

NURSING CONSULTATION IN PEDIATRIC ONCOLOGY: A TOOL FOR EMPOWERING PARENTS

Consulta de enfermagem em oncologia pediátrica: ferramenta para o empoderamento dos pais

Consulta de enfermería en oncología pediátrica: herramienta para el empoderamiento de los padres

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ABSTRACT

Objective: to understand the contribution of the nursing consultation to the health education of the relatives of children undergoing outpatient chemotherapy. **Method:** a qualitative field survey was carried out at in a town in the State of Sao Paulo with 15 families seen at the nursing consultation. Data collection was performed through a semi-structured interview and analyzed through content analysis technique. **Results:** a central thematic category was identified: “The nursing consultation as a tool for empowering the parents”, supported by the nuclei of meaning: fundamental, support, reception, trust and bonding, learning and confidence. **Conclusion:** the nursing consultation was revealed as a moment for providing empowerment for the child’s family through knowledge acquisition regarding the diagnosis, treatment and way of coping with the oncological child, which provides the parents with greater confidence to care for their child.

Descriptors: Oncology; Pediatrics; Nursing in the Office; Family; Empowerment.

RESUMO

Objetivo: compreender a contribuição da consulta de enfermagem para a educação em saúde dos familiares de crianças em tratamento quimioterápico ambulatorial. **Método:** pesquisa de campo de abordagem qualitativa, realizada no interior do estado de São Paulo com 15 famílias atendidas na consulta de enfermagem, por meio de entrevista semiestruturada. Os dados foram analisados com a técnica de análise de conteúdo. **Resultados:** identificou-se uma categoria temática central “A consulta de enfermagem como ferramenta para o empoderamento dos pais”, subsidiada pelos seguintes núcleos de sentido: fundamental, apoio, acolhimento, relação de confiança e vínculo, aprendizado e segurança. **Conclusão:** a consulta de enfermagem foi revelada como um espaço que proporciona o empoderamento da família por meio da aquisição do conhecimento sobre o diagnóstico, o tratamento e a forma de lidar com a criança oncológica, o que possibilita aos pais maior segurança para cuidarem do filho.

Descritores: Oncologia; Pediatria; Enfermagem no Consultório; Família; Empoderamento.

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RESUMÉN

Objetivo: comprender la contribución de la consulta de enfermería para la educación en salud de familiares de niños en tratamiento ambulatorio de quimioterapia. **Método:** estudio de campo de enfoque cualitativo, realizado en el interior de São Paulo, con 15 familias atendidas en consulta de enfermería, por medio de entrevista semiestructurada. Los datos fueron analizados con la técnica de análisis de contenido. **Resultados:** se identificó una categoría temática central “La consulta de enfermería como herramienta para empoderamiento de los padres”, auxiliada por los siguientes núcleos de sentido: fundamental, apoyo, acogida, relación de confianza y vínculo, aprendizaje y seguridad. **Conclusión:** la consulta de enfermería fue revelada como un espacio que proporciona el empoderamiento de la familia por medio de adquisición de conocimiento sobre el diagnóstico, el tratamiento y la forma de tratar con el niño oncológico, lo que les propicia a los padres mayor seguridad para cuidar del hijo.

Descriptores: Oncología; Pediatría; Enfermería de consult; Familia; Empoderamiento.

INTRODUCTION

Cancer in children and adolescents (from 1 to 19 years old) is considered the first cause of death in Brazil. In 2017, there were around 12,600 new cases of cancer in children and adolescents in Brazil, and there are an estimated 12,500 new cases for 2018.¹ Nowadays, about 80% of children and adolescents with cancer diagnosed early can be cured, nonetheless, a barrier is lack of information and knowledge about the disease progress, which might be confused with common diseases.²

Cancer is a complex and aggressive disease, with specialized treatment, which, even with updated technology and therapy, still faces a considerable death rate. The discovery of the disease is related to suffering, pain, and fear, requiring the attention of the team to the physical, psychological and social needs not only of the client but also of the family seeking the strength to initiate the therapeutic plan with safety and peacefulness.^{3,4}

A study conducted at the *Instituto Nacional de Câncer (INCA)* [Brazilian National Cancer Institute] showed that relatives of children bearing cancer have difficulty understanding or understanding illness. Only when they arrive at the institution, after the referral, then they can be included in the health system. They claim to be a very shocking and painful experience because it is a diagnosis very close to death.⁵

When the family receives the diagnosis that their child has cancer, it generates fear of the disease and the aggressive treatment to which the child will submit. The person accompanying the patient starts to dedicate himself exclusively to therapy, leaving aside his social life, employment and family.⁶

The parents also end up experiencing a great deal of suffering together with the child, feeling helpless before the diagnosis, which ends up bringing a great mismatch throughout the family structure. The family life is unstructured due to the necessities of change in the daily

routine for the adequacy of the treatment to be performed in outpatient clinics or hospitals.^{6,7}

Currently, the treatment for cancer is mainly associated with chemotherapy, which brings many concerns, uncertainties and especially pain during invasive procedures. The adverse effects of this therapy vary according to each diagnosis and treatment performed. The most frequent are as follows: apathy, anorexia, weight loss, alopecia, bruises throughout the whole body, nausea, vomiting, and indisposition with resting need.³

Even when the treatment is performed on an outpatient basis, without hospitalization, the family is vulnerable, since the treatment is usually weekly, with frequent visits to the ambulatory where the child undergoes various invasive procedures, with changes in an emotional state. Then, it is important to have the accompaniment of different family members, in order to not overload a single person.

Nursing care in pediatric oncology should be expanded, in other words, actions should not be limited to technical procedures, but extend beyond this: consider the emotional, cognitive and intuitive aspects so that the family and child develop skills to deal with the adversities imposed by the treatment.⁸

The difficulties pointed out above indicate the necessity for caring for the child and his/her family in a differentiated manner, seeking a more humanized care. In addition to meeting physical needs, it is fundamental to welcome their emotional and social needs.

To carry out this comprehensive care, it is necessary to know the entire framework of the child and his/her family coping with an onco-hematological condition. An important tool for the aforementioned involves the Nursing Process (NP), the Nursing Care Systematization (NCS) and the nursing consultation.

The NP is the instrument that allows adequacy in the nursing registers with the function of planning, organizing and directing their practice.⁹ It is composed of 5 stages, namely: history, diagnosis, planning, implementation, and assessment.¹⁰

The NCS aims to organize the nursing care to plan the activities to be performed, and also to guarantee to the patient the quality of care to be rendered.¹¹

The Resolution of the *Conselho Federal de Enfermagem (COFEN)* [Brazilian Federal Nursing Council] No. 272/2002 - revoked by the Resolution No. 358/2009 from the *COFEN* - addresses the NCS as being a private activity of the registered nurse in the various healthcare settings, which assists in the identification of health situations, which may contribute to the promotion, prevention, recovery and rehabilitation of the client's health, family and community.¹²

In 1993, the Resolution No. 159/93 from the *COFEN* that addresses the nursing consultation was approved. It should be a mandatory role for registered nurses at all levels of health care, whether public or private, in order to carry out a

health care plan that is adequate to health needs.¹³ In article 1 of the second paragraph, it is explained that the nursing process has the same meaning as nursing consultation when performed in households, schools, associations, institutions providing ambulatory services, etc.¹⁰

The nursing consultation is an interactive, systematic and educational activity, aiming to provide integral care to the child and his/her family, targeting to seek the health-disease context to either prevent or detect early health problems and guide care actions to be undertaken.^{14,15}

It is private to the registered nurse and used to promote health for the client, family, and community, then aiming at people's life quality. It should be performed in the first contact, providing educational and systematized actions with an emphasis on the organization of the work process, thus facilitating the promotion, diagnosis, treatment, and prevention.¹⁶

It is conceivable to say that the nursing consultation happens at all times during the care performed, but in the daily routine of the nurses, it is difficult to keep records of the actions developed in the full care. In order to perform quality work, nurses must develop their actions by conducting their professional practice through the application of systematization.

The ambulatory nursing consultation is crucial to conduct nursing care and treatment, as it allows a good bond of trust with the family and patients with oncological diseases, followed in a chemotherapy ambulatory.^{17,18}

Caring for children bearing cancer requires the nursing team to have technical and scientific competence to perform such activities. The planning of appropriate actions should meet your social, physical and psychic needs. This team is responsible for preventive measures and for the protection of injuries, to make an early diagnosis of complications of the treatment and to be sensitive to perceive the individualities and particularities of each one to face the challenges.¹⁹

One of the functions of the registered nurse in oncology, is to act as an educator towards the family in order continue providing care at home with quality and safety, then helping the family to cope with their problems. One of these major issues faced by the family is related to the Gastrointestinal and Hematological Systems. In solving these problems, the development of an educational tool for providing better family guidance, related to eating at home, can contribute significantly.²⁰

Therefore, the study's goal is to assess and understand the contribution of nursing consultation to the health education of the relatives of children undergoing ambulatory chemotherapy.

METHODS

It is a field survey with a qualitative approach, which was carried out in a Pediatric Onco-hematology Ambulatory from the São Paulo State countryside. Fifteen families who

had their children undergoing chemotherapy treatment attended the nursing consultation by the registered nurse from the aforesaid setting, thus allowing the data theoretical saturation.^{21,22}

Data collection took place over the period from March 3rd to July 8th, 2017, through a semi-structured interview, which occurred in two moments. In the first one, it was sought to identify the socio-demographic data in relation to the family and the child being treated to characterize the study participants. In the second moment, it was sought to explore the object to be investigated by the following guiding questions - "What is your view about the care provided by the nurse in this ambulatory?" and "Do you consider that the care provided by the nurse helps you caring for your child undergoing chemotherapy? If it is either the case or not, please, explain why."

The data were analyzed using the content analysis technique proposed by Bardin, following the steps of pre-analysis, material exploration and results processing, through the process of inference and interpretation of the meaning units.²³

This research followed the ethical precepts addressed in the Resolution No. 466/2012 from the National Health Council, and the project was approved by the Research Ethics Committee under the Legal Opinion No. 2,033,859 and the *Certificado de Apresentação para Apreciação Ética* (CAAE) [Certificate of Presentation for Ethical Appreciation] No. 61425016.7.0000.5413. And to guarantee the anonymity of the participating families, the letter "P" was used, followed by a numerical sequence, such as "P1", "P2", etc.

RESULTS AND DISCUSSION

Participants' profile

Among the 15 participating families, the main informant was the mother. The majority of those mothers belonged to the age group from 22 and 39 years old, lived in a common-law marriage, in their own house and dwelt with up to five people. As to professional activity, it was verified that nine mothers were from the home. Considering the 15 families, ten had family income between one and three minimum wages.

Concerning the children, the number was proportional between the sexes and the age groups, except for the ages between four and six years old. The diagnosis of leukemia was predominant. At the time of data collection, it was observed that most of the children were in therapy for more than a year, five of which were assisted weekly and four, every two weeks, by the nurse. It is important to highlight that, in the scenario of this research, the frequency of the nursing consultation is determined by the proposed chemotherapeutic therapy, as well as by the medical consultations for outpatient follow-up.

Central thematic category

The nursing consultation as a tool for empowering parents

This theme is permeated in this study by the recognition of the value of the nursing consultation as a tool for empowerment the participating families. The process of empowerment comes from the support, the way of welcoming and the relationship established between nurse, family, and child, which contributes to learning and safety in the process of caring for the child.

Fundamental: The nursing consultation was perceived by the participants of this study as an excellent and important tool that helps and strengthens the parents and the child/adolescent during the cancer treatment.

[...] it gives us the guidance we need. So, it is fundamental [...]. (P13)

[...] it's very good, it helped me a lot. It gave me a lot of strength, and so I found the service very good, great for me, both for myself and my daughter. (P1)

[...] assistance in treatment and care [...]. (P4)

Support: Parents realized that the constant stay of nursing professionals at this stage of the treatment helps them by supporting them, encouraging them and clarifying doubts in the correct way and facilitates the process of coping with the child's treatment.

[...] encouraging us to move on. You know, let's just say, I do not know. You know, we have support not only structurally but also psychologically... I do not know if this is the right answer or not, but you help a lot in the sense of facing the treatment. (P5)

Welcoming: The nurse's welcoming, approach, and dialogue helped parents feel emotionally stronger and overcome their fear of their children's diagnosis and treatment.

[...] I was afraid, [laughing]. I was scared because of this situation, right? But I felt very welcomed if it is in this sense. Very welcomed indeed. (P8)

They also addressed that when they received examples of positive treatment situations, they felt encouragement, faith, and hope for their children's recovery.

[...] it gave me a lot of psychological strength, you know. It's the way of the treatment, of course, the assistance helps us a lot, because we are well welcomed, so I felt like home [...] both, for me and for her [...]. The way to talk to me, to give me strength, to say how other cases were like, for instance. That a child had a great result,

that I could give you the same hope, that it was going to be all right, and that's what happened; so, I said that I went ahead, and thanks God, the result is here. So, it helped me a lot. (P1)

Having a conversation, supporting, sometimes I came sadly. [...] It helped me to have a little more hope, right, because we did not have it. It helped me in hoping for his healing. (P12)

[...] an environment that made us totally comfortable, very welcomed. (P7)

Trust and bonding: The participating families reported that the care given to the professional, received in the scenario of this research and the fact that they were listened, provided the establishment of a relationship of trust and bonding between the child, the family, and the team, which contributed for childcare safety.

[...] in addition to the professional service we were given, we also had the assistance that we can say, [...] we had a support [...] we created a bond [...] and the nursing professionals as well. This gave confidence to G. [...]. (P7)

They have illustrated that the relationship and the bond built between the family, the child and the nurses is established by the way of approach, through the attention given and the strategies they use to minimize the suffering of the child, such as playing with painful procedures.

Apart from the work you do, there is all the affection you give to children you take care and also to us. So, considering the guidance that you give and the work you do, I say you do a little more. (P13)

[...] for the attention, it's about playing, talking, [...] getting to talk about things. They teach, they also help a lot of people, right, [...]. when it comes to taking his vein, he's joking. For example, the other time he asked: not aunt, I want this one, aunt P. [...]. (P14)

Learning: All the participating families reported that the nursing consultation enabled some form of learning and that this enabled them to take better care of the child. Some reported that they were able to clarify all their doubts and acquire new knowledge to take care of the child in the face of the situation they were experiencing.

[...] I learned many things that I had no concept, you know! I learned this way until I took better care of it [...]. (P1)

I learned a lot, I learned what he can and what he cannot, when it comes to taking care of the bath, to wash the catheter. It helped a lot. I think it takes away all my doubts [...]. Oh, about chemotherapy, cooking (food preparation), the allergies he sometimes gives, the pains he has. (P2)

[...] it always clarifies all my doubts. [...] everything I need to know, like, what it takes to take care of my daughter or baby, I always ask. Then they explain to me... how to care about bacteria, about bruises, nail care, feeding always explain to people [...]. (P6)

[...] it helped me a lot. [...] always guiding me. [...] warning me to take care of him, that until then, I did not... and doctor put me like that. But I was not very aware, so I did not know much. So, it was more in this part guiding me how to take care, as it is, to take care of him in some areas that he cannot do, in these cases. (P3)

[...] helped in everything, [...] how many doubts I did not take with you! Can G. eat that? It's, like, at home, what I could do. The part of the hygiene she would have with her. It is, from the contact she would have with other people, what she could eat or not. (P7)

When reporting the knowledge acquired through the guidelines received by the nurse, they report that they learned to deal with the new situation, to take care of the child with an oncological complaint. They emphasize the learning process about the clinical and behavioral changes of the child when dealing with the illness.

[...] we learn to deal with situations, you know, even to observe. In case it is, how can I say, observing if what she is talking about is something that may have some, that she is really feeling something or that may have some danger or if it is, just to make a little advantage or something, right. And learn to take care of her, in some situations, right, because she was never a child that used to get sick. And now we go through all this, we learn to cope with the disease... to have patience, to know that many things, sometimes we think it's craftiness, but no, then we go to talk and see that it is something that is part of the symptoms, which is not craftiness [...]. (P10)

[...] he gave all instructions on how to treat and how to deal with the C. [...]. (P15)

They have reinforced that received guidelines made possible the development of their attention to the clinical changes and reactions of the child after the accomplishment of the chemotherapy, since the early identification of adverse effects of this treatment, prevents complications.

[...] at home you are always attentive to everything with her [...] a little paler, [...] she is more agitated or more stopped [...] when she is more agitated it is because of the chemo reaction, right? She had chemotherapy once, that when she got home, she was totally dizzy, [...] paying attention to her day-to-day. [...] so she had difficulties here, so chemotherapy is doing a different reaction, for example, because chemotherapy can cause a stroke, it can cause a lot of things. So, if you do not pay attention to what you're saying to us on a daily basis here, you know, it's complicated. (P5)

In the reports the importance of the guidance given by the nurse for the development of the care to the child also in the home emerges. This is reinforced mainly by maternal cognitive limitations.

[...] the symptoms she has, [...] I am a lay mother, about treatment, care, right. When you do, you begin to do chemotherapy, you start to stay alert to everything, to a cough, to a stuffy nose, for example, to fall when you have very low platelets is dangerous [...] it's at home I learned to give the smallest details, [...] it helps a lot at home, you know, day to day. (P5)

Participating families reported that the nursing consultation enabled them to learn about the disease, treatment and care actions of children undergoing chemotherapy. They emphasized the care with food, with the environment to which the child will be exposed, with the playful and physical activities that can be performed with the skin, and the measures of prevention of infection and accidents.

[...] it helped a lot, both in the feeding part what can and what cannot, what he can play with, what he cannot, about his illness that I did not know much about, and then they explained everything to me. [...] not what to eat. I did not know that I could not eat sausage, yogurt, many things he could not eat that I was giving, which I did not know. They helped me with playing, what he can and what he cannot do. They helped me a lot because I did not know I could not fall and get hurt. (P11)

[...] told me the treatment and how to take care of P, so that was fundamental. [...]. (P13)

[...] do not take her indoors, hygiene, cleaning, avoiding people who have some kind of illness near her, food, all kinds of food care, health, well-being, with everything - I learned here [...] taking care of the house, because I do not have to take care not only of her, but also of the house, of the environment, of the food and of those who are close to her. All this I learned here. (P15)

Some families reported that acquired learning goes beyond information about the disease, its treatment, and care of the child. They report that this new situation has awakened in parents the need to learn new talents, such as having more patience to care for the sick child, being more affective, caring for others and being more supportive.

[...] over there I learned a lot of good things here. Treating others well, caring for people, is having a lot of patience, a lot of patience, I learned a lot here [...]. (P9)

[...] I learned here that we have to help ourselves, that we have to support ourselves, that nobody is alone, that we are not alone in the world. So, that there are several mothers who go through the same situations better or worse than mine [...] we learn to be aware of the people around us, to be willing to help people more, so sometimes it's just a hug, sometimes it's only a conversation. This I learned here, everyone is together, where everyone is fighting together, and we needed unity and help each other. That's what I learned here. (P15)

Confidence: In the statements, it was evident that the experiences obtained through the care provided by the nurses enabled the development of the families' confidence to take care of their children undergoing chemotherapy treatment.

[...] we end up having more confidence, because we are seeing that she is really getting the care she needs. I get calmer [...] So, it gave me more confidence. Sometimes when I talk to you a little something, when I arrive and you say: how is M. doing? Sometimes it is something that I have not yet told the doctor about her, and sometimes I talk to you and you ahead to talk to him about our conversation, explains everything [...]. (P10)

Look, I came in here feeling down, you know? Without a direction, but I left feeling like another person, I left with my head straight, I left here powerful and, I left peaceful. (P1)

The empowerment of the participating families was revealed in this study by the grant that the nursing consultations provided during the treatment, and by the learning acquired in this space, which allowed the relationship between the people involved and the acquisition of confidence to carry out their children's treatment and care.

Empowerment is recognized as a social process of recognition, promotion and use of personal skills to recognize their own needs, solve their own problems and mobilize the resources needed to feel control in their lives. The following prerequisites for establishing the empowerment process are needed: developing bonding, commitment and responsibility between mother and child.^{24,21}

In the reports of the families participating, it emerges that the support and the welcoming received in the nursing consultations led to the overcoming of the fear coming from the process of illness and treatment of the child. They also recognize that this strategy has made it possible to encourage and hope for the recovery of their children.

The nursing consultation, when performed for chemotherapy treatment, is fundamental to face the diagnosis, guide about the therapy and the side effects. It is the right time for clarification and encouragement of treatment, establishing a relationship of trust and autonomy.²⁵

When revisiting the literature, it was identified that the diagnosis of childhood cancer found brings feelings of sadness, despair, impotence, and hopelessness to the family regarding the prognosis, due to the stigma of the disease and possibility of loss. This causes disruption and changes in daily family activities.^{26,27}

After confirming the diagnosis of cancer in the child or adolescent, the family members present reactions denying the disease with feelings of family destruction, requiring the support of professionals and especially the psychological intervention to alleviate fears and sorrows, then facilitating their acceptance and treatment.²⁸

In regard to the mothers' social life, the study by Costa *et al.*²⁹ showed that, by facing the child's illness, they presented changes in their professional, family and social life, leaving their jobs, domestic services, spouses, children to dedicate themselves exclusively to the sick child. They were isolated from the external environment and visits were restricted due to the low immunity of the child with high risks of acquiring infection.

For both the child and the family members, the discovery of cancer presents, in an invasive way, changes in the habits of family life, bringing disruption in the daily life with a single objective that is of treatment. The child undergoes withdrawal from social life, experiencing routine and invasive and painful procedures, side effects and frequent visits to pediatric oncology.³⁰

Signs of indignation, doubt, dread, and compassion were identified in a study to verify maternal feeling after the diagnosis was revealed. In this case, even in the face of this finding, they have shown themselves as a fortress to help their children.³¹

Faced with the need to take care of the child/adolescent, mothers feel obliged to change the habit of life leaving everything behind, prioritizing the integral care for their child. They say that at first, they feel lost, making them cling to faith and religion to keep the family structured and have the strength to support and assist the child in coping with the disease in search of healing.^{32,33}

Spirituality has been pointed out in other studies as an important tool for the process of acceptance, improvement of treatment, strengthening of the person and encouragement to face the disease with the expectation of cure.^{31,34,35}

It is by trusting in God that caregivers get support and hope in confronting child cancer in search of a miracle to cure the disease.³⁶

The results found in this study are corroborated by Marchi *et al.*³⁷ They affirm that cancer disease, although known by all, no one expects to have to deal with it in their family environment. When this happens, families experience feelings of despair and dread, which are only diminished by the contribution of nursing professionals in deconstructing the incurability of this disease.

During the beginning of treatment, the child and family feel fragile in an unknown place, where the need arises to approach the nursing team to hear and clarify their doubts, providing them with support, comfort, and affection.³³ These aspects were pointed out by the families participating in this study when they were attended by the nurse in the nursing consultation, as well as by the other professionals of the health team.

The treatment of cancer is very aggressive. As much as the family understands its importance and necessity, people are never able to face the changes anticipated in this therapy that causes suffering for all. Therefore, the results of this study are reiterated by families when they recognize the importance of the role of the nurse and the team in supporting and educating in a humanized, integral way using clear communication to understand the guidelines.⁶

The participating families pointed to the nursing consultation as an important strategy in this learning process to care for the child bearing an oncological condition and undergoing chemotherapy treatment. In their statements, they portray that this care provided not only the clarification of doubts, but also learning to deal with the new situation experienced and with the reactions of the child during the treatment period.

Nursing professionals have a fundamental role in supporting and clarifying doubts vis-à-vis the treatment, guiding the prognosis and the possibility of cure.³⁷

Nursing becomes more present in the life of the child/adolescent/family throughout the chemotherapy treatment, providing a better quality of life due to its role - clarification, aid, and demystification of the disease.³⁸

The nursing team is considered of utmost importance to the family and to the child by being close and accessible to integral care, providing necessary guidance, clarification, and care. The longer the therapy period, the greater the affective bond established with the team, and the confidence in the treatment.³⁹

Within a multidisciplinary team, the nursing team is indispensable to assist the patient in all their health needs, individually and humanized, including the family in the care process and adopting measures of interventions to minimize the child's suffering.³⁰

The child, with the immune system deficient due to illness and treatment, presents changes in the daily routine affecting more the emotional aspect. In the face of special care, they stop attending schools, playing with friends and

eating what they like. This fact causes changes in the daily routine of the child and his/her family to adapt to the new routine, and to meet the child's needs.⁴⁰

In this process of adaptation, families pointed out that the educational action developed by the nurse during the nursing consultations made it possible to learn about the clinical changes and reactions of children after chemotherapy, about feeding and care for the environment, as well as activities to prevent infection and accidents.

The literature reinforces that the nurse is a key part of finding the means, together with the family, to keep the child active in the games that do not present risks to his life and complications to the treatment imposing on its limits and responsibilities, since the children are restricted mobility due to the side effects, indisposition, and the implanted devices that are used for infusion of the medicaments.⁴¹

As an educator, nurses are fundamental in guiding parents about the need for food changes that the child should make while undergoing chemotherapy, with safety and quality.²⁰

The results found in this study reinforce the importance of nursing consultation in the preparation of the family for home care during the course of chemotherapy. Nursing professionals, especially registered nurses, should perform the role of educator by developing resources and strategies for the care of the child and the family members who accompany the treatment. The guidelines have a focus on care after chemotherapy with information on how to behave in the face of the complications of the disease and the side effects at home so that there is support and adequate assistance.^{42,43}

The guidance manual on side effects and specific care during chemotherapy treatment is made available and directed to each family member, during the nursing visit before the first cycle of chemotherapy, proving to be effective and necessary during the treatment, mainly ambulatory, for the withdrawal of doubts and continuity of care at home.⁴⁴

Other studies, such as the one by Cruz *et al.*,⁴⁵ point out guidelines that should be directed to parents and/or family members during treatment, such as the drug to be given, side effects and care to avoid infection, especially after chemotherapy.

These guidelines on the therapy to which the child/adolescent will be subjected and its side effects, such as nausea, alopecia should not be restricted to the family. It is necessary to include the child, especially the school-age child, because she has the capacity for understanding. This will facilitate the acceptance of the disease and adaptation of adornments to improve its self-image, such as wearing a scarf, cap, and hat.⁴⁵

In a study performed by Sarmiento *et al.*,⁴⁶ it was evidenced the importance of conducting guidelines in the presence of the child before starting treatment, such as personal hygiene care, food care, side effects and the possibility of cure, since professionals knowledge and language, providing better understanding and minimizing negative effects during therapy.

The child, knowing the form of his therapy, can be prepared to face the invasive procedures to be performed, developing personal techniques to minimize his/her suffering in order to obtain the better quality for his/her therapy. On the other hand, he/she may have different feelings knowing the need for treatment and not want to give continuity due to suffering.¹⁹

The families also pointed out how valuable it is to build the relationship and bond between family, child and professional, the approach and attention given to the child in nursing consultations, because the nurse uses the toy as a tool to minimize suffering in relation to the invasive and painful procedures to which their children were frequently subjected during chemotherapy.

The benefits of play for a child's development is not only considered a strategy to ensure qualified assistance, but a legal right. Nursing must have the knowledge that it is a legal part of nursing care and that it is fundamental for integral and humanized care.⁴⁷

For a humanized care with the children during the painful procedures it is essential to explain what is going to be accomplished, in what form and what its necessity, allowing during the application of the technique, it can play and talk to avoid repeated punctures, thus favoring a less traumatic cancer treatment.³³

The therapeutic toy during the procedures to be performed with children can be an instrument capable of reducing their fears and anxieties, thus allowing a less traumatic and peaceful treatment during their ambulatory stay.⁴⁸

With the use of playful activity in children/adolescents undergoing chemotherapy, its importance is demonstrated by allowing trust and a better bonding with the child, adolescent, and family, by bringing a humanized care, reducing fears and traumas, making the environment more comfortable with benefits to the therapy.⁴⁹ Unfortunately, there are also some difficulties in the use of this instrument due to the great demand for care, the deficiency of specialized employees, adolescents who are in the technology age, professionals with no affinities, and still lack of implementation and training for the staff.

The therapeutic toy is a playful strategy used to provide confidence, joy, decrease pain, fear and relieve stress during the procedure to be performed. It is fundamental to create links with the team and especially with the nurse to reach the health needs of the child/adolescent.^{50,51}

In some studies, it has become evident that some techniques of distraction, massage, art therapy, touch therapy, music, physical activities and hypnosis present a satisfactory result for the reduction of pain and anxiety in children and adolescents undergoing cancer treatment during the painful procedures.^{52,53}

To assist oncological children, health professionals should be alert to qualified listening, and also to patient and family health needs, welcoming and providing

emotional support throughout the treatment to strengthen the bond and decrease the impression of the diagnosis by designing cure.^{39,54}

The participants of this study also pointed out that empathy, communication, welcoming, and support were important tools that made it possible to alleviate the weaknesses of the treatment process and strengthened the bond of trust between the family, child, and staff during nursing care assistance.²⁶

According to Santos et al.,³⁹ one of the important roles of the nursing team is to maintain a humanized and differentiated care with the patient/family in order to ease the pain suffered throughout the process.

In contrast, there are factors that prevent more humanized care for cancer bearing children. One of these is exemplified by the lack of understanding or lack of cooperation during the care to be provided due to stress and family problems in the face of therapy.⁵⁵

The nursing team that works in a pediatric oncology ambulatory must keep up-to-date to contribute qualified care, strengthening the link between the child/adolescent, the family and the professional to allow a contextualized and humanized action.⁵⁶

The nurse has, as its attributions, guidelines and continued education with the goal of improving the health of the population, efficient assistance to the client with cancer and ambulatory chemotherapy. It is up to the nurse, who is the coordinator, to manage so that all of the team participate and seek improvement in the quality of care and safety.⁵⁷

The results of this research corroborate the process of empowerment proposed by Gibson,²⁴ which was carried out in three stages. In the first moment, the contact with the reality, in other words, the diagnosis of cancer of the son and the chemotherapeutic treatment. In the second moment, the family develops the critical reflection of the lived situation and identifies its potentialities, fragilities and the available resources for the care. And, in the third moment, he becomes confident to advocate for the child, to interact with the health system, to negotiate care and to partner with the health team. This trajectory contributes to the development of safety and maternal ability to care for the child.

Considering the aforesaid, there is a proven nursing consultation and the knowledge acquired through this tool has awakened support, security and autonomy in the families for the care of their child, a priori fragilized by the diagnosis and the chemotherapeutic treatment. With the empowerment process, the family feels more self-reliant and able to take better care of the child, especially the mother. They can gain a sense of mastery and ability to choose the suitable approach for taking care of their children.²⁴

CONCLUSIONS

Herein, the empowerment of the participating families comes from the process of care provided by the registered nurse during the nursing consultations. They were able to underline the importance of consultations, support, welcoming, bonding and trust, which are factors that have contributed significantly to the process of caring for children undergoing ambulatory chemotherapy.

The nursing consultation was confirmed as a space that offered the dialogue with the families, then making it possible to acquire knowledge concerning the diagnosis, treatment and way of coping with the oncological child, with more autonomy during the treatment and the process of caring for the child, even at home.

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