

The (im)possibilities of play for children with outpatient cancer treatment*

As (im)possibilidades de brincar para o escolar com câncer em tratamento ambulatorial

Las (im)posibilidades de jugar para el escolar con cáncer en tratamiento en ambulatorio

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ABSTRACT

Objectives: To identify the mediators of play in the lives of children with cancer in outpatient treatment, and review the opportunities of using them, considering the limitations imposed by the disease and the treatment. Methods: Qualitative research, according to the creative and sensitive method implemented; it was focused on group dynamics "Playing on stage." Twelve (12) children participated, who were being treated for cancer in an outpatient service at a hospital in Rio de Janeiro. Results: Two themes emerged: mediators of the possibilities of play (instruments and signs), and mediators of the possibilities of play in social interaction (people and environment). In situations of impossibilities and restrictions, the children found alternatives to overcome the obstacles and to continue playing, within their abilities. Conclusion: The professionals who care for these children must seek knowledge about the needs the children have (as human beings in development), identifying situations that may determine the possibilities of playing and, along with the child and family, transforming them into other possibilities. Keywords: Games and toys; Child health; Pediatric nursing; Oncology

RESUMO

Objetivos: Identificar os mediadores do brincar na vida da criança com câncer em tratamento ambulatorial e analisar as (im)possibilidades de utilizá-los diante das limitações impostos pelo adoecimento e tratamento. Métodos: A pesquisa qualitativa implementada segundo o método criativo e sensível teve como eixo a dinâmica grupal "O brincar em cena". Participaram 12 escolares em tratamento ambulatorial para câncer, em um hospital no Rio de Janeiro. Resultados: Emergiram dois temas: mediadores das (im)possibilidades do brincar - instrumentos e signos e mediadores das (im)possibilidades do brincar na interação social - pessoas e ambiente. Nas situações de impossibilidades e restrições, os escolares superaram obstáculos e reinventaram alternativas para continuarem brincando dentro de suas possibilidades. Conclusão: Os profissionais que atendem essas crianças devem buscar conhecimentos acerca das necessidades que elas tem enquanto seres em desenvolvimento, identificando situações que podem determinar (im)possibilidades de brincar e, junto com a criança e família, transformá-las em outras possibilidades.

Descritores: Jogos e brinquedos; Saúde da criança; Enfermagem pediátrica; Oncologia

RESUMEN

Objetivos: Identificar los mediadores del jugar en la vida del niño con cáncer en tratamiento en ambulatorio y analizar las (im)posibilidades de utilizarlos delante de las limitaciones impuestas por la enfermedad y tratamiento. Métodos: Es una investigación cualitativa, implementada según el método creativo y sensible; tuvo como eje la dinámica grupal "El jugar en escena". Participaron 12 escolares en tratamiento de cáncer en ambulatorio, en un hospital en Rio de Janeiro. Resultados: Emergieron dos temas: mediadores de las (im)posibilidades del jugar (instrumentos y signos) y mediadores de las (im)posibilidades del jugar en la interacción social (personas y ambientes). En las situaciones de imposibilidades y restricciones, los escolares superaron obstáculos y reinventaron alternativas para continuar jugando dentro de sus posibilidades. Conclusión: Los profesionales que atienden a estos niños deben buscar conocimientos acerca de las necesidades que estos clientes tienen considerando que son seres en desarrollo, identificando situaciones que pueden determinar (im)posibilidades del jugar y, junto con el niño y la familia, transformarlas en otras posibilidades.

Descriptores: Juegos y juguetes; Salud del niño; Enfermería pediátrica; Oncologia

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INTRODUCTION

Under the denomination of cancer there is a group of diseases that have in common the proliferation, out of control, of abnormal cells. Currently, it is considered an important cause of morbidity and mortality among children. In Brazil, the incidence of this disease grows approximately 1% per year. The types of the most frequent cancer types are the leukemia, the central nervous system tumors and, the lymphomas, which represents from 0,5% to 3% of all types of tumors affecting most of the population⁽¹⁻³⁾. With the scientific advancement in treatments (chemotherapy, radiotherapy and surgery), the possibility of cure can reach 70%, for some types if diagnosed early and treated in specialized centers.

With the oncological treatment evolution, in the last decades, the cancer that affects children stopped having the acute characteristic of inevitable death; it has become now a chronic disease with possibility of cure. This change contributed to have a broader view in the form of considering the children with cancer — that goes beyond biological and physiologic aspects and now includes the psychosocial dimension⁽³⁻⁴⁾.

When a child is diagnosed with cancer, the child and his family face a period of adaptation to the new reality and, for that reason, the dynamic routines of the family are modified. The child starts having special health care needs, due both to the course of disease and treatment, which are characterized as a long period. During this period, the child is submitted to several examinations and prolonged hospital admissions for treatments (chemotherapeutic, radio-therapeutic, surgical, medicinal, and others) that sometimes provoke limitations and physical and psychological deficiencies. The comings and goings to the treatment center (for admission or outpatient treatment) disturbs the child's routines, exposing him to suffering and pain, interrupting the school activities, removing him from the social and familiar environments and, interfering with his capacity and wish of playing.

The literature⁽⁵⁻⁷⁾ has been pointing more to the benefits of playing in the well-being of the children hospitalized with cancer instead of those being treated in the outpatient service. When the treatment in the outpatient service takes a central place in the life of the child, he remains more time at home than at the hospital, changing, in that way, the social space of playing. Meantime, little is known about playing when the child remains at home and in other spaces of the community, including the outpatient treatment spaces. These multiple spaces contribute to the social interaction of child-child and adult-child and create opportunities to manipulate instruments (toys and games) which would promote the development: cognitive, social, motor and linguistic (signs), among others that are socio-cultural mediators important⁽⁸⁾ for the well-being of the child.

The development of the child happens in the relation with the world, in the social interaction, in the handling of instruments and in the apprenticeship of the signs meaning that belongs to a specific cultural group. These elements work like mediators of development and of evolution of the human race. The instrument has the function of regulating the actions on the objects and enlarges the child's capacity of acting on the nature, helping him to realize concrete actions. On the other hand, the sign is thought as a psychological instrument that has the function of assistant the children on his psychological activities, serving of help for maintaining the attention and the memory and, for accumulate information⁽⁸⁾. Consequently, the act of playing has an important role in the child development, since it reunites a set of mediators, turning the basic functions (psychological elementary) into more elaborated functions (psychological superiors)⁽⁸⁾.

The child development consists of the child capacity of moving from an elementary level to a more elaborated level where he can realize tasks and understand what is going on his environment. This transformation is gradual and happens in the relation of the child with the mediators, such as: the social interaction of the child with the environment and the use of signs and instruments culturally determined⁽⁹⁾.

The act of playing is a necessity for the healthy child and also takes part in the process of becoming sick; through the playing the child creates, recreates, becomes socialized, learns and develops⁽⁵⁻⁶⁾. This need does not stop existing when the child becomes ill⁽¹⁰⁾, however it can pass unnoticed when this aspect is related to children with cancer in the hospital environment and also in his home or community, all of this product of the seriousness of the disease and the complexity of the treatment.

OBJECTIVES

To identify the mediators of playing in the life of the child with cancer being treated in an outpatient service, and to analyze the (im)possibilities of children using these mediators considering the limitations imposed by the sickness and treatment.

METHODS

The qualitative research was developed in accordance with the creative and sensitive method, taking as a fundamental base the dynamic-group of creativity and sensibility. In this type of dynamic-group, the participants of the research prepare an artistic production mobilized by a subject that generates a debate related to the object of study. The production gives incentive the participants to talk about themselves through what they produced, evoking his values and beliefs in subjects that are of

common interest to the group(11-13).

The researcher assumes the presenter's role with the help of a assistant who registers (verbal, photographic and phonographic) the meeting events. When the dynamic-group event ends, the data registered are put together with the researcher's notations that were written down on his field diary to compose the primary research report.

Children in school age are able, through games, of acting in a cognitive sphere that depends on external motivations mediated by the act of playing⁽¹³⁾. According whit this, was created the dynamic-group "playing on the stage", that privileges the playing and the gaming compatible with the level of development and the conditions of health and disease of the research participants. Therefore, the dynamic-group was the combination result of two techniques: the "Modeling" that used mass to model and "My house... my world" with drawings and miniature toys⁽¹³⁾.

The elaboration of the children's artistic production was orientated to generate debate by means of the question "At my home I play of... with... in...". The preference for the expression "at my home" was due to the fact that a child with cancer when is being treated in an outpatient service, confirms that is not interned in the hospital.

The dynamic-group "Playing on the stage" was implemented in five moments. First, the participants presented themselves and were identified with badges (including the researcher and her research assistant) who made contact with materials to be used in the preparation of the production. In this moment, the researcher promotes an environment of welcome and comfort, in a way that everybody could see each other and share the available toys in the space of playing. The materials used by the children were colorful pens and crayons, wax chalk, leaves of paper A4, leaves of brown paper, miniature toys and, mass of modeling. In the next step, it was explained the objective of the dynamic-group and what were the expectation regarding the group production, based on the question that generated the debate (written in a paper for all to acknowledge). The third moment was destined to prepare of the artistic production; each child worked individually on his production; the group shared everything that was in the production space; each one presented the produced material, expressing collectively his experience with the game and with playing. The last moment was dedicated to the socialization of the productions' meanings, when also took place the data validation. The meeting was registered with a voice recorder (tape type) and the productions were photographed with a digital camera.

The children who participated in "Playing on the stage" were those who met the following criteria: being a schoolboy and being treated in an outpatient service. There was no discrimination by gender; were excluded from

the study the children who were residing in support homes, since the approach was centered in the experience of playing in the home environment and in the community.

To guarantee the anonymity, the schoolboys were identified with the initial letter of his name. When there was more than one name with the same alphabetic letter, was added a number according to the participation order in the dynamic-group. It was adopted the letter "A" to identify the girls and "O" for the boys.

The scenery of the group-dynamic game was the outpatient department of pediatric oncology at a well renowned hospital for cancer treatment, located in the city of the Rio de Janeiro. During all field work stages, were carried out four meetings, totalizing 12 children (seven girls and five boys), on the days and times in which they were waiting for some type of professional service (medical consultation, laboratory tests, and chemotherapy or radiotherapy treatment). The first meeting happened in the waiting room of the ophthalmology doctor's office of and the next ones in the meeting room of the outpatient department.

After the project research approval by the Research Ethics Committee of the institution (Protocol 023/08), was made contact with the workers and people in charge for the sector to explain the nature of the research, the objectives, the methodology and mode of operationalization. Subsequently, it was visited the sectors with purpose of become acquainted and interact with the team that work in those services; it was observed the waiting room, the recreation room, the chemotherapy room and the doctor's office.

To register and selection of the subjects, we checked the consultations schedule for the week and waited for the child and his relative arrive, on the day scheduled for the service, moment in which was made the first contact. First, was presented and explained, to the responsible, the research objectives, the methodology, the guarantee of anonymity, the voluntary participation, the way in which the meetings will take place and in which circumstances it will occur (group-dynamic game mediated by toys). All people that was contacted expressed the wish of the child participation in the research. After that, the child was invited to participate explaining to him, in a language appropriated to his level of development and cognitive capacity, the same aspects discussed with his responsible.

The next step was to make a list of the names and contacts of the voluntaries, writing down also the day in which the child would return to the hospital. Subsequently, was established a telephone contact - or in person in the outpatient service, with the responsible for the child, aiming to compose four groups. Before beginning the dynamic-group, it was explained the

Consent Form to the responsible for the child, before his signature; this was in accordance with the ethical precepts defined by the National Council of Health (Resolution n.°196/96)⁽¹⁴⁾.

For analyzing the data, it was adopted the French Discourse Analysis⁽¹⁵⁾; taken as the base of analysis the texts produced in the dynamic-group of creativity and sensibility. The option for this theoretical frame was because the approach of children when playing is part of his daily life and the meanings are produced from their personal experience.

The method to analyze the children discourse was done in stages: initially, in the textual discourse was eliminated superficial aspects, in other words, the linguistic surface (raw empirical material) was turned into discursive object (linguistic materiality and enunciation time determination). The analytical reading of the discursive object pointed to indicative clues in the analytical devices that are constituent of the discourse in the text, with this stage was to find the discourse in the text, with this the analyst becomes prepared to configure the discursive formation. Is understood as discursive formation a given ideological formation - in other words - a given social-historical conjuncture determines what can and must be said⁽¹⁵⁾.

Subsequently, the discursive object was converted into the discursive process. In this stage, the different discursive formations are linked to ideological formations that govern these relations. In this way, was achieved the constitution of the discursive process, responsible for the effect of meaning produced in the symbolic material⁽¹⁵⁾.

RESULTS

The process analysis led to the categorization of two subjects: mediators of the (im)possibilities of playing (instruments and signs) and mediators of the (im)possibilities of playing in the social interaction (people and environment).

Mediators of the (im)possibilities of playing - instruments and signs

One schoolboy pointed out, simultaneously, to the vest and the skate as instruments mediators of the possibility and the impossibility of playing. His deformity thorax condition (after removal of lumbar neurofibroma) implicates in the continuous use of the vest for correction of the posture during the week. The physiotherapist recommended that he can play with the skate on weekends when, during the day, can remains without the vest.

... of skate, I play with the skate only on weekends because I

am left without the vest. (Schoolboy R)

The use of the thoracic vest promotes physical restriction and interferes in the necessary body mechanics to play with the skate, condition in which resides the impossibility of playing with the skate as a mediator instrument of playing along the week.

The conversation between the schoolboy (N) and the field researcher (first author), presented new impossibilities.

The treatment disturbs, even once, I stayed with pain while I was playing... I was feeling pain sometimes, but now I don't feel it any more. (The schoolboy N)

And when you were feeling pain, how was it to play? I asked to N.

I didn't want to play because my belly was hurting. (The schoolboy N)

The treatment as the origin of pain was something that confused the child desire of playing. Though there was attempt to keep on playing even in the cases of weak and occasional pain; when the pain was sharp he was not able of playing. In other words, the intensity of the pain was a determinant of the possibility or impossibility of playing; when the pain was weak he kept on playing, and when it was strong he didn't play because it was hurting his belly. Being so, the pain becomes like a sign that imposes limits to the desire of playing of the child with cancer.

In Vygotskyana perspective, the pain was the internalized sign origin of the displeasure, suffering and restriction. It represents the child experience and the way in which he gives new meaning to suffering and to the restrictions imposed on his way of living, including there the act of playing as origin of pleasure. The pleasure of playing is the opposite of the displeasure produced by pain.

In the following dialog, the schoolboy M and the field researcher (first author) spoke about the chemotherapeutic treatment like a factor that generates the impossibility of playing.

Oh! Then you can go out to the street every day? I questioned M. For sure! Except when I am doing chemotherapy... my aunt picks up us (him and the brother) and, sometimes, in the weekend, when I'm not doing chemotherapy, we sleep there - in her home. (The schoolboy M)

The chemotherapeutic treatment was a sign that restricts the child to go out from house, to play in the street or to sleep in the home of the aunt, as he was used to do regularly on weekends. Apparently, he appropriated of other experiences (speeches already

heard) and, internally, he reconstructed them, saying that during the cycle of chemotherapy he must stay away of potential sources of infection, due to the immunosuppression caused by medicine. So, resting was an additional sign containing a new meaning for the impossibility of going out from the house.

The discourse analysis - considering what was not made explicit - indicates that when the child is doing chemotherapy, he does not sleep at the aunt's home, doesn't play in the street, and doesn't interact with other children who don't belong to his familiar nucleus. Consequently, his activities of playing are restricted to the house environment and mediated by people who participate of his most immediate familiar circle.

Mediators of the (im)possibilities of playing in the social interaction – people and environment

The schoolgirl A2 pointed out that, before the cancer, his mother allowed her to play out of the house (at the home of a friend) and now she doesn't let her any more.

Before, (becoming ill) my mother allowed me to play at Caca's house (fictitious name), now she doesn't let me anymore. (The schoolgirl A2)

The mother of the schoolboy M also worries about his well-being, she does not allow him to play out from house during the outpatient chemotherapy phase of treatment.

I cannot go out from the house because she (mother) is afraid of the misty because I have a low immunity... For example, if tomorrow (Saturday) I begin with the chemotherapy, I cannot go out to the street because of the low defense (neutropenia). Then, I stay at home and my mother let me get my books until Wednesday (the boy has a protocol of five days of chemotherapy). (The schoolboy M)

For both children, the motherly protection represents a preoccupation with the well-being of the child and the prevention of infection, due to the low immunity resulting from the cancer treatment.

Before and now are time marks that reveal the motherly protection that in exchange restricts the number of people with whom the child interacts socially and also the number of spaces where the playing can occur.

The motherly protection prevents the schoolboy(M) going out from the house, because during the chemotherapeutic treatment phase increases the child probabilities of becoming ill due to the low immunity, a common averse effect in these cases.

In this sense, the exposure to the mist and the cancer treatment, acquires two different new meanings in the child imaginary. The first was built in the mother-child interaction and the second in the child interaction with the health professionals and in the perception of the medicine effects on his body. In both circumstances, the protection was an internalized sign, in the child imaginary, that pointed the impossibility of playing, due to the interaction restrictions with people and with the environments where the playing happens.

The schoolgirl A points out to the impossibilities of having social interaction when playing in other environments, besides his own house. The playing in other environments is possible on the days in which she visits her grandmother's home. There, she meets with other children and plays and interacts with them. In the meantime, in most occasions, she plays in the environment of her own house and interacts with her sister.

In that way... I have the house of my relatives, but I cannot go out, so... my father works, my mother... there is no way I can go out, but when I go to my grandmother's house, I can play there, but I play more at my own home with my sister. (The schoolgirl A.

The impossibilities of playing were highlighted in the interdiscourse and not in what was said by the schoolboys, such as: motherly protection, restriction of environments and, reduction of people with whom the child can interacts; the possibility of playing is stated as an alternative of inclusion of playing and having fun, in the life of the child. In this sense, the limitations imposed by low immunity (due to cancer treatment) and the limitations of the family to accompany the child in playing outside the home environment were offset by playing with people of her own family (his sister at the home environment) and with the engagement in reading, activities that require a lower level of energy.

DISCUSSION

Among the outstanding mediators of the impossibility of playing were the physical restriction, the interference in the body mechanics, the pain and, the chemotherapeutic treatment. The vest was the instrument mediator of the physical restriction and of the interference in the body mechanics to play with the skate.

The physical restriction, related to the disease and to the treatment, promotes alterations in the rhythm of life of children with chronic diseases, being necessary to increase the cares so that the child doesn't suffer falls and as a result become hurt. The prevention of accidents of this nature obstructs the exacerbation of the symptoms and the worsening of the disease state⁽¹⁶⁾. In this sense, the temporal dimension and the negotiations with the physiotherapy compensates the wish that children have of playing, with the new possibility of having fun in weekends, when he was allowed to be left without the vest.

The pain internalization, as an adverse effect in the treatment, was defined by the remembrance of the pain and by the displeasure of playing. The pain worked in an unconscious process, transforming an internal element (the lack of motivation to play) in an external element (getting involved in playing in accordance with the intensity of the pain). The pain was a source of displeasure, of lack of incentive, of discomfort and of limitation for the schoolboy engaging in playing. For the child with cancer, the pain and the discomfort produce as a result a state of anxiety, compromising physical, emotional and behavioral aspects, also damaging his general state or exacerbating the state of pain⁽¹⁷⁾.

As a consequence, the more intense were the pains, the bigger the impossibility of playing; the less intense were the pains, the bigger the possibility of getting involved in activities.

Along with the development of the child, gradually the experiences with the world and the people are internalized and, with that, a transformation takes place in his behavior. The internalization is the internal reconstruction of an external operation⁽⁸⁾. In this sense, the chemotherapy was internalized as an impossibility of playing out from the house or moving in spaces out of the house, during the week or in the weekends.

In the impossibility of playing on the street environment, due to the motherly protection, translated as resting during the chemotherapeutic treatment, appears the possibility of playing with the sister and the brother, also of reading books, in that way the school boy fills voids left by the impossibility of playing out of the house and with other children.

The environments (street, friends' house, relatives' house and others) received a new meaning in the (im)possible alternatives of playing, originated by the restriction of opportunities and the social interactions in the act of playing. The restriction of the people with whom the child can be with (as a result of the motherly protection), the risk of becoming sick (due to low immunity) and, the accidents and the pain, limited the child contacts with his equals and also imposes restrictions to the social interactions with those relations.

The school phase is the period when the child becomes associated with colleagues of the same age group. The sense of belonging to a group is of extreme importance for children of that age, their games demand physical and intellectual skills and creation of fantasies. When he becomes ill, the relatives are more selective regarding the risks presented by the games that could affect the physical integrity of the child. Consequently, there are social relations ruptures of the child with his equals, also removals of friends with whom he was used to play (when he was

not sick), and the avoidance of inappropriate games in his new way of life. This condition may favor the isolation of the child and makes it difficult to interact with peers who are not suffering a similar process of disease, or even those with whom he maintained contact before the onset of cancer^(16,18-19).

The schoolboy - treated in an outpatient service for cancer - learns, by socially interacting and by relating with other environments, to accept the impossibilities of playing and the need to adapt to play within the field of the possibilities, also to surmount obstacles, assuming a sociocultural behavior appropriated to environment in which he survives⁽⁸⁾.

CONCLUSIONS

The schoolboys regard the (im)possibilities, mediated by the motherly protection, as a care to the maintenance of the health and as a reduction of the risks resulting from the treatment. This protection was determined by the cultural environment of the family and by the professionals of health with whom the child interacts socially. For that reason, the house and the hospital environment will provide the instruments (skate, vest, book) and signs (the treatment, the pain, the physical restriction, the low immunity, among others) of cultural mediation, which were internalized and transformed into behavior in the child relation with playing.

To playing in the street or in other environment is necessary to consider the (im)possibilities and restrictions that the child will have when engaging in play. Confronted with the impossibilities, the schoolboys will seek opportunities, reinventing alternatives (such as reading and playing at grandma's house) to fill the void left by the occasions in which they don't play the usual games.

The team of nursing, due to its direct contact with the child and his family during the hospital admission, as well as in the outpatient department, need to include in the set of instructions for at-home child care, the themes playing/games, and not only focusing on the assistance and guidance on subjects related to the disease and treatment.

This study focused on some aspects of the (im)possibilities of playing in children with cancer, being treated in an outpatient service, in the context of their homes and community. We believe that other studies about the development of children with cancer are necessary and very important. Having in mind that the material used in the analysis was the discourse of the children, and that, they didn't point to relations between the types of playing and its adaptation (or not) to the condition of becoming ill, it is necessary to deepen this knowledge through studies that could establish these articulations.

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