

## Rescuing the pleasure of playing of child with cancer in a hospital setting

*O resgate do prazer de brincar da criança com câncer no espaço hospitalar*

*Rescatar el placer del niño que juega con cáncer en el espacio de hospital*

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### ABSTRACT

**Objective:** to dimension spaces and people that act on playing of children with cancer in outpatient treatment. **Method:** qualitative research developed with the creative sensitive method. A total of twenty two family members of seven children with cancer in outpatient treatment at a public hospital in Rio de Janeiro participated of this research. Data were generated in the family members' homes, from September 2011 to May 2012. **Results:** after the diagnosis of childhood cancer, there was a change of scene and in the people who interact and play with children. Hospital has a central place for it, since children discover the pleasure of playing in this setting. **Conclusion:** the health care professional, especially nurses, who work on hospital care needs, should develop the ability of facilitate playing and therefore, enable care that promotes childhood development.

**Key words:** Play and Playthings; Cancer; Child Development.

### RESUMO

**Objetivo:** dimensionar os espaços e as pessoas que atuam no brincar das crianças com câncer em tratamento ambulatorial. **Método:** pesquisa qualitativa, desenvolvida pelo método criativo e sensível. Participaram 22 familiares de sete crianças com câncer em tratamento ambulatorial em um hospital do Rio de Janeiro. A produção de dados ocorreu nas residências dos familiares, no período de setembro de 2011 a maio de 2012. **Resultados:** após o diagnóstico do câncer infantil, houve mudança nos cenários e nas pessoas que interagem com as crianças nas brincadeiras. O hospital assume lugar central e, nele, as crianças descobrem o prazer de brincar. **Conclusão:** o profissional de saúde, especialmente o enfermeiro que atua no cenário hospitalar, precisa desenvolver habilidade para ser facilitador da brincadeira e assim proporcionar cuidado promotor do desenvolvimento infantil.

**Descritores:** Jogos e Brinquedos; Câncer; Desenvolvimento Infantil.

### RESUMEN

**Objetivo:** dimensionar los espacios y la gente que trabaja en el juego de los niños con pacientes ambulatorios de cáncer. **Método:** investigación cualitativa desarrollada por el método creativo y sensible. Eran 22 familias de 07 niños con cáncer que reciben tratamiento em el ambulatorio de un hospital de Río de Janeiro. La producción de datos ha ocurrido en los hogares de los familiares, a partir de septiembre 2011 a mayo 2012. **Resultados:** con el diagnóstico de cáncer en la infancia, hay un cambio de escenario y de las personas que interactúan con los niños en los juegos. El hospital ocupa un lugar central, allí los niños descubren el placer de jugar. **Conclusión:** los profesionales, especialmente las enfermeras que trabajan en el ámbito hospitalario deben desarrollar la capacidad de ser un facilitador del juego y con ello proporcionar atención promotora del desarrollo del niño.

**Palabras clave:** Juego e Implementos de Juego; Câncer; Desarrollo Infantil.

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## INTRODUCTION

During treatment of childhood cancer, the child is subjected to several tests, prolonged hospitalization and several therapeutic modalities, such as chemotherapy, radiotherapy and surgery that sometimes provoke limitations in physical and psychological disabilities<sup>(1-2)</sup>.

The constant visits to the treatment center for hospitalization as well as outpatient follow-up, expose the child to pain and suffering, and may still cause disruptions in school and move them away from social and family life, which can interfere with their ability and desire to play<sup>(1,3)</sup>.

Playing is a child's need and means, for her/him, the means by which they develop themselves in all aspects, whether physical, emotional, cognitive and social<sup>(4)</sup>. The maintenance of playful activities for children with cancer is recognized as an important tool for improvement of positive coping regarding the disease and treatment<sup>(1,5)</sup>.

Despite the benefits of playing for the child with cancer, the impact of the disease and treatment leads to deprivation of this activity. In particular, active play/games are part of these restrictions and are gradually extinguished from day to day, due to their clinical fragility. Children need to stop playing with their pets at risk of acquiring a disease due to low immunity that occurs at certain periods of the treatment, depriving them even more<sup>(1)</sup>.

Based on the above, it is clear that cancer brings limitations to the life of the child that can interfere with their development. It is important to remember that in addition to promote children's development, playing is also a source of pleasure for the child, it is when she/he, for a moment, forgets the difficulties of the illness and treatment and what they are going through to enter a fantasy world<sup>(6-8)</sup>.

The professional in charge for the child must, along with his/her family, pursue strategies to maintain the best possible quality of life during treatment, highlighting the need to play as fundamental in any stage, both for their individual development as during the illness process.

Before the planning of possible strategies to be used in order to maintain playful activities and the promotion of child development for children with cancer, it is necessary to make an approach to the reality of their lives, so as to know how playing activities are developed during treatment.

Literature points out some benefits of playing for the welfare of the child with cancer, among them, the better acceptance of the treatment and the invasive and painful procedures, facilitating the continuation of child development and better coping with the illness condition<sup>(1,3,5-8)</sup>. However, little is discussed about the maintenance of play during outpatient treatment, spaces and people who are active in playful activities for these children.

To support playing as child development promoter, this study was based on the development theory stated by Vigostky<sup>(4)</sup>. For him, the importance of toys is clear in all age groups, since it contains all the trends of development.

One of the central points of this theory is that higher psychological functions have a sociocultural origin and emerge

from basic psychological processes of biological origin<sup>(4)</sup>. Thus, social interaction between children in different social spaces, such as family and school, is critical to the development of more elaborated psychological functions.

The higher psychological functions are referred to as those which are not innate, in which human beings develop through their relationship with the world and with others, it is a typically psychological human functioning, such as our capacity for planning, voluntary memory and imagination. They differ, therefore, from the basic psychological processes present in small children and animals, such as automatic reactions, reflex actions and simple association, which are of biological origin<sup>(4)</sup>.

To better understand the child development process, Vigostky<sup>(4)</sup> classified three development zones: the real development zone, which is related to what has been learned, or what the child can do alone; the potential development zone, related to what can be learned with the help of others, whether an adult or a more experienced child and the zone of proximal development, the gap between the two development zones already mentioned. In this interval, new functions are potentially being developed and new learning is created, as it is, therefore, a dynamic space<sup>(4)</sup>.

The toy creates a zone of proximal development in children, namely an area amenable to transformation by learning<sup>(4)</sup>. The adult's role in promoting child development, through the zone of proximal development, is to act by creating conditions for children to play, encouraging and proposing playful activities as something present in the child's life.

The playfulness, so important for the mental health of human beings, is an aspect that deserve attention from families and professionals who care for children in cancer treatment as it is a time when the child expresses herself/himself. It is also a right of every child to exercise emotional relationship with the world and the people around her/him. It also allows a service that provides care and respect according to their needs and peculiarities, and allows them to enjoy some form of recreation, which is their right and guaranteed by the Brazilian National Council for the Rights of Children and Adolescents (CONANDA)<sup>(9)</sup>.

On this basis, we formulated the following guiding question: what are the spaces used to play by children with cancer in outpatient treatment?

## OBJECTIVE

This research was designed to dimension the spaces and people who lead playful activities for children with cancer in outpatient treatment.

## METHOD

Qualitative research, developed through the creative sensitive method (CSM), which has its foundations based in the following triad: group discussion, participant observation and creativity and sensitivity dynamics<sup>(1,10)</sup>.

During the dynamics of creativity and sensitivity, the research participants elaborated a production of artistic type that is mobilized by a generating matter of debate related to

the objectives of the study. This artistic production motivates participants to talk through what they produce and hence evoke their values and beliefs relating to matters whose interests are common to the group<sup>(1,10)</sup>.

Based on the recommendations of the method, we used the dynamics of creativity and sensitivity called "speaker map". The guiding question which generated the debate was: in which spaces and with who does 'child's name' play with when she/he is hospitalized?

Participants were 22 family members of seven children with cancer in outpatient's treatment at a public hospital of reference for the treatment of disease, located in the city of Rio de Janeiro.

The selection and recruitment of participants occurred in the pediatric oncology clinic where children were being treated and the production of data took place from September 2011 to May 2012, in the homes of the children.

The inclusion criteria of the subjects in the study were: a) family members of children in outpatient cancer treatment at the time of recruitment; b) families living in the city of Rio de Janeiro or in neighboring cities with up to 100 km distance from the treatment center. Exclusion criteria were: a) the families of the children who resided in support homes, since the study has focused their home environment; b) family member aged less than 12 years old; c) family presenting psychiatric problem, as this could interfere with the reliability of the research data.

To guarantee anonymity, participants were identified with numbers organized by the participation in the research.

As a criterion for termination of field work we used the sampling process of theoretical saturation. In this case, the researcher stops collecting data when she/he finds that interaction in the research field is no longer offering new elements to mark or deepen the theory of the research object<sup>(11)</sup>.

The study was approved by the Research Ethics Committee of the institution in which children were receiving cancer treatment (CAAE Protocol 0016.0.007.00-11). All participants signed a consent form after being informed of the study objectives and agreed to participate.

For data analysis, we used the method of the French Discourse Analysis (DA)<sup>(1)</sup>, taking as a basis the transcribed texts generated in the creativity and sensitivity dynamics. Upon completion of the analysis of the empirical material, two thematic units emerged, namely: deprivation of the pleasure of playing and the rescue of the pleasure of playing.

## RESULTS

### The deprivation of the pleasure of playing

When family members started talking about playing in the child's life, they highlighted that with the diagnosis of childhood cancer, he/she was removed from their social life due to the need for hospitalization and chemotherapy and thus they, had ceased interacting and playing in two important social spaces, the family home and the school.

In the family environment, the illness interferes with social interaction and playing among siblings, as the demands of treatment reduce the time of coexistence among them:

*With treatment he stays in hospital for a long time [...] I hardly see my brother so we don't play. (Family member 7)*

We add that the Family member 14 brought in the discourse the problems experienced by the healthy sibling of a child with cancer, suffering deprivation of contact with the hospitalized brother, and with his mother, who monitors the treatment of the sick child:

*When he is undergoing chemotherapy we do not see each other because he is in hospital with our mother [...] I do not see my brother nor my mother. (Family member 14)*

In addition to the repercussions about playing in the family, among siblings, cancer interferes with social interaction and in playing at school environment. With this, their teachers and school friends fail to act in the zone of proximal development of the child, helping her/him to acquire new skills.

It is possible to observe by the discourse of the Family member number 10, that treatment implies staying away from school, which is where the child has contact with her/his peers to play:

*She (child with cancer) is not going to school because of the problem (cancer), she just stays at home [...] she has no children to play with, she just had them at school. (Family member 10)*

In addition to the child school leave due to treatment period, the sequels left, as the difficulty to sit, can be limiting for the return of the child to school life:

*She went to school but became ill [...] she had a little problem because a surgery was done to remove the tumor (osteosarcoma in the bones of the pelvis and coccyx), [...] she does not sit right in those school chairs, she is in pain and feels sick. (Family member 19)*

### The rescue of the pleasure of playing

After talking about the spaces where children are deprived with the diagnosis of cancer, family members reported those where they play during outpatient treatment. The hospital highlighted the regularity and consistency in the child's life:

*During one year of treatment, he was about 5 months at home and the rest in hospital, then at home he hardly played [...] he only plays in the hospital playroom. (Family member 13)*

In the discourse of Family member 13, we observed that the cancer treatment time and the duration of hospitalization interfere with the engagement of children in playful activities, as it also determined the space where they happened. In a period of 12 months, the child was hospitalized seven months and stayed only five months at home. Consequently, the child played more in hospital than at home.

In the hospital, the space of the playroom provides opportunities to play because it offers logistics, with toys, games and computers. So the hospital is a place that provides social

interaction with adult volunteers and with children living the same illness conditions:

*Where does she plays when she is not in hospital? It's easier to talk about the time she spends in the hospital. Here at home she hardly plays. She loves playing there in the hospital playroom with the toys they have there and also with voluntary staff. (Family member 19)*

Other family members have highlighted, besides the hospital, the home support to cancer treatment and parties hosted by hospital volunteers, as other scenarios to play, with which it maintains group ties for social interaction and promoting child development.

Therefore, being on the child support home or hospital for cancer treatment provides the possibility of interaction, play and rescue the pleasure of living and to live with their peers:

*After he became ill, sometimes when he is in the hospital or sleep in the support home, he plays with other hospitalized children, that is why I drew the home support and children staying there. (Family member 7)*

The rediscovery of the pleasure of playing and the child's potential to interact and play with peers living the same situation of health and disease in a children's party, organized by hospital volunteers, provides surprise and happiness to family members:

*It had been a year since she had played the last time, the first time she played after this treatment was at a party that hospital volunteers organized ... I was surprised and happy to see how she played with the children's hospital at the party. I was amazed, amazed! (Family member 22)*

In the rescue of play, the child begins to have contact with new plays, different from those of before the disease process and learn new ways of playing to keep their development process mediated by playing:

*She loves playing in the hospital, there she learned a few plays that she had not learned at home, she did not know. She learned how to assemble a puzzle, playing video games, playing computer and mobile games. The hospital staff gave her leaves to draw and paint and then she was taking an interest in this type of game, in the past she did not play any of that. (Family member 17)*

The playful activities learned by children at the hospital became part of the set of playful activities made at home. Thus, the hospital space plays were taken by the child to her/his home, and the child rescued the pleasure of playing in family:

*After she played puzzle in the hospital, I bought a game and she taught my grandson to reassemble as well, now they play together puzzle here at home. (Family member 16)*

## DISCUSSION

The research results showed that cancer and its treatment limit the social interaction among children in two contexts

that are critical to their development, their family environment and school.

In the family, childhood cancer acts changing the routine and family dynamics, interfering with relationships and interactions among family members and affecting relationships in different ways. Family members begin to experience long periods of hospitalization, frequent hospitalizations, aggressive therapy, interruption of daily activities, financial adjustments, distress, pain, suffering and the constant fear of the possibility of death<sup>(12-13)</sup>.

Still in the family context, there was emphasis on the repercussions in the relationship between siblings, who have less time living together and hence play less. Moreover, healthy siblings experience deprivation of maternal interaction, since, in most cases, it is the mother who follows the routine treatment of children with cancer.

These results are in agreement with a study that pointed out that healthy siblings often find it difficult to understand the absence of the mother. It is important to pay attention to the effects of childhood cancer on them to minimize adjustment difficulties, as they are often neglected during childhood cancer experience in the family as the focus of health professionals, family and friends is on the sick child. They are likely to develop depression, anxiety, behavioral problems and post-traumatic stress. Nurses should be aware of the negative impact of cancer in healthy siblings and include them in their plan of care<sup>(14)</sup>.

In the school context, it was observed that the demands of treatment had repercussions in the school leave, so the children lost their conviviality and the possibility of social interaction with peers and friends.

The school leave occurs due to frequent hospitalization, signs and symptoms, treatment and physical limitations<sup>(1)</sup>. However, it is essential for professionals, including nurses, and family members, to understand the importance of maintaining this link to favoring the maintenance of child development during cancer treatment. The nurse must, along with family, seek strategies to reduce school leave time, child maintenance in hospital classes, learning and encouraging the school to reintegrate the child into regular school as soon as possible.

Even when the child already has clinical conditions to return to school, the after-effects resulting from cancer and its treatment can lead to adaptations of the environment needs to meet the child's needs. The non-adaptation of the school may delay the child's reintegration into the school environment.

The non-adaptation of the school setting for the child's disability depicts the indifference of the Brazilian educational system, because when these needs are disregarded, the school functions as a social exclusion mechanism and prevents the pleasure to live and play, which are crucial to children's development. In this case, a contact of hospital staff with the school, before the child can return, is considered essential for the success of this step<sup>(15)</sup>.

For some children, the hospital can be seen as a place that refers to suffering and stress<sup>(3)</sup>, but our findings show that it is also a major playing site, and constitutor of rescuing the pleasure to play. These data are consistent with a study published in 2009, in which the hospital cannot be understood by the child or by ill adolescents as an environment of only pain and suffering<sup>(16)</sup>.

It is always necessary to find a spaces that can be availed for the development of recreational and educational activities, since hospitalization should not interrupt children's development<sup>(13)</sup>.

In recent years, the quest for humanization of care has been growing, which can be reached through several strategies. When it comes to children, one of countless ways to humanize the care is to promote and provide what every child like and need to do, play<sup>(7)</sup>.

At the hospital setting, the primary site of play was the playroom and the ability to interact and play in a space intended for this purpose favors the expression of their emotions, and help them understand their experience and help the promotion of overall health<sup>(17)</sup>. In the playroom, they learn new games that are compatible with their process of illness and treatment. From this perspective, playing in the hospital setting is seen as a therapeutic space that promotes the continuity of the child's development<sup>(18)</sup>. In addition, playing in the hospital helps the improvement of child's quality of life, softening the impact of the illness in the psychic and physical spheres<sup>(17)</sup>.

In a study conducted with children as subjects, it was reported that activities in the playroom were very important to the hospital life, for the distraction that these resources provide prevented boredom<sup>(19)</sup>. We realized by the discourse of family members who, in this space, through interaction with other children in the same illness condition, she/he begins to understand her/his limitations and gives meaning to new playful activities, incorporating them in their daily lives.

Another aspect revealed in the study is that to play and interact with the children in the same condition of illness and voluntary workers, the child undergoing cancer treatment rediscover the pleasure of living. These data are confirmed when the authors point out the benefits of the incorporation of playful activity to help children relieve the burden of cancer treatment, which is a way to promote holistic and quality care<sup>(6)</sup>. With this, children with cancer, aided by the playful activities, are slowly transforming their existence and rediscovering themselves<sup>(3)</sup>.

Among the new playful activities learned from the illness and contact with the hospital environment, we can cite electronic games and video games, computer games and even games using cellphones. With respect to virtual games, in interactive spaces children can choose those that meet their physical and mental abilities, kind of disease, and the therapeutic goals. They also have the ability to practice leisure activities, which in real life they may be unable to perform due to the complexity of the disease and treatment and its adverse effects<sup>(8)</sup>.

We have seen that the care model centered in treatment makes the institution implement volunteering policies, delegating the volunteer group activities aimed to play, to meet the demands of playing children, without, however, having to invest resources in this as a significant activity and therapy for the child. Volunteering should be complementary to the policy and not their own institutional policy. Respecting playfulness in childhood is a fundamental right under the Statute of Children and Adolescents and need to take center stage in the hospital investment policy.

We know the importance that volunteers have in the performance of children's playful activities, however, having

specific professionals for this purpose would be interesting. A study conducted with children's caregivers in chemotherapy found that they considered important to have a specific professional to play with the kids<sup>(7)</sup>.

The lack of professional service for this purpose can lead to underutilization of spaces for play, according to a study published in 2010. The author states that, although there is a place for this practice, playroom was not explored in all its potential<sup>(19)</sup>.

Institutions that can provide specific human resources for the playroom should be encouraged to do so. However, having a person dedicated only to this activity should not fragment the child care, leaving the responsibility to play only for these professionals. Joining efforts rather than dividing them is necessary<sup>(20)</sup>.

Besides the benefits of having professional service designed to play with the children, it is desirable that any health professional who intends to work with them, should incorporate playful activities on their care process, as play is inseparable from the child. We also need professionals to understand that this activity is an inherent part of the care provided by us<sup>(20)</sup>.

## FINAL CONSIDERATIONS

The illness caused by childhood cancer involves changing spaces and the people who interact socially with children in playful activities. The hospital is an important place, rescuing the pleasure of play and child development. For children with cancer, the hospital is not only a place for pain, stress and treatment of disease, but also the main place for fun, joy, living and learning.

In the hospital playroom, children with cancer have contact with playful activities that require less physical effort, such as puzzles, videogame, games in the mobile device and drawing, incorporating them into their daily lives. These playful activities are different from those performed before the illness, but they are also promoters of child development.

Social interaction in the hospital playroom, at parties organized by hospital volunteers and support house for child with cancer have made these spaces acquire visibility as promoters of child development mediated by playful activities.

The rediscovery of the pleasure of playing, as well as providing benefits to the biopsychosocial development of the children, and for family members, when they realize the child reacting and playing, they also feel encouraged to continue the fight against cancer.

An important finding of this research was the fact that while children are in outpatient treatment, that is, are not hospitalized, the hospital remained as the main place of playful activities. This shows that the institution should encourage child development and comprehensive care, and not just performing dressings.

The health professional, especially the nurse, who works in the hospital setting, needs to develop skills to be a facilitator and promoter of playful activities in the hospital environment in order to provide more individualized and comprehensive care for the child, as this activity is essential for child development.

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