing care.

## METHODS

This was an exploratory, descriptive study with a qualitative approach. The phenomenon was analyzed and understood based on the speeches of sixteen individuals. Such an approach allows us to uncover social processes that are still little known (referring to particular groups), and to create new approaches and concepts<sup>(9)</sup>. The study was carried out in a support house for children with cancer located in Belo Horizonte - MG.

The inclusion criteria selected individuals aged 18 and over who were accompanying a child during the stay in the hospital and support house for at least one year.

After approval by the Research Ethics Committee, a date was scheduled with management from the support house to conduct a presentation of the study project, explain the objectives, and clarify their relevance in promoting more qualified assistance; at that time, 25 pre-selected participants were present. A time for questions was opened after the presentation and participants confirmed their participation in the study; the possible individual interview dates were informed at the same time.

The interviews took place in the support house, in a private and comfortable room, in order to offer privacy and quietness without the presence of the nursing team, which was the main focus of the study. Eight visits were conducted over the course of two months. In each visit, the study objectives were explained and those interested and with availability on that day were interviewed. Two interviews were performed on average in each visit.

The interviews followed a semi-structured script and were recorded. Participants were identified by the name of flowers to ensure anonymity, and their speeches were recorded on digital media and transcribed integrally, including signs for pauses, intonations, and emotions such as laughter and mourning; the original speeches were stored. The data saturation occurred when

discourses did not bring any new information other than the previous ones, or when highlighted issues began to repeat, and new features were no longer identified in the speeches.

The theoretical-methodological referential, the Discourse Analysis, and the Pêcheux's theory, when language is not conceived as a system of formal rules with discursive studies, however, it is thought in its practice, were used for data analysis. Moreover, there is the attribution of the work with the symbolic, with the political division of senses because it is unstable and mutant. The object of study appreciation is the speech, not the phrase because this escapes from appreciation, word for word, in an interpretation as a closed sequence in itself<sup>(10)</sup>.

The study was initiated after a favorable opinion of the Ethics Committee from a higher education institution in Belo Horizonte, Minas Gerais, under number 1761208 and CAAE 58866116.1.0000.5134. Subjects were informed about the ethical aspects of the study, voluntary participation, anonymity, the possibility of withdrawal without prejudice, and risks and benefits; a copy of the Informed Consent Form (TCLE) was given to participants to sign it according to Resolution n.466/2012 of the National Health Council.

## RESULTS AND DISCUSSION

The characterization of the analyzed sample represented sixteen mothers whose age range was between 33 and 58 years. They were predominantly from cities of the countryside of Minas Gerais. All interviewees said they left their jobs because of the demand for their children's treatment. Out of the 16 children treated, 62.5% had been on treatment for more than four years, 25% for more than three years, and 12.5% for less than two years.

Most of the diagnoses were Acute Lymphocytic Leukemia - ALL (75%), followed by non - Hodgkin's Lymphoma (18.75%), and Osteosarcoma (6.25%). All mothers stated that the treatment, regardless of time and type of cancer, is filled with ups and downs with significant improvements and equally marked worsening.

Data analysis showed the emergence of three categories from the mothers' perception: mothers reveal their fears, professional ethics as a fundamental element of humanized care, and affection during care.

### Mothers reveal their fears

The participants explained the fears of the experience of hospitalization, where insecurity and fear, together with the lack of knowledge, resulted in despair. Each speech emerges loaded with feelings and memories: "Because we call a lot, I called all the time, I was afraid, I panic [agony], I did not understand anything that was happening, for me my boy was going to die at any moment you know [cry]..." (Rose). "And I, frankly, I was so desperate that if there was not [strong mourning, despair, pain]... a screen in that window, I would have jumped out [anguish]" (Orchid).

The impact caused by the unknown is the worst possible, it brings anguish and a sense of impotence added to the fear that dwells throughout the treatment, as evidenced in the speeches: "When we start the treatment, we immediately get nervous, afraid of death, afraid of his hair falling, afraid of the child being trapped in that bed, losing weight, suffering without eating right [emotion, watery eyes]...these sad things like this" (Petunia). "There was a time when I only thought about giving up [sadness], getting our things and getting away from that place. You know, I was thinking of letting my daughter live her last days in peace, in an environment of peace [anguish, pain]..." (Tulipa). "It is a very difficult time for us, not only for the child but for me as well as a mother and I see her suffering there ..." (Violet).

Another highlighted point is the emotional instability generated by the lack of communication/dialogue among professionals and companions that can generate conflicts. Conversely, once parents understand the care and perceive that they are included in the process, they begin to recognize the professionals and are satisfied with the reception: "At first, when we are desperate, we may not be able to return an appreciation for your dedication [emotion and tears], but as time goes by, you will be present in our prayers and hearts [tenderness]. Maybe money does not pay, but our gratitude and God's pride in seeing the love given to another human being, of course, pay your dedication and affection" (Lavender). "But, in the look of that child, in a smile, in the trust of parents, in the small details [emotion]" (Rose). "Those there all the time putting up with us, are you, so [euphoria], thanking and saying that you manipulate, that is, not manipulate (smile), influence our lives a lot right now. I, therefore,

keep your faces with me until today, of all those who helped me in the first hospitalization [gratitude and happiness]" (Violet).

Cancer is generally seen as synonymous with pain, death, and suffering. The diagnosis of cancer can result in varying aspects of each individual. However, reactions such as fear, anxiety, denial, hopelessness, and loss of control are usually common feelings<sup>(11)</sup>.

Child-juvenile cancer completely changes the dynamics of patients and accompanying mothers because it replaces the family routine for hospital routines that are composed of frequent hospitalizations and long and aggressive therapy. In addition, there is an interruption in the interaction with other family members. The result could not be different from constant negative feelings, among them: loneliness, anguish, suffering, and fear<sup>(12)</sup>.

Many behaviors relate to the difficulty of mothers in dealing with the experience of the illness and the hospitalization of their child. Given this scenario, they become fragile and feel unprepared to face the treatment with their children, living moments of uncertainties and anxieties in the face of the care provided. Therefore, it is important that the care team understands the value and stimulation of their involvement in the care<sup>(13)</sup>.

Encouragement for the hospitalized patient should be a key component of the team's intervention in order to assist in communication with these families about cancer, which possibly reduces maternal depressive symptoms<sup>(14)</sup>.

Thus, the dedication to the care offered is necessary for the children and their mothers, establishing relationships of trust and respect between the health professional, the patients, and their families, contributing, in a positive way, to this hospitalization process<sup>(15)</sup>.

It is believed that cancer results in a mixture of feelings in all of those involved. In the patient, because he needs to adapt to a treatment that causes suffering and extensive and uncertain invasions; in the family, because experiencing this unexpected situation that causes pain, financial problems, and feelings of guilt and anger among others; and in the team because they feel sadness, fragile, and powerless in the face of the situation. Therefore, the balanced between the professional and humanized care can help these families through facing the difficulties lived during these critical periods<sup>(16)</sup>.

### **The professional ethics as a fundamental element of the humanized care**

This category evidenced the importance of a professional posture during the assigned care. According to the mothers, respect is directly related to the sense of confidence and the certainty on the quality of treatment. Participants believe that there is a need to invest more in ethical training, revealing in their speeches a negative impression about the ethics of some nursing professionals: "He told me, therefore in passing, that it was an examination and that I did not need to worry that my son was not going to be crippled because of the exam [anger and dislike]. So, I found it strange, the manager who studied the most among them there was telling me this [indignation]" (Plumeria). "I did not say anything because otherwise, it is worse, there is less care, the time to give medication is delayed, these things [evidence of fear and fear]. So, I was very sad, very distressed [sadness, crying], I still feel it today you know..." (Rose). "[Cry] some of them made me feel so much sorrow [anguish]. Even my little girl got (...) the nickname of broody hen in the hospital, given by a nurse [memories of revolt and sadness]" (Orchid).

Simple complaints were clear among the testimonies of these mothers such as the lack of dialogue and support within hospitals and even the desolation and disillusionment experienced by them from the nursing staff: "I could not explain to my daughter why she was there [sadness], why God ... had let her be there [crying and anguish], and there in the hospital I also did not find anyone to help me explain this to her [manual demonstration of tightness in the chest], that what was there would help her to heal and why she had to be pierced you know [crying and agony]" (Petunia). "You have to look at it there, because these are human lives, even if it was an animal we have to have mercy [revolt and indignation]. Even more for a human being, who thinks, who speaks, all right, who has reasoning right? It's not just anything; it is life, they are taking care of life [sadness and anger]" (Orchid).

Next, in contrast to the previous speeches, a team that knows and believes in the importance of information as an essential element in the help given to parents to face the condition of cancer in their child, that is, professionals that contribute to the adherence and embracement of all involved as highlighted here "I talked about how am I going to be able to work at home with this colostomy ? [anguish]. You understand, how can I

do it, and she taught me [pause and gratitude] then you take a bowl, you do this, do that ... [satisfaction]..." (Begonia). "Another good thing, too, was when the nurses were going to do something, they would come like that and explain everything to me [satisfaction]. They explain why they had to stick in one place and could not do it in another ... these things [gratitude]..." (Violet). "Every day there was a head nurse who would come to the room (...), she always involved me in the conversations, and this brought me even closer to my daughter. It helped us a lot" (Lavender).

The care involves ethics, principles, and values and must be provided, indispensable, with care, affection, and respect. Both authors state that the purpose of this care is the understanding of the importance of the process and the increasing of the confidence and inclusion of the mothers inside the hospital unit, guaranteeing greater comfort in a cruel, cold, and fearful moment<sup>(17)</sup>.

Nurses play a key role in ensuring that the care encounter involves awareness and sensitivity in the interaction with the other. Involving the mothers in the therapeutic plan for their child, clarifying risks and benefits, maintaining empathy, sensitivity, flexibility, and effective communication, increases the confidence and tranquility toward the team and adherence to the proposed treatment<sup>(13)</sup>.

It is emphasized that the PNH states that, in the same diagnosis, in addition to what people present as similarities, it is necessary to accept that there are points of singularity, such as the identification of signs and symptoms that express themselves in an individual in an exclusive way,<sup>(5)</sup> which also demands exclusive attention.

It is heartbreaking to imagine an experience like the ones mentioned in the speeches. It is the role of the nurse to inform patients and their mothers, as an educator, the essential points for understanding the treatment. It is essential that this professional report on the procedures performed by the nursing team and the entire propaedeutics of the treatment, aiming at increasing adherence since the mother's understanding of the given guidelines stimulates the child's participation in the care that is considered necessary.

Communication in the hospital environment facilitates the meeting of the triad (patient, mother, and team) and when it is combined with the respect and appreciation of

the other's speech, relationships based on affection and trust are created<sup>(18)</sup>.

### **Affectivity during the care from the mothers' perception**

The speeches that compose this category evidenced the need for caring, love, attention, and patience within nursing care. Numerous reports highlighted the lack of affection during treatment and how it had a negative impact on coping: "It was a very exhausting relationship [pause and sadness]. Before, I thought it would help me deal with this problem, but in fact, what I realized was the generation of one more problem [anguish and bitterness]" (Magnolia). "It was as if we were too heavy a burden for them to carry, you know? [Anguish]. They do not look in our face, do not answer what we ask, make ugly faces, these things, right?" (Lavender). "We get more sensitive, right? [emotion]. So, simple things such as, talking, explaining what they're going to do, without getting "faces and mouths," [antipathy] do you know ?!" (Petunia).

The need to value these aspects was in evidence in some speeches. At times, it was possible to see even the change in the countenance of these mothers when they recognized the affection within the care: "She would come, she would talk to her what she had to do it, that it would hurt immediately, but then it would stop [approval] because it was for her to heal, it had to be this way. Moreover, she always explained things to me, she asked me for help, you know? [a smile try]. When she was in the hospital, I felt useful and not just a worthless mother who could not do anything [gratitude]" (Petunia). "It is like I said anyway ... it was good because, whenever I needed it, they helped me. They paid attention, the medicines at the right time [gratitude], explained everything they were going to do, so, they helped me a lot [sigh of relief]" (Amaryllis).

It can be seen from the speeches that, in order to motivate the team, their recognition of the mothers' perception of this humanization becomes important. Such as placing themselves in the shoes of others at all times during the care, sharing the suffering of the family and offering an effective support: "So, this is too beautiful, to know that there is someone who sees you there, as a person too [emotional crying], that there is someone who does not want to just pass on and give medicines and perform an examination and that is it [disapproval] ... And she always stopped

in my son's bed and played with him, and him so at the time at four or five years old, he loved it... when she arrived [memory and a light sketch of a smile]" (Plumeria). "What was left to him after so much suffering [tears] was the affection of these nurses to get a vein, to be careful to say that it would hurt, but that was going to be fast, the care to shave his head when his hair began to fall in large amounts [recollection, sorrow]... the drawings made in the dressings in all changes, those things that have no price [smile]" (Jasmine).

The speeches also showed that if the team is attentive, through a sensitized listening, it will detect the need for affection in the families. The need for information for these mothers inserted in the care and the whole process of the child's life becomes clear, besides the valorization of each action, speech, and moment, that is, everything related to the treatment.

When health professionals do not have a clear perspective of this type of valorization, they tend to reduce the possibility of adequate responses to the family needs, to their interaction with mothers, and consequently, to the quality of care contributing to increased anxiety and insecurity in all involved: "God is Love, so you already enter the service with Love in the front, you understand ?! [euphoria]. Because we need a lot of love" (Lavender). "When we love, simple things end up paying off the effort, for example, my daughter's will to live [gratitude]" (Tulipa).

By giving attention and valuing the family members of a child with cancer, it is possible to answer such supplications as demonstrated in the following speeches: "I, therefore, asked for greater support for us who are mothers and do not want to see our children suffer, but we also do not know how act to help [feeling of appeal and despair]" (Petunia). "Hope they do not think that they waste time [tenderness]. When they dedicate a little more time to talk to us, they are investing in the happiness of a family [intonation and gestures of self-affirmation]" (Jasmine).

The recognition of professionals about the existence of life, both in the patient and his mother, is extremely necessary besides the neoplasia, including the existence of personal points and motivations for the child and the parents, in order to boost acceptance of the treatment: "He mattered to them ... even though he was small there, he could talk, he could speak [memory]" (Magnolia). "She was very happy [euphoria and remembrance]. She said she could not be discouraged because there were a lot of

people who really believed in her [joy]. Then I realized that she was empowered by a very simple but human gesture ... [gratitude]. She had another goal to fight [emotion and tears]" (Tulips).

The coexistence during hospitalization is facilitated when family members collaborate in the care. The family is the key piece in the healing process as it helps the child cope with insecurity and loneliness. This therapeutic relationship can be maximized when health professionals are interested in valuing the affective relationship between family and hospitalized clients<sup>(19)</sup>.

The more effective the communication between health professionals and the family, the lower the anxiety of mothers and the greater propensity for their involvement, favoring adherence to treatments, the process of facing the disease, and autonomy. On the other hand, when mothers do not find this support, there is a tendency to give up treatment and surrender to the disease<sup>(19)</sup>.

Mothers tend to perceive the hospitalization of the child through the interaction with the health team and the care provided, valuing the technology and dedication of these professionals, however, above all, the affection and feelings such as respect and consideration, indispensable in interpersonal relationships. The speeches presented reveal that there are still affective gaps in nursing care<sup>(16)</sup>.

Nursing stands out because of its proximity to the patient, and is, therefore, a profession responsible for a holistic view, contemplating the biological, mental, emotional, and spiritual dimensions of a human being in the caring process. Empathy and ethics in actions ensure the bonding and existence of support for parents involved in the treatment. When the team understands the degree of importance of the mother's involvement, it activates components that enhance the mother's confidence, overcoming the reason that implements the technique, facilitating the encounter with sensibility. Thus, care management is incorporated with the management of emotions, mediating pediatric care and attention<sup>(20)</sup>.

## FINAL CONSIDERATIONS

From the three categories analyzed, it became possible to understand the perception of the mothers of children with cancer about humanized nursing care.

In general, the main fears revealed are death and uncertainty about the treatment. The lack of information, ties, and confidence in the team were present as the main triggers of these feelings. Listening to family grievances, doubts, and fears, and their inclusion in the caregiving and bonding helps to decrease feelings of helplessness and insecurity. Mothers begin to trust the team and know that they can count on the much-needed support during this journey.

The lack of information and the threatening and disrespectful behaviors reveal the professionals' lack of a good stance and even reflects the need for an enhanced approach to the subject during the formation of these professionals. When the mothers perceive that the team welcomes the child and not the illness, respecting values and feelings and transmitting affection, they believe that the care provided is humanized and essential.

According to the speeches, the humanized care is one that is based on professional ethics, technique, confidence, empathy, affectivity, and always considers the subjectivity of each individual involved in the disease process.

Hence, the professionals' knowledge about the quality of the humanization in the care provided, according to these mothers, allows reflection and restructuring of the actions used during the care. In addition, it makes the relationship more pleasant, motivating both parties involved in the process, helping to improve the environment in which the child is.

The speeches analyzed in this study showed a discrepancy in relation to the assistance. Some mothers felt completely welcomed and supported; however, others felt helpless and disrespected. It is important to highlight the need for changes in care management, valuing those involved in the process in a multidimensional manner, acknowledging the relevance of the complexity of the individual as a human being.

The humanized care happens when everyone involved is included; when it becomes possible to create new ways to care for and manage that care. Knowing the people involved is fundamental to assist in the development of these new approaches and actions and, consequently, to improve the care.

One limitation of this study was the use of one single scenario, showing a punctual reality that nevertheless may reflect important aspects

of this humanized care universe for the child with cancer and his/her family.

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**Note:** Study completed from the field research for the Completion Work of the Undergraduate Nursing Course at the College of Medical Sciences of Minas Gerais. There was no financing agency.

**Received in:** 19/07/2018

**Approved in:** 12/04/2019

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