

## The use of playing by the nursing staff on palliative care for children with cancer



*O uso do brincar pela equipe de enfermagem no cuidado paliativo de crianças com câncer*

*El uso de jugar del equipo de enfermería en cuidados paliativos de niños con cáncer*

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### ABSTRACT

This study aimed to describe ways of using play by the nursing staff on palliative care of children with cancer and analyze the facilitators and barriers of the use of playing on this type of care. Qualitative, descriptive research developed on November 2012 with 11 health professionals, in a public hospital of the state of Rio de Janeiro. Semi-structured interviews and thematic analysis of the information were conducted. The use of playing before procedures was highlighted as a facilitator on palliative care. The child's physical condition, one's restriction, resistance of some professionals and the lack of time for developing this activity, made the use of play harder. We concluded that playing enables the child with cancer, in palliative care, a humanized assistance, being fundamental to integrate it on the care for these children.

**Descriptors:** Palliative care. Pediatric nursing. Play and playthings. Neoplasms.

### RESUMO

O estudo teve como objetivos descrever as formas de utilização do brincar pela equipe de enfermagem no cuidado paliativo de crianças com câncer e analisar as facilidades e dificuldades do uso do brincar neste cuidado. Estudo qualitativo descritivo, realizado em novembro de 2012, com 11 profissionais de saúde em um hospital público do estado do Rio de Janeiro. Foram realizadas entrevistas semiestruturadas e análise temática das informações. A utilização de brinquedos antes da realização de procedimentos foi apontada como facilitador no cuidado paliativo. A condição física da criança, sua restrição e, também, a resistência de alguns profissionais, bem como a falta de tempo para o desenvolvimento dessa atividade, dificultaram o uso do brincar. Conclui-se que o brincar proporciona à criança com câncer em cuidados paliativos um atendimento humanizado, sendo fundamental integrá-lo aos cuidados a essas crianças.

**Descritores:** Cuidado paliativos. Enfermagem pediátrica. Jogos e brinquedos. Neoplasias.

### RESUMEN

Este estudio tuvo como objetivos describir las formas de utilizar el jugar por parte del personal de enfermería en los cuidados paliativos para los niños con cáncer y analizar las ventajas y dificultades de la utilización de jugar en el cuidado. Estudio descriptivo cualitativo, realizado en noviembre de 2012, con 11 profesionales de la salud, en un hospital público en el estado de Río de Janeiro. Se realizaron entrevistas semiestructuradas y el análisis de la información. El uso de los juguetes antes de la realización de los procedimientos fue designado como facilitador en los cuidados paliativos. La condición física del niño, la moderación, la resistencia de algunos profesionales y la falta de tiempo para desarrollar esta actividad, obstaculizan el uso del juego. Llegamos a la conclusión de que el juego proporciona al niño con cáncer en cuidados paliativos servicio humanizado y es esencial para integrarlo con cuidado.

**Descritores:** Cuidados paliativos. Enfermería pediátrica. Juego e implementos de juego. Neoplasias.

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## ■ INTRODUÇÃO

Cancer is the name given to a group of diseases that have in common the uncontrolled proliferation of abnormal cells that invade tissues and organs, and may cause metastasis, this is spread to different regions of the body<sup>(1)</sup>.

According to estimates of incidence of the National Cancer Institute, only in 2012 11,530 new cases of cancer in children and adolescents up to 19 years were expected<sup>(1)</sup>. Despite the severity of the disease, it is known that around 70% of children and adolescents can be cured if early diagnosed and treated in specialized centers<sup>(1)</sup>. This possibility of healing is due to the technological advancement in different treatment modalities such as surgery, chemotherapy and radiotherapy.

Even with all progress, unfortunately, not all children can achieve cure. When the chance of cure is away, he/she is diagnosed as beyond the possibility of cure and thus, the goal of treatment becomes palliative. The transition from clinical to palliative care should be gradual, being important a clear communication, established from a trust relationship, considering emotional aspects and respect for the child and her/his family<sup>(2)</sup>.

A German study showed that, in recent years, children in palliative care spent more time at home and kept their family life. However, there is still need for advancements to provide added comfort and relief of suffering of these children<sup>(3)</sup>. In the United States, there is a diversity of models in providing palliative care for children with cancer, with the notable importance of including the family in the care and respect to spirituality, culture, ethical aspects, the maintenance of good communication and control of symptoms<sup>(4)</sup>.

The national scientific literature indicates that palliative care aimed at children should be conducted with a view to provide comfort, welfare, safety and improved quality of life with measures to relieve pain and suffering<sup>(2,4)</sup>. Furthermore, we must create opportunities to childhood own activities, such as playing and playthings.

Playing is an important activity in the child's life and is essential for her/his motor, emotional, mental and social development. It is the way he/she communicates and actively express her/his feelings, anxieties and frustrations<sup>(5-8)</sup>. It is clear, therefore, that care in pediatric oncology brings challenges for the nursing staff, it requires, in addition to material resources, professionals who are prepared to meet the particularities that permeate the child's universe<sup>(6,9)</sup>.

Unfortunately, playing sometimes goes unnoticed when it comes to children with cancer, due to the disease severity and complexity of its treatment<sup>(6)</sup>. Moreover, for those in palliative care, little is known in the use of this re-

source as an ally of nursing care<sup>(5)</sup>. It is believed, however, that nursing should promote comfort and quality of life to the child without the possibility of cure, creating means to recruit a comfortable and pleasurable environment where playing is included.

Thus, the study questions were: (a) how may the nursing staff use playing in palliative care for children with cancer? and (b) what are the facilitators and barriers of playing in palliative care for children with cancer? We established the following objectives: (a) to describe ways of playing by the nursing staff in palliative care for children with cancer and (b) to analyze the facilitators and barriers of playing in the palliative care.

## ■ METHODS

This study was extracted from the research: Playing in palliative care for children with cancer in the perception of the nursing staff<sup>(10)</sup>, developed by the Center for Research and Study on Comprehensive Health of Children and Adolescents from the Fluminense Federal University. This is a descriptive study with a qualitative approach<sup>(11)</sup>. The scenario was a ward of hospitalization in a university pediatric hospital in the city of Rio de Janeiro, which is a referral for childcare throughout the state. The inpatient unit has forty-six beds, with a Nurse for every six beds, dedicated exclusively to children with hematologic cancers (leukemia and lymphoma), whether or not under palliative care.

The nursing staff in this ward has eleven nurses on duty and two nurses during the day, besides forty-two assistants and technicians distributed in shifts.

The study subjects were: eleven professionals of the nursing staff, including four nurses and seven nursing technicians. Inclusion criteria were: professionals with at least one year of experience in the ward, so they would have time together with the children and they could talk about their experiences. We excluded professionals who were on vacation, medical leave or any other type of leave from the hospital ward.

The number of participants was determined during the process of data analysis and the organization of statements, which allowed the identification of data saturation, ie, the existence of recurrence of ideas, pattern behaviors, practices and worldviews<sup>(12)</sup>.

Data collection was conducted in November 2012, through a semi-structured interview<sup>(11)</sup>, with the following questions: 1) How do you believe that the nursing staff can play in the palliative care of children with cancer?; 2) What are, for you, the negative and positive effects of playing with children in palliative care with cancer?; and 3) What are the

barriers and facilitators that you believe could happen in playing activities for children with cancer in palliative care?

The interviews were recorded with an mp3 player, with prior permission of the subjects. The anonymity of participants was ensured using alphanumeric codes to identify them. Thus, the nursing technicians were identified with the letters NT and nurses with NU, followed by a number in sequence ordering of the interviews.

The study was approved by the Ethics and Research Committee of the Hospital, under protocol number 13/12. All the recommendations of Resolution 466/12 have been met and the participants have integrated in the study only after signing the consent form.

The participants' statements were transcribed and data were analyzed through thematic analysis, following the steps of the analytical method: initial reading, material exploration, processing and interpretation of results<sup>(11)</sup>.

For the operationalization of the analysis process, after transcribing the interviews, we began reading the material for its exploration. Subsequently, the classification of statements were conducted by colorimetric method. After this step, we pooled the data, generating the specificity of thematic units.

## ■ RESULTS AND DISCUSSION

The information obtained in the interviews were grouped according to thematic axis in two thematic units: recognizing ways of playing by the nurse staff in palliative care for children with cancer and recognizing the facilitators and barriers of playing in palliative care for children with cancer.

### Recognizing ways of playing by the nurse staff in palliative care for children with cancer

The nursing staff used playthings, taking them to the bed to reassure, entertain and guide the children before carrying out painful, complicated and traumatic procedures, because it makes the child calmer and hence the procedure is facilitated. They also used the plaything to teach the child about what is happening to her/him:

*Playing can be conducted in many ways, we can take the toys to the bed distracting the child before a medication or a complicated procedure [...] makes the child calmer [...] it is easier to perform the procedure (NT2).*

*I think it can be used in different ways, especially when carrying out very traumatic procedures, or as a way to ex-*

*plain, teach and make the child understand the language of what is happening (NU5).*

Nurses should provide opportunities for children to play, being appropriate to their stage of development. During their care, there are many resources, such as drawings, paintings, music, toys, among others, used to minimize the experience of illness and hospitalization<sup>(13)</sup>.

One measure that may be used by the nursing staff in order to minimize trauma in hospitalized children regardless of being in palliative care is the therapeutic play, which should be handled by the child in order to better understand the performed procedures.

Therapeutic play is a resource for the health professional to approach the child's world, giving the nurse a better understanding of the needs of the child, assisting in the preparation of children for therapeutic procedures and allowing a stress relief<sup>(14)</sup>.

According to the interviewees, there is often lack of time by the nursing staff to play with the child. However, it is imperative that playthings is incorporated into daily nursing care activities because of the importance of play for hospitalized children, especially for those who find themselves with cancer in palliative care, since comfort and well-being becomes the main focus for this type of care. Thus, the subjects indicated that they take the children to the recreation room to play with volunteers, college students, storytellers and doctors of joy:

*Even the nurses and technicians do not have time, there are always ways to make the child play, such as taking them to recreation [...] In addition, volunteers always come here to play with them (NT10).*

*Here at the hospital, we have a recreation room, where children play [...] we also have storytellers who come here, the doctors of joy, college students who do plays and play with them (NT1).*

Some hospitals have initiatives such as the "Doctors of Joy", which are part of a civil society, a nonprofit organization that visit hospitalized children in order to provide joy, making them more willing and improving their health condition.

In addition to the "Doctors of Joy", we highlight the hospital playroom, which in recent years has proven to be a reality in the hospital ward and is presented as a way of playing in the use of palliative care for children with cancer. According to the law number 11,104, the hospital playroom became mandatory, it is a space provided for educational games and toys, where children learn to share toys, history, emotions, joys and sorrows about the condition of

hospitalization<sup>(15)</sup>, which promotes comfort, welfare, safety and relieves to the suffering of children in palliative care.

Along with the hospital playroom, some hospitals are attended by storytellers and volunteers who make themselves available to go to hospitals to bring a little joy and fun for the hospitalized children.

Storytellers perform reading books, and this is an activity that provides physical and mental well-being. Reading is considered therapeutic and should be practiced in hospitals, with the aim of relieving the suffering of patients during hospitalization<sup>(16)</sup>.

It is essential that the nursing staff, directly linked to the care provided to hospitalized children participate in the activities proposed by the "Doctors of Joy", storytellers and volunteers. Thus, they will have a moment of fun with the children, approaching them, gaining their trust and respect.

A major goal of palliative care is adding quality to the days of hospitalization, emphasizing the emotional, psychological and spiritual<sup>(5)</sup> care, these, which can be improved with playing and collaborating to a child's development, as it provides welfare, comfort and, joy.

### **Recognizing the facilitators and barriers of playing in palliative care for children with cancer**

For the nursing staff, playing left the child less agitated, facilitated their work, interaction and communication with the child:

*It makes the child less agitated, facilitating team work and increasing the child's trust in the nursing staff (NT2).*

*It is the best way of communication between the child and the staff (NT1).*

*Playing facilitates interaction with the staff, helping in our work (NU8).*

Playing helps in communication between nursing and child during care and especially in the preparation of a painful procedure<sup>(7)</sup>. Thus, it provides better communication and interaction, facilitating the work developed by the nursing staff with the child with cancer in palliative care.

Nursing care in the context of palliative care should consider the patient as unique, complex and multidimensional: biological, emotional, social and spiritual. This type of integrated and humanized care is only possible when the nurse makes use of sensitive communication with the child and their family, bringing up their concerns and fears that they need to work, live and overcome<sup>(2,5)</sup>.

Health professionals reported, however, that the physical condition of children in palliative care could reduce the desire to play:

*What I see in here is that when the child is very ill, very ill, near to death, playing is not important to her/him, she/he gets no reaction in relation to play, she/he wants their parents presence, someone to love and feel protected (NT 10).*

*There are children who are very depressed, we cannot include them in the play, sometimes volunteers and storytellers arrive and they do not even want to get close, they say, I am sleeping (NT 6).*

Based on the statements, it is noticed that when the child is at the stage of sadness and depression, the presence of parents or significant family member is more important and valued by her/him than playing.

It is known that among the strategies of care with family members of these children, we include the incentive to stay longer together, promoting trusting relationships with parents and involvement of healthy siblings' in child care<sup>(4)</sup>. In this sense, integrating play in family relations of children with cancer in palliative care emerges as an essential component of nursing care.

The recognition of the stages of death and dying in the daily care of professionals favors actions to assist the child and her/his family<sup>(2)</sup>. These sentences are part of the grieving process and is essential to the child's will to be respected at this time, where the play can cause several benefits. It is the duty of the professional to stimulate play, thus, it should not be imposed to the child to participate in activities in which they are not comfortable with.

Nursing care in the terminally ill child should be guided by actions that seek to meet their bio-psychosocial needs, taking into account the innumerable demands that may arise at this time<sup>(17)</sup>.

When speaking of the restrictions to play, professionals highlighted that some children cannot get out of their bed or have a limitation that prevents them from playing as their peers, leaving them angry and sad:

*Difficult would be the restriction on the bed, when the child cannot get out of bed or interact in play as they want, so they get very angry (NT 11).*

*Children who have certain limitations and sees some children playing in a way that he/she cannot makes him/her sad (NT 3).*

The play is a necessity of childhood and the means by which it develops in all physical, emotional, cognitive and social aspects, naturally. During the period of hospitalization of the child, beyond difficulties that the disease itself brings, the conditions of hospitalization and illness can affect the child integrity<sup>(18)</sup>.

Given this fact, among the possible strategies used with the child to face some restrictions is the play, especially reading, which can be used anywhere, being these normal practices of her/his time of life<sup>(8,18)</sup>. Besides reading, drawing and painting are excellent strategies to be used by children with restrictions to play<sup>(13)</sup>.

Interviewees also reported about the resistance of the members of the nursing staff for playing in caring for children in palliative care:

*The nursing staff can be the barrier, because some professionals find unnecessary to worry about it and become resistant to include playing in child care (NT 2).*

*Barriers may come from the staff that sometimes find play unnecessary, they give attention to the child, make the procedures, medication, and do not talk to the child and they think that playing in their care is silly (NU 7).*

The professionals in the nursing staff, often, in order to meet the demand and the physiological need of the child, seeking the recovery of his/her health, devote little or no part of his/her time to the psychological and social issues of the hospitalized child<sup>(18)</sup>. However, we know that play is important for children with cancer<sup>(19)</sup> and the nursing staff must recognize this need, providing means for its realization and incorporating it in nursing care.

Another aspect that complicates the use of the play is the lack of time by the nursing staff:

*Time is also a barrier, because the staff have many things to do, so they do not have time to play with children (NT 2).*

*The biggest barrier is the time, sometimes you want to play, become more for that child, but we have plenty to do, we work on chemotherapy, administration of medication, puncture assistance finally as much as we want to play, we do not have time for this (NT 6).*

Regarding the lack of time, interviewees highlighted that, regardless of nursing staff desire to play with the child, they have no time. Similar findings were found in a study of children in child outpatient waiting room, in which the interviewees acknowledged the benefits of playing for

children. However, lack of time was one of the reasons described which hindered the realization of play<sup>(20)</sup>. Thus, it becomes imperative to reorganize the work process in health facilities, so the children's play is not taken as a secondary aim in healthcare practice with children, but accepted as an integral part of the care of these little ones.

Although the nursing hospital routine requires that activities are carried out within a certain professional standard, it can be said that playing as a form of palliative care for the child with cancer has the potential to facilitate the work of the nursing team. The play provides the communication and interaction with the child in pursuit of not only meeting their physiological needs, but the child's world and thus, allowing the integrality of care.

## ■ CONCLUSION

This study aimed to describe the ways of playing by nursing staff on palliative care for children with cancer and analyze the facilitators and barriers of playing in care.

Many ways of playing were highlighted, among them, bringing playthings to the bed to calm, entertain and guide children before performing procedures. Furthermore, taking the child to a recreation room, where there are storytellers, volunteers and "Doctors of Joy". Finally, strategies were used in order to provide playing for all children, despite their restrictions.

Our research has shown that playing by the nursing staff on palliative care for children with cancer facilitates communication, interaction and helps in relieving tension of the child to perform painful and traumatic procedures and thus provides humanized care.

As barriers, physical restrictions for playing, as well as the fact that the child does not feel like playing at this stage were highlighted. There are also some resistance from some professionals to use playing; they do not think it is important. Another barrier was the lack of time for professionals to engage in the activity of playing.

In summary, it is considered that the nursing staff recognizes the role of play as a form of care for children with cancer in palliative care, but despite this, the barriers of its use were greater than the facilitators. In this sense, the play is still not widely used in a structured and organized manner, which implies the need for thinking and acting by the nursing staff, so they need to be oriented to play as a way to give the children with cancer a more humane and comprehensive care in palliative care.

As limitation of the study, we highlight the scarcity of publications related to the use of play for this specific group of children in palliative care to expand the discus-



sion and comparison with other researches. In this sense, we suggest new research should be developed addressing the issue in the perception of other subjects, such as family members and the children themselves.

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