Nursing difficulties in...



RESEARCH

Dificuldades da enfermagem na utilização do lúdico no cuidado à criança com câncer hospitalizada

Nursing difficulties in using playfulness to care for a hospitalized child with cancer

Dificultades de la enfermería para usar el lúdico en la atención al niño con cáncer hospitalizado

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ABSTRACT

Objective: describe difficulties faced by the nursing team in using playfulness during care for a hospitalized child with cancer. Method: descriptive research, with a qualitative approach, conducted in a pediatric inpatient sector at a hospital in the state of Rio de Janeiro, Brazil. The subjects were 11 professionals from the nursing team. Data collection took place in April 2012, by means of non-participant observation and semi-structured interview. Results: the following thematic units have emerged: difficulties related to toys in the sector; difficulties related to child's behavioral conditions; and difficulties related to work dynamics: lack of time. Conclusion: we found out the need for paying attention to children's peculiarities and needs, since playing is part of child development and we cannot deprive them from growing up in a healthy way. Descriptors: play and playthings, hospitalized child, pediatric nursing, cancer.

RESUMO

Objetivo: descrever as dificuldades enfrentadas pela equipe de enfermagem na utilização do lúdico durante o cuidado à criança com câncer hospitalizada. Método: pesquisa descritiva, com abordagem qualitativa, realizada em setor de internação pediátrica de hospital no estado do Rio de Janeiro. Os sujeitos foram 11 profissionais da equipe de enfermagem. A coleta de dados ocorreu em abril de 2012, por meio de observação não participante e entrevista semiestruturada. Resultados: emergiram as seguintes unidades temáticas: dificuldades relacionadas aos brinquedos no setor; dificuldades relacionadas às condições comportamentais da criança; e dificuldades relacionadas à dinâmica de trabalho: falta de tempo. Conclusão: constatou-se a necessidade de atentar às particularidades e necessidades das crianças, pois o brincar faz parte do desenvolvimento infantil e não se pode privá-las de crescer de forma saudável. Descritores: jogos e brinquedos, criança hospitalizada, enfermagem pediátrica, câncer.

RESUMEN

Objetivo: describir las dificultades enfrentadas por el equipo de enfermería para usar el lúdico durante la atención al niño con cáncer hospitalizado. Método: investigación descriptiva, con abordaje cualitativo, realizada en un sector de hospitalización pediátrica de un hospital en el estado de Río de Janeiro, Brasil. Los sujetos fueron 11 profesionales del equipo de enfermería. La recogida de datos se llevó a cabo en abril de 2012, a través de observación no participante y entrevista semi-estructurada. Resultados: las siguientes unidades temáticas han emergido: dificultades relacionadas con los juguetes en el sector; dificultades relacionadas con las condiciones de comportamiento del niño; y dificultades relacionadas con la dinámica de trabajo: falta de tiempo. Conclusión: se constató la necesidad de prestar atención a las peculiaridades y necesidades de los niños, ya que el jugar es parte del desarrollo de los niños y no podemos privarlos de crecer de forma saludable. Descriptores: juego e implementos de juego, niño hospitalizado, enfermería pediátrica, cáncer.

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INTRODUCTION

ancer is considered a major cause of infant morbidity and mortality. Among the various usual types in childhood, there is a predominance of hematological cancers, such as leukemia, which is the most common in most populations, representing from 25% to 35% of all types; acute lymphocytic leukemia (ALL) is that with highest incidence among children from 0 to 14 years. The leading causes of hospitalization in pediatric units are related to the profile of morbidity and mortality and, in this regard, cancer also constitutes a major cause of hospitalization for many children.¹

The diagnosis of childhood cancer is accompanied by various kinds of feelings, such as anger, fear, anxiety, helplessness, hopelessness, sadness, despair, and, especially, fear of death. It causes great impact on the child and her/his family, being an extremely devastating event, capable of causing changes and unexpected reactions.²⁻³ Even being regarded by many people as a disease leading to inevitable death, it has currently shown prospects of cure for children around 70%. Their chances of cure increase when provided with early diagnosis and treated in specialized centers.⁴

Hospitalization, for treating cancer, generates changes in child's daily life, requiring the establishment of new relationships with unknown people and environments, as well as constant adaptations. Children in general, particularly preschool children, have difficulties to deal with the unknown, such as, for instance, the use of technological resources and invasive procedures, and, when exposed to these situations, they become insecure and anxious. To minimize such feelings, children seek support from people they trust, in this case, their relatives, however, these individuals are not always able to help them, also feeling threatened and insecure in a strange environment. ⁵⁻⁶

In addition to hospitalization, there is also the cancer itself as a striking factor in a child's life, both due to the course of disease and to the type of treatment deployed, which is characterized by being long and by limiting some activities, such as, for instance, playing.⁷

During hospitalization, the child spends most of her/his time along with health professionals, and the nursing team constitutes the professional category having more contact to her/him. In this sense, nursing plays an important role in reducing the impact of childhood hospitalization. To do this, professionals may use a differentiated approach within their unit, by using strategies that contribute to improve coping with hospitalization and, as a consequence, to improve child's clinical status.

One of the strategies that can help the child to cope with hospitalization is using playfulness as a part of care. Using playfulness in a hospital setting is a booster in the child's adaptation process, because playing constitutes an appropriate strategy for coping with hospitalization.⁸

Among the benefits of playfulness in child care stand out an improved positive coping with illness and hospitalization and the promotion of a bond between the child and the professional team.⁸⁻⁹ Despite benefits are known in the literature, in the everyday practice of care for these children, we can see that playfulness is not widely used as a resource to care for hospitalized children with cancer, yet.

The observed reality of underuse of playfulness in clinical practice makes us think through the assumption that there are difficulties preventing the widespread use of this resource. These difficulties need to be known so that we can advance in the attempt to expand the use of playfulness, considering that its beneficial effects are already known and proven.

In this sense, this research had as object the use of playfulness by the nursing team during the care for a hospitalized child with cancer. The following guiding question was adopted: "What are the difficulties faced by the nursing team to use playfulness during nursing care for a hospitalized child with cancer?".

METHOD

This is a descriptive research with a qualitative approach.¹⁰ The setting was a pediatric inpatient sector, specialized in hematologic diseases, which treats children with leukemias and lymphomas. The hospital is a public institution in the state of Rio de Janeiro.

The sector consists of 13 beds, out of which 12 are located in a single physical space, forming a large ward. The beds are divided by boxes and curtains and there is 1 bed on the outside, but within the same hospitalization sector, which is reserved for children under contact precautions.

It has 2 bathrooms to be used by children, one for girls and another for boys, 1 room for procedures, purge, nursing office, and recreation room, which is the toy library. On the outside, in the hallway, there is a space intended for companions, with a place to wash clothes and a cupboard to store personal items.

The study subjects were 11 professionals from the nursing team, out of which 4 are nurses and 7 nursing technicians, working in the pediatric inpatient sector, scenario chosen for the study. The criteria for including subjects were: a) professionals with at least 1 year working at the sector chosen for the study, because, this way, they have spent some time along with children and can talk about their experiences and difficulties to use playfulness; and b) professionals working in direct child care. Only the professionals who were on sick leave and on vacation were excluded from the study.

We emphasize that 23 nursing professionals work in the sector, 8 of them are nurses and 15 nursing technicians. During data collection we had contact to 13 professionals, who were invited to participate in the study; out of these, 11 agreed and 2 refused, as they did not feel at ease to be interviewed or observed.

The number of participants was defined over fieldwork, when, by organizing the testimonies, we sought to identify the "saturation point", i.e. the existence of redundancy and repetition of ideas, behavioral patterns, and world views. Thus, when we found recurrences in the empirical material collected, we concluded the fieldwork.¹¹

Data collection was conducted in 2 stages and it started after approval of the study by the Research Ethics Committee of the institution concerned, under the Protocol 275/11. The first stage consisted of non-participant observation, conducted in April 2012, which totaled 25 hours. We used an observation script that served as a guiding instrument for this stage.

The observation script had topics related to the physical structure of the sector, such as colors of the walls, presence or absence of children's motives and toys. Besides the way of approaching the child adopted by the nursing team during procedures. Thus, by means of non-participant observation, we could identify the sector's physical characteristics and the nursing team's work dynamics.

We highlight the fact that, before starting our non-participant observation, all subjects were informed about the research and their inclusion was confirmed only by signing the free and informed consent term.

The second stage of research consisted in conducting a semi-structured interview, with open and closed questions. Among the closed questions there were identification data, such as name, educational status, and working experience in the sector. Among the open questions there were: "What do you understand as playfulness?"; "Do you use playfulness during care for a hospitalized child with cancer?"; "In your opinion, what are the difficulties in using playfulness during nursing care for a hospitalized child with cancer?".

For a comprehensive and accurate record of subjects' speeches, the interviews were recorded by using an mp3 player. They were held in a room used by the nursing team, which is within the inpatient sector, where it was possible to keep silence and privacy for interviews. The anonymity of participants was safeguarded all the time; we used color names to identify them, followed by job: nursing technician or nurse.

After collecting data, respondents' speeches were fully transcribed and data were analyzed by using thematic analysis. The following steps were taken: fluctuating reading by means of comprehensive contact to the material; material exploration and delimitation of thematic units; and processing and interpretation of results.¹⁰

We add that data from non-participant observation formed a text that was related to data from the transcription of subjects' speeches, in order to illustrate and instantiate their content.

RESULTS AND DISCUSSION

From respondents' answers the following thematic units emerged: difficulties related to toys in the sector; difficulties related to child's behavioral conditions; and difficulties related to work dynamics: lack of time.

Difficulties related to toys in the sector

Among the difficulties in using playfulness in child care, the subjects took a position and related them to the lack of toys in the sector.

Here there is no toy, there is nothing to entertain the child, to draw her/his attention. (Orange, female nursing technician)

Professionals pointed out, besides the lack of toys in the sector, the difficulty of children to bring their own toys, as not every type of toy is accepted in the unit.

The only difficulty I have is that not any kind of toy may be brought to the ward. Furry toys we ask parents not to bring. (Gray, female nurse)

Furthermore, toy handling by the child under contact precautions is another difficulty they face, because when toys are left by them, other children can handle these objects, becoming exposed to the risk of infection.

The only difficulty concerns these guidance issues, for instance, a child who is under isolation and leaves these toys scattered around the sector, then, other children take them. (Gray, female nurse)

We add that, during non-participant observation, we identified that there is a shortage of toys in the toy library of the sector. In this hospital, the toy library is named "recreation room". In this space, there is TV, DVD player, and video game, however, it does not have many toys for children to handle, only rather big toys, such as a horse-shaped mini-seesaw. The other toys were removed as advised by the Committee on Hospital Infection Control (CCIH).

The toy is used as an instrument to facilitate care for a hospitalized child, and this is a mediator of professional's approach during procedures, however, the shortage of toys in the pediatric sector still constitutes a limiting factor in using playfulness to care for a hospitalized child. However, some studies show that creative actions during care are able to produce rewarding results, not only for children, but for the team as a whole. ¹² Even with lack of resources, the team must resort to creativity during care, for instance, by telling stories, playing with the child using a toy of her/his own, and singing songs the child likes.

Another aspect to be highlighted is that the shortage of toys in this environment may be a result of standards from the CCIH of each hospital, because the toy can be a vehicle that facilitates cross-infection within the wards.

In the hospital setting, the toys belonging to toy libraries are shared by children and become a medium that enables the transmission of pathogens. Moreover, children can bring toys of their own into the hospital and share these objects with other children. In order to prevent them from missing such a good time, the institution must take measures to clean

and disinfect these toys on a regular basis. There is also a need to develop protocols for disinfecting toys, especially for children under contact precautions, because, in some cases, they cannot attend toy libraries, they have to enjoy leisure activities within their own bedroom.¹³

According to Law 11,104, enacted on March 21, 2005, the health facilities providing pediatric inpatient care must have a toy library. According to article 2 of this law, the toy library is described as a space having toys and educational games, designed to encourage children and their companions to play.¹⁴

When there is a space designed for playing within a pediatric inpatient sector, this reflects an institutional concern with the overall well-being of children, providing greater confidence for her/him and her/his family members. This space helps preserving the child's emotional health, facing unknown situations to the child, improving child's adaptation to the hospital environment, lessening traumas, and making the environment less hostile.¹⁵

When discussing this thematic unit, we noticed that still exist a shortage of publications addressing the subject, something which demonstrates the importance of broadening the discussion on the use of toys within the hospital and, also, on the way how providing the child with pleasure safely. There is a need to adopt cleaning and disinfecting protocols for these toys within the hospital, in order to avoid depriving children from having recreational time within a completely foreign environment to her/him.

Difficulties related to child's behavioral conditions

In this category, the professionals reported as difficulties in using playfulness the behavioral conditions of children during hospitalization, because they become anxious, tearful, vulnerable, depressed, and do not show willingness to talk and interact with the team. Thus, interpersonal relationship and dialogue are compromised, since the child refuses getting closer to the team, thinking she/he is about to undergo some procedure.

The greatest difficulty is when the child is very fragile, very depressed, within this period the dialogue becomes difficult, talking [...] the interpersonal relationship with the child is more difficult. (Purple, female nursing technician)

During non-participant observation, we found out that in some situations the nursing team tried to interact and play with the children who showed to be more apathetic, distant, and silent, and the reaction of most children were crying, getting closer to their mothers, and non-acceptance of the procedure they were about to undergo.

Furthermore, we observed that most hospitalized children were at the preschool and school age groups. A preschool child still lacks the cognitive structure needed to understand the experience she/he is going through. At this age group, the child has difficulty to deal with new situations, showing up insecure and fearful, seeking support from her/his relative to minimize ansiedade. In turn, the child at the school age group has developed her/his cognitive skills and is able to differentiate her/his ideias from those of other people and, also, to express them. This child is able to identify any clue that is outside the usual context set by her/himself. In

This way, we could identify, through non-participant observation, the situational coping difficulties at each developmental period. Children at the preschool age group resorted to their mothers or cried when someone from the nursing team got closer. Those at the school age group had a better response to procedures, even in the absence of their parents. Therefore, the nursing team must be aware of the different stages of child development.

When a child is hospitalized, she/he experiences different situations within a completely foreign environment, her/his daily routine is completely modified. As this is an impersonal environment, full of taboos and meanings that impact on the daily context of this child. Hospitalization leads the child to move away from her/his home and family, having to adapt to a completely different environment, with different routines and people, besides procedures causing discomfort.¹⁸

Children not always accept contact, talking. [...] They dislike getting close, they think we are about to do something bad and are not open to dialogue. (Green, female nursing technician)

Sometimes, she/he is so anxious that cannot understand what we are talking about, she/he cannot interact with us, it is more difficult, indeed. (Rose, female nurse)

The child may also be afraid of the nursing professional or of the procedure she/he is about to undergo, even if this does not cause any pain; she/he associates the presence of this professional to procedures that may cause she/him a painful sensation, something which, in most cases, hinders the team to get closer so that the needed actions are taken.

Sometimes, she just cries, when the child is very young she/he wants only her/his mother, she/he associates everything to sticking, we cannot even get close, they cannot see anyone in white, regardless of who this person is, it is hard to get close to the child. (Red, female nursing technician)

Another important aspect that must be highlighted is chemotherapy, because it generates undesirable effects such as nausea, vomiting, fever, malaise, fatigue, and pain.¹⁹ These effects make children rather unwell, making them unreceptive and hindering us to get closer and also to use playfulness. It is known that these effects have various lengths of time,¹⁹ affecting the child at different levels. In this sense, some behaviors may be related to the side effects of antineoplastic chemotherapy, which triggers adverse effects and children are hardly able to take them.

A study carried out in 2010 claimed that when a child is undergoing chemotherapy, she/he suffers both a physical and emotional stress, as the adverse effects of chemotherapy agents and hospitalization cause uncertainties regarding cancer. ²⁰ In the same study, children reported, as side effects of chemotherapy, malaise, lack of appetite, and vomiting. In addition to these effects, they mentioned the physical changes resulting from chemotherapy, such as, for instance, alopecia and weight loss, and they said these are the most impactful. ²⁰

A child with cancer expresses her/his perception of pain in response to numerous situations, such as: pain related to some physical change, pain resulting from treatment,

pain due to detachment from relatives and friends. When undergoing situations of rupture of friendship and loss of bonds, children can take defense behaviors against these attacks, becoming rebellious, impatient, and insecure.²¹

Difficulties related to work dynamics: lack of time

The subjects also pointed out difficulties related to work dynamics: lack of time. The professionals reported that during care for hospitalized children with cancer, they have little time to play with these patients, as well as to explain the procedures.

Sometimes, we do not have much time, there are shifts when it gets complicated to stop and play for a while with them and explain a procedure. (Yellow, female nurse)

We have little time to play with them. (Blue, female nursing technician)

We observed, within the data collection period, that nursing used a few times the resource of playfulness to care for these children. During procedures, sometimes, a user-friendly language was employed, with simple words to explain them, but most of the times no type of toy or play is used.

Nursing care is not just an act that involves using techniques and technologies, but, above all, it consists in knowing how to deal with the other, seeking to know her/his peculiarities, in order to extend this care, both for the child and for her/his relative.²²

In most cases, the nursing team is responsible both for the management of care and for bureaucratic issues inherent to the sector where it operates. It faces a quantitative work overload, often evidenced by the responsibility for more than one hospital sector, as well as a qualitative work overload, observed in the complexity of human relationships, for instance, nurse/patient; nurses/health professional; nurse/relatives.²³⁻²⁴

In order to be a nurse in pediatric oncology, the professional must understand the importance of providing a humanized care, which permeates the children's world, where specific material and therapy resources are not their main focus.²⁵ In this sense, when caring for a child, the nursing team needs to adopt a holistic approach and aimed at human contact, looking at the child as a human being who needs care procedures inherent not only to her/his illness, but also to her/his psychological and social status.

Even if the hospital routine requires that activities are fulfilled within a certain time, there is always a need to be aware that using playfulness may be a facilitator of nursing practice, as it enables the establishment of bonds with the child, so that care is efficiently provided and takes less time.

CONCLUSION

Throughout this study, with a qualitative approach, we sought to describe the difficulties faced by the nursing team in using playfulness to care for hospitalized children

with cancer. Non-participant observation, combined with semi-structured interview, allowed us to describe these difficulties, so that it becomes feasible to overcome them.

Playing is important for any child, especially when she/he is affected by a disease such as cancer and needs to be hospitalized. Thus, by using playfulness, the nursing team can have a valuable tool to provide these children with care, however, the survey indicated that there are difficulties to use it every day in an inpatient sector, yet.

The difficulties pointed out by the nursing team are related to the lack of toys in the sector, as well as to the type of toy allowed or not in the hospital environment. Moreover, the very child's behavior during hospitalization was indicated as the cause of difficulty in using playfulness, as well as the lack of time for professionals to play or explain the procedures that children will undergo.

We know that, often, a poor appreciation of this practice may be due to the prevailing health care model, ruled by the biomedical paradigm, which focuses on treating the disease, rather than the biopsychosocial paradigm, which looks at the subject in the broadest sense, seeking to meet the psychological and social aspects, besides the biological.

In order to move towards a biopsychosocial health care model, there is a need that schools of Nursing and health institutions educate professionals about the peculiarities of each subject they care for, as well as her/his needs. In the case of a child, regardless of the environment where she/he is, playing is part of her/his development and, moreover, this is a right, thus, we cannot deprive her/him from the opportunity of growing up in a healthy way.

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