

EXPERIENCE OF CHILDREN WITH CANCER AND THE IMPORTANCE OF RECREATIONAL ACTIVITIES DURING HOSPITALIZATION

A EXPERIÊNCIA DE CRIANÇAS COM CÂNCER NO PROCESSO DE HOSPITALIZAÇÃO E NO BRINCAR EXPERIENCIA DE NIÑOS CON CÁNCER EN EL PROCESO DE HOSPITALIZACIÓN Y AL JUGAR

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ABSTRACT

The present study addresses childhood cancer, hospital-based treatment and play activities. It aimed to learn whether the children were aware about the reasons for their hospitalization and how play-based activities were developed in an inpatient unit. It is an investigative exploratory qualitative study. Thirteen children between the ages of 6 and 10 years participated in the project. They had been admitted to the oncology unit of a hospital in the city of Aracaju. Data was collected between July and August through an open-ended questionnaire form and a field journal. All children reported to enjoy playing; the activity eased the trauma of hospitalization and the treatment's invasive procedures. The study concludes that play is important for coping with hospitalization.

Keywords: Neoplasms; Children; Hospitalization; Pediatric Nursing.

RESUMO

O estudo aborda o câncer infantil, o processo de hospitalização exigido para o tratamento e a inserção das atividades lúdicas no hospital, tendo como objetivo identificar o conhecimento da criança com câncer sobre sua hospitalização e a utilização do brincar em uma unidade de internamento. Trata-se de um estudo investigativo, exploratório, com abordagem qualitativa. Participaram do projeto 13 crianças na faixa etária de seis a 10 anos, internadas nas enfermarias da unidade oncológica de um hospital público do município de Aracaju. A coleta foi realizada nos meses de julho e agosto e utilizou-se como instrumento um formulário de perguntas abertas e um diário de campo. As crianças, na sua totalidade, relataram gostar de brincar e refletiram a brincadeira como maneira de amenizar o trauma da hospitalização, sendo os procedimentos invasivos o maior causador desse trauma. Conclui-se, portanto, que as atividades lúdicas são importantes para o enfrentamento da hospitalização.

Palavras-chave: Neoplasias; Criança; Hospitalização; Enfermagem Pediátrica.

RESUMEN

El presente estudio enfoca el cáncer infantil, el proceso de internación requerido para el tratamiento y la inclusión de actividades lúdicas con el objetivo de identificar el conocimiento de los niños con cáncer acerca de su hospitalización y de los juegos en una unidad de internación. Se trata de una investigación de carácter exploratorio cualitativo. Participaron en el proyecto 13 niños entre 6 y 10 años internados en los pabellones de la unidad de oncología de un hospital de la ciudad de Aracaju. Los datos se recogieron en julio y agosto utilizando un formulario de preguntas abiertas y un diario de campo. Los niños, en su totalidad, manifestaron que les gustaba jugar, que el juego era una forma de disminuir el trauma de la internación y que los procedimientos invasivos eran la principal causa de traumatismos. De ello se deduce que las actividades lúdicas son importantes para hacer frente a la hospitalización.

Palabras clave: Neoplasias; Niños; Hospitalización; Enfermería Pediátrica.

INTRODUCTION

Cancer starts when an abnormal cell is transformed by genetic mutation of the cellular DNA. This mutated cell forms a cell clone that proliferates abnormally ignoring growth-regulating signals of the surrounding environment.¹

The disease has a considerable impact worldwide and presents increased statistical significance. In 2010, there were approximately 489,270 new cases of cancer in Brazil, mainly amongst women. Cancer is the country's leading cause of death in children and adolescents aged between 1 and 19 years old.²

Childhood cancer is a chronic and potentially fatal disease and its diagnosis used to be equivalent to a death sentence. Fortunately, in recent years, 70 to 80% of the cases are curable due to new treatments. It is estimated that 1 in every 250 adults has survived cancer during childhood.³⁻⁵

Children with cancer undergo very difficult situations – the possibility of their own death or of his playmates, loss of identity and self-esteem, mutilation and culpability in face of their family suffering. Children may become passive in order to be accepted by the multidisciplinary team as a collaborative patient and to avoid rejection.⁶ Besides, they suffer physiological effects of chemotherapy that require continuing monitoring even after cure.⁷

This context characterizes the hospital as a place of physical and emotional suffering since the child's body is invasively and painfully manipulated with little or no explanation about the procedures. In addition, they are forced to deal with unfamiliar people, are expected to follow rules and schedules and, moreover, behave themselves. Hospitalization turns out to be a terrifying experience that may trigger irritability, fear, anger, despair, anxiety, stress, guilt, depression, apathy and a tearful behaviour.⁸

The child's acceptance of the disease depends largely on his parents' reaction since they will convey all the feelings that arise after the diagnosis. Children will actually discover the disease when they need to cope with treatment effects that demand a lengthy hospital stay and when they have to undergo invasive and painful procedures, such as chemotherapy and its side-effects.⁹⁻¹⁰

In view of this new context it is necessary that the child has adequate tools within his own domain so as to adjust to this new situation. Recreational activities offer pleasure and fun to children allowing them to feel like healthy kids again.¹¹

Children's need of recreation during illness and hospitalization should not be undermined. Playing allows the expression of feelings, preferences, fears and habits by transferring and projecting them to the characters of the game which creates a "make-believe" situation. Recreational activities provide confidence in an unfamiliar environment with unknown people; they allow non-verbal communication, acting as a mediator between the child's familiar world and the new environment.¹² They also contribute to moral development and stimulate con-

centration, attention, memory, imagination, interest and curiosity which are essential to child development.¹³

School-age children can understand, in a simplified manner, what is happening to their body and why hospitalization is needed; they are also able to express their opinions on hospitalization and on the importance of recreational activities. This study aims at identifying cancer children's knowledge on hospitalization and the role of games in an inpatient unit. It also intends to find out which nursing procedures are most difficult to such patients.

MATERIAL AND METHOD

This is a qualitative study that does not intend to list or measure events nor to employ statistical analysis instruments. Descriptive data (of people, places and interactive process) was obtained through direct contact with the studied situations.¹⁴ It is an exploratory research that involves bibliographic survey and interviews with people who have had practical experience on the issue, providing better knowledge to the researcher.¹⁵

It was carried out at a paediatric oncology inpatient unit of a public hospital in the city of Aracaju. It was approved by the Research Ethics Committee of the Federal University of Sergipe (protocol No 1344.0.000.107-10). The unit for neoplastic and hematologic diseases has sixteen beds for boys and girls who came from the whole state and from neighbouring regions. The subjects of this study were school children aged between 6 and 10 years¹⁶ who had cancer.

During the study period there were thirteen patients in the unit. One of them had not cancer diagnosis and four were under six years old and were therefore excluded.

Data was collected between July and August via a structured questionnaire and a research diary. The questions addressed the children's knowledge about hospital admission, their opinion about hospitalization and recreational activities and which hospital procedures were most distressing to them.

Interview was recorded after the legal guardian signing the Term of Free, Prior and Informed Consent (FPIC) if the child showed willingness to participate in the study. The child's hospital routine care was recorded in a diary, which was used later on.

After collection, narratives were transcribed in order to categorize data. Participating subjects were identified with pseudonyms from cartoons characters. Data was catalogued and analysed using Bardin's thematic content analysis whose stages are: pre-analysis; material exploration and treatment results; inference and interpretation.¹⁷ Questions were categorized, analysed and compared with current literature on the subject.

RESULTS AND DISCUSSION

The following categories emerged:

REASON FOR HOSPITALIZATION

The process of child hospitalization should be as less traumatic as possible. Hence children (especially school aged ones) should be informed about the reasons for admission, the procedures and hospital routines. In our study six children were unaware as to the causes for hospitalization, as seen below:

I don't know [...] it's because of my arm [...] a disease [...] it's rare! I think I hurt myself against something (Peter Pan, seven).

[...]No (Snoopy, eight).

Children are usually unaware of what is going on around them and are subject to socialization rules and rituals of the adult world.¹⁸ However, they have the right to be told, within the limits of their intellectual capabilities, about the disease since information and care mean respect for the patient. They should not be treated as passive objects submitted to hospital interventions and family decisions; the opinion of each child or adolescent should be taken into account.¹⁹

I don't know, and I am not going to talk (Casper, ten).

The traumatic experience of hospitalization triggers different reactions: some patients feel lonely and isolated. Better interaction between nursing staff and patients could contribute to making hospital environment more familiar and safer.

Recreational activities enable children to feel more integrated with the multidisciplinary team and with other patients and relatives, minimizing their feelings of loneliness. Moreover, as a result of these relationships, children stop focusing on pain and on changes caused by hospitalization, which favours adherence to treatment and increases their chances of recovery.

I know why I am sick [...] it is leukaemia in the blood (Road Runner, ten).

[...] I came to undergo chemotherapy to stop the disease (Bugs Bunny, nine).

Only two children were aware of the causes of hospitalization and knew what would happen during hospital stay; they seemed to be more confident and receptive to the interview, and had better interaction with other people.

Although being very important, there is no right moment to reveal the diagnosis to a child. When information is properly exposed it favours children interaction, provides confidence and reduces anxiety. Furthermore, it significantly improves their commitment to treatment, which soothes them.

Hospitalization may be a moment to learn about the disease and to become more active as to the decisions to be taken. Children have the opportunity to interact with other kids in the same situation as well as to exchange experiences and feel more accepted.²⁰

HOSPITALIZATION EXPERIENCE

When asked if they liked being in hospital, children replied:

It's bad, you get punctured all the time! (Bart, six).

I don't like it because it is bad (Snoopy, eight).

It's very bad [...] (Bugs Bunny, nine).

During hospitalization children face many problems such as long hospital stays, readmissions, aggressive treatments with undesirable effects, separation from relatives, anguish, pain, little understanding of the disease and fear of death.²¹ Even children who are informed about the disease refer to hospitalization as a negative experience.

Children need to be aware of what they will see, hear and feel during hospitalization. An honest approach to pain, medical and nursing procedures results in trust and cooperation. Healthcare aims at providing full bio-psychosocial support to both children and relatives, since hospitalization means an aggression to the child's magical world and requires professional understanding.¹⁹

It's good [...] there are toys. It's you and the toys that I like. (Buttercup, eight).

Well [...] [laughs] I like it here [...] (Road Runner, ten).

Such statements express the positive influence of a group of volunteers dressed as clowns, present at some interviews. Toys and playing are therapeutic and educational tools for hospitalized children since they re-establish physical and emotional confidence. They provide a less traumatizing and more cheerful environment, thus offering better conditions for recovery.²²

CHILDREN'S OPINION ABOUT PLAYING

When children were asked about playing in the hospital and about those who join them they said:

I like playing ball [...] I don't know [...] I like playing with my school mates (Snoopy, eight).

I like videogames. I play alone. I don't like playing with those who don't know how to play. (Bugs Bunny, nine). I

like to play. I play with my friends [...]. computer games (Casper, ten).

The paediatric unit deals directly with children who undergo long and traumatizing hospitalization. This requires a playroom where activities are developed to improve children's confidence and coping abilities.²³

The school to which children refer is the existing playground at the hospital, where they could play, paint, draw and relax. However, it was only open in the afternoon. During data collection we could notice the children's excitement early in the afternoon due to the opening of the playroom. In the morning they were usually impatient, unreceptive and tearful since the entertainers were not present and there were no recreational activities.

On Fridays children got anxious once they were visited by a group of volunteers dressed up as clowns that played with them. Such activity provided happy and relaxing moments, shown by the children's contagious laughter and good mood.

All study participants said they liked to play. For them, playing is an essential daily activity that does not require explanations. When a child plays in hospital he manages to alter the environment where he is, as if going back to his life before admission. This may have a positive effect on recovery. Playing is a free activity with therapeutic effects since it promotes children's wellbeing.²⁴

Pleasure provided by playing encourages children to discover themselves, understand reality and boost their creativity. Playing promotes children development, fosters interaction and resolution of conflicts and develops autonomy, responsibility and creativity. It also enables the child to create new meanings on the purpose of playing, showing an active stance meanwhile.²⁵

CHILDREN'S FAVOURITE GAME

When asked "Which is your favourite game in hospital?" the answers were:

Ball [...] football! I can see it from downstairs [...] it is good [...] I like to watch [...]. I play at home [...] I play at the computer [...] a car [...] there is only one car, a horse and a doll [...] (Bart, six).

I like! I play [...]! With the bicycle! It belongs to the school [...] the helicopter [...]. Oh, on the bed [...] it's mine [...]. the motorcycle! That motorcycle I brought from home [...] I play by myself [...]. I am the only one to use the bicycle! (Road Runner, ten).

I like to play at the computer (Snoopy, eight).

I play with the toys that are here: I write, I draw, I like to play with the plane, I like stories, I like painting (Jimmy Five, six).

Playing at the computer, with the motorcycle [...] drawing the letters of the alphabet. I like to play with the dolls and I like to watch cartoons (Buttercup, eight).

Six to ten year old children are more sociable and like playing in groups; they are interested in computer and video games and have the required logical reasoning to engage in simple strategy games. The most suitable activities and toys for this group are: clay modelling, colouring, computer games, dolls, crosswords, puzzles, skipping ropes and collective games with rules and goals that encourage competition.²⁶

Puppets are also very useful to the treatment: when a child makes his own toy he becomes an active subject and imprints his individuality on it, besides taking control of situations that arise during hospitalization. Puppetry allows children to express desires and anxieties and is therefore a good means of communication between child, family and the health professional.²³

Toy lending libraries in hospitals could be particularly interesting, considering the kid's age group and the goal of providing humanized care to sick children.²⁷ According to the researchers, the toys used in this unit were appropriate for each age group. However, toys were distributed randomly and the age group was not considered. Directed play activities would be ideal to potentiate their benefits to child development.

THE WORST PROCEDURE ACCORDING TO CHILDREN

Children undergoing cancer treatment are submitted to an array of daily procedures that become part of their routine, like chemotherapy sessions, injections, lumbar punctures to collect cerebrospinal fluid, and others.¹⁹ All children mentioned punctures as being the worst procedure.

To have a vaccine (Casper, ten).

To be punctured (Jimmy Five, six).

To have the veins pierced. This is the worst of all (Bugs Bunny, nine).

Ah! To be punctured all day long [...] just punctured [...] only two so the vein doesn't get tired (Peter Pan, seven).

Due to their limited understanding about anatomy, they feel threatened when the skin is perforated by a needle, because they believe that the internal body content will escape through the hole. Magical thinking and symbolism, characteristic of that age group, hinder some interventions. Exams are also

frightening to them due to the size of the equipment, the wiring and the strange noises they never heard before.¹⁹

I don't know [...] I don't like when they puncture me so! I don't like exams! One that makes a lot of noise (Buttercup, eight).

Treatment and examinations abruptly change the child's life and limit his choices; he is forced to live in a strange and painful world. Hospitalization requires adaptation to a restricted routine; undergoing painful procedures means a complete departure from his normal life at home. This situation disrupts the child's bio-psychosocial system and produces stress; depending on his age and the way he experiences disease, physical and psychological adjustments to treatment may be required.²⁹

In the following words, Bart translates the emotional distress caused by maternal absence and removal from family life that overshadows the physical pain caused by the treatment. This can be alleviated by the presence of relatives and recreational activities.

I wanted to stay a long time with my mother [...] only with my mother (Bart, six).

Distraction techniques used by the staff and the children's parents facilitate procedures and reinforce the child-family bonding. There is scientific evidence that distractors used in accordance with the child development stage reduces behavioural hazards, suffering and encourages cooperation. Furthermore, when used by parents, especially during punctures, it strengthens child-family relationship.³⁰

CONCLUSION

The present study highlighted the importance of being clear and giving the affected children and their families explanations about the disease and the treatment before the procedures. Patients who were given such information perceived the hospital as a place for rehabilitation and cure and became more active during their hospital stay.

It is visible that children do not like the hospital environment, mainly due to the changes in their routine, to the strangers they have to live with and to the invasive procedures they need to undergo. This experience could be less traumatic if interaction between nursing staff and children was improved and recreational activities during hospitalization were developed.

Thus, health professionals should be aware of the importance of recreational activities during hospitalization. Games and playing promote relaxation and are essential for child development. They should be developed according to the child's

age and cognitive evolution and are not to be interrupted at any point or circumstance in life.

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