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Guidance on chemotherapy aimed at children with cancer: a sensitive creative method

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ABSTRACT

Aims: to identify the guidelines on chemotherapy aimed at children with cancer as seen by family members; to discuss the importance of these instructions which are provided by health professionals regarding these children. **Method:** This is a qualitative approach research, implemented according to the sensitive creative method. Participants were seven family members of children on chemotherapy in a hospital in Rio de Janeiro. **Results:** through thematic analysis the categories “chemotherapy on instructions provided to children with cancer” and “the role of professionals in carrying out the instructions provided on chemotherapy to children with cancer” emerged. **Discussion:** professionals should pass on the guidelines to children because family members have difficulty doing this. The strategies used must be appropriate for children, and must be performed at the beginning of the chemotherapy. **Conclusion:** one must take into account the ability of children to understand their disease and treatment, and target them, respecting their level of development.

Descriptors: Oncologic Nursing; Chemotherapy; Family; Child.

INTRODUCTION

Cancer is a disease stigmatized as a death sentence and, when it affects children, the fears and insecurities are intensified as they are in the early stages of life and cannot live their dreams and materialize their plans^(1,2).

Despite this stigma, it is estimated that 70% of children with cancer can be cured if diagnosed early and treated properly in specialized centers⁽³⁾.

There are several forms of treatment for childhood cancer and the main forms are chemotherapy, surgery and radiotherapy. However, chemotherapy is most frequently used, and it may be associated with other methods⁽⁴⁾.

Currently, part of the chemotherapy treatment is performed in an outpatient clinic, favoring the permanence of the child in family life. In this sense, outpatient chemotherapy is an alternative to minimize damage related to the breakdown of family ties. On the other hand, the side effects of chemotherapy arise at home, and they are sources of stress for children and their families⁽⁵⁾.

The treatment of children with cancer should be comprehensive, on the physical, psychological and social needs. The family should be included and their right to all information ensured as well as the search for the promotion of atraumatic care to minimize the effects of treatment. Regarding this, research indicates the importance of developing educational interventions aimed at the family of children undergoing chemotherapy. However, little is discussed in terms of the development of guidelines with the children^(6,7).

Although the family is part of the therapeutic process, the preparation and the guidelines on chemotherapy should also be addressed to sick children. Those who are of school age (6-12 years) already have some ability in terms

of logical and coherent thought. They are able to identify, understand and solve some events that occur around them, and understand the changes occurring in their bodies and in their lives^(6,7).

When children are not properly directed, family members may find it difficult to explain their situation^(7,8,9).

A Swedish study aimed at exploring the daily lives of children six months and one year after the cancer diagnosis interviewed patients and parents. The study highlighted that the children had the desire to know about the disease and treatment, as this gave them some control of the situation they were experiencing⁽¹⁰⁾. Thus, a study that addresses the ideas of the family on the guidelines to be made, along with the children with cancer undergoing chemotherapy, makes it important, since they are key to the successful treatment of the child.

Based on this, the questions that guided this study were: what are the guidelines for chemotherapy that should be conducted with children with cancer in the eyes of family members? Why is it important that health professionals provide these guidelines to children with cancer?

The ideas of the family members were defined as an object of study in terms of the instructions provided on chemotherapy directed to the children. The objectives were to identify the guidelines on chemotherapy that should be conducted to children with cancer, in the eyes of family members, and discuss their importance.

METHOD

The qualitative research was carried out according to the sensitive creative method (SCM), which has its foundations based on the

triad group discussions, participant observation and dynamics of creativity and sensitivity. The steps occur simultaneously within each dynamic. For this, besides the researcher, who acts as coordinator of the group, there is a need for a research assistant who, during the dynamic, observes and describes the behavior of the participants, acts by controlling the audio recorder, and also makes the photographic records.^(11,12)

Based on the guidelines of the sensitive creative method (SCM) for the development of this research we used the dynamics of creativity and sensitivity entitled almanac. This activity consists of producing pictures and texts for addressing the theme of the research. These are made through collages of pictures, drawings and phrases on paper, guided by a question to generate debate⁽¹²⁾.

At the beginning of the dynamics the researcher presented the art materials and subsequently released the generating question for debate. The question was in a place where everyone could see. For this dynamic the following question was asked: what are the guidelines that should be performed by professionals for children on chemotherapy? Did the individuals have enough time to develop individual creative ideas? After each family presented what was produced, the group discussion began.

The participants of the dynamics were seven family members, including two mothers and a grandmother of seven children at school age undergoing chemotherapy. The inclusion criteria were: to be directly responsible for child care; to meet the treatment routine and be aged 18 years or older. The excluded individuals were the family members with other children who required full-time care, thus preventing their temporary absence to participate in the dynamics.

To guarantee anonymity, participants were identified with the letter "F" for family, followed by a number according to the order of participation in the survey.

The criteria used for closing the fieldwork was the sampling process by theoretical saturation, in which data collection is stopped when it appears that the fieldwork no longer offers new elements to deepen the theory of the research object⁽¹³⁾.

The survey was conducted in a pediatric federal university hospital located in the municipality of Rio de Janeiro. In this hospital, the scenarios used for the selection of participants and the realization of the dynamics were the two sectors in which chemotherapy is administered in children: the chemotherapy clinic and the hematology ward.

Three dynamics almanac were performed. The first, in the hematology ward, featured three participants: F1, F2 and F3. The second, in the room for chemotherapy outpatient procedures, featured two: F4 and F5. The third dynamic, featuring the participants F6 and F7, was also in the hematology ward. It is noteworthy that in the participants' selection and in all the dynamics two researchers took part; one as the coordinator of the dynamics and the other as an assistant.

Thematic analysis was used in the data, based on the texts generated by the creativity and sensitivity dynamics. The following steps of the analytical method were followed: initial reading, material exploration, processing and interpretation of results⁽¹⁴⁾.

The research followed the decisions of the National Health Council Resolution 466/12. It was submitted to the Research Ethics Committee (REC) of the institute where it was performed and was approved with the opinion number 747,383 and CAAE number 32908214.6.0000.5264.

RESULTS

Through the analysis process two thematic units emerged: guidance on chemotherapy performed along with the children with cancer and the role of professionals in carrying out the guidelines for chemotherapy performed with children with cancer.

Guidance on chemotherapy focused on children with cancer

Among the guidelines to be used with the schoolchildren, family members pointed out that professionals should talk about the disease:

I think they should always guide children. Not to hide their illness. (F2)

I think they should know everything, especially from the age of five on, because they already have the notion of what is happening. A little baby does not know, but a child like mine, a young 10-year-old lady, understands everything. (F6)

They also highlighted the need to explain the whole treatment process, including information in terms of the medications administered: effect, dose, administration time, types of venous catheters; in case of transfusion, the reason for the procedure and all the necessary steps to carry it out:

Children ask many questions; they want to know everything, understand about the medicines, catheter types; they want to know it all! For how long he will be having blood transfusions. He asks why and I'm afraid he is getting worse. (F2)

My son asks everything; even if I do not ask, he has his own doubts. He wants to know how many chemotherapies he will go through; how many hours it will take; his problem is the delay and having to stand here waiting. He gets anxious; he asks to stop and to go home, because he has been on chemotherapy for an "eternity". (F5)

The side effects of chemotherapy are also guidelines that family members deemed important:

There are times when he (son) does not want to eat anything; he is not hungry or his mouth hurts because of some small wounds (mucositis). This information is important to help understand why that happens, right? (F4)

They should know about the nausea, because they feel very sick, they cannot eat, cannot drink; they just throw up and have diarrhea (F6).

Another aspect mentioned by participants as important to be addressed in the professional guidelines was the possibility of changes in body image, such as alopecia, weight gain and loss and the use of masks:

Hair loss is a very complicated issue. It is better that professionals talk about the possibility of it, so the children can get ready for it. (F7)

He was very thin, he lost too much weight. Then he got all swollen up; really fat; I had to buy clothes for him. Appearance changes a lot. (F1)

Regarding the use of the mask, it is a problem for him. He feels ashamed because people look at him, but they don't know why he is wearing it; they don't know what his problem is. (F6)

Caregivers also talked about some limitations imposed by the treatment, saying it is difficult to keep children indoors. It is hard not to let them go to the beach, to the swimming pool, practice some activity that involves more physical effort, go to school or eat raw fruit:

I think we should talk about the limitations, because, unfortunately, by the end of the treatment he doesn't have a normal life. Children cannot eat fruit because immunity drops and gets neutropenic. They can't play ball, play in the sun, take a pool bath, let alone go to the beach, because many leisure activities are forbidden and it also causes suffering. They have to understand why. (F6)

He can't go to school because it is an enclosed environment, and sometimes there is a sick child and we don't know about it, and he can't be in contact with these children. He misses going to school, studying. (F4)

Some people have reported that when children learn that another child who was also in treatment has died, they question why and feel afraid that they will die like their friend. In this sense, they believe that professionals should address this issue:

We had a case (child death during treatment) here, you know? My daughter got really scared; if anything

happened she thought she was going to die the same way. (F7)

When children see that another child who was being treated is gone (dies), they can't understand it; they get scared; ask why, as those mates were undergoing treatment; and ask if it will happen to them as well. (F2)

The role of professionals in carrying out the guidelines of chemotherapy conducted with children with cancer

Family members say they have difficulties in tackling the disease and the effects of treatment, highlighting that this is the role of health professionals:

He didn't have much of an idea of what the disease was and I didn't tell him. He kept asking me to speak and I just cried. (F1)

I think professionals should talk to them, because they speak and the children listen and go home aware of it; (...) the care they must have. He takes it in a better way. At home I just reinforce what was said. It's easier this way, he understands it better. Because when I speak, he thinks that the father and mother are lying. (F4)

They also mentioned the possible strategies used by professionals to carry out the guidelines. There was an emphasis on the drawings, pictures, ludic metaphors as blood factory, jokes and languages aimed at the child's age, as facilitators of the guidance and understanding of children:

Professionals have to say, make things clear, speak in a way that children can understand (...)kids understand things better with pictures, drawings and games. (F6)

For example, a doctor explained about the blood factory, which is located in the bone marrow where blood is made; explained about the soldiers and he understood. With drawings, dolls, toy soldiers (...) I think they understand it better. (F2)

Participants also claim that the guidelines should be undertaken by professionals before or at the beginning of chemotherapy, so that the child knows everything that's going on and what can happen during treatment:

I think it's better to explain everything before chemotherapy. (F3)

It is best before chemotherapy, sit down and explain everything about chemotherapy. (F2)

DISCUSSION

The survey data show that caregivers understand that school-age children (6 to 12 years) are able to understand the disease they have, and professionals should guide them. When informed, they become active subjects in their health-disease process. Health professionals should not ignore this ability to understand the point of relaxing them during treatment⁽¹⁾.

Being involved in the therapeutic process with the necessary guidance, participating in

decision-making, being free to express their preferences are not only children's rights, but they also reduce the chance of non-adherence to treatment, promote trust in health professionals and cooperation as well as helping to fight the disease and to cope with the therapy^(15,16).

Nevertheless, a Brazilian study conducted with nursing professionals showed that it is still common to guide the guardians without involving the children in the educational process. Some practitioners claim to know that children at school age have the ability to understand their disease, but admit that they provide little guidance to them and, when they do it, the information is minimal⁽⁷⁾.

Study participants believe that professionals should tell children everything in terms of treatment, answer their questions and clarify doubts, without hiding any information. This finding is consistent with another study that highlighted the role of the health professional as educator who must guide children about their treatment, aiming for understanding of all aspects of the process⁽¹⁾. From this knowledge, in terms of what drugs can cause, it is believed that children will be better prepared for their administration. They also feel more confident in terms of being submitted to the catheter, of carrying out maintenance, and waiting the necessary time for the chemotherapy session without being consumed by anxiety⁽⁶⁾.

As highlighted by relatives, anti neoplastic drugs can cause numerous side effects that generate unpleasant symptoms. In this regard, a study conducted in the UK, in order to explore the vision of children and adolescents under cancer treatment and present a conceptual model of communication and information sharing, showed that children care about the symptoms and their permanence, and would

Silva LN, Silva LF, Goes FGB, Machado MED, Paiva ED. Orientações sobre quimioterapia junto à criança com câncer: método criativo sensível. *Online braz j nurs* [internet] 2015 Dec [cited year month day]; 14 (suppl.):471-80. Available from: <http://www.objnursing.uff.br/index.php/nursing/article/view/5310>

like to have more direct communication with health professionals⁽¹⁷⁾. It was observed that the effects cited by participants are those that cause feeding difficulties such as nausea, vomiting, mucositis and lack of appetite and could harm children's nutritional status. The literature states that the power of the children subjected to chemotherapy requires further attention, since their nutritional status directly affects the severity of side effects, increases or decreases the risk of infection, and interferes positively or negatively in the treatment⁽¹⁸⁾. It is important for them to know that they need to eat despite these effects, avoiding complications and negative interference in treatment⁽⁶⁾.

As for body image changes, the use of masks, weight gain and loss, hair loss, among others were cited. It is reported that children already understand the changes occurring in their bodies and care about it. Studies^(6,19) show that the school-age children are already concerned about self-image, and to minimize the losses from the changes caused by the disease and chemotherapy, health professionals should educate them in terms of what changes can happen, especially those that are visible to their eyes and the eyes of the people around them and which may cause strangeness.

Caregivers also highlighted issues relating to the limitations imposed by the treatment. It can be said that the discovery of cancer and its treatment altered the rhythm of life for children and their families and some limitations related to lifestyle and food are imposed. The activity of playing, which was previously a priority, gives way to special care; children are restricted from going to the beach and to school; they cannot eat certain foods and practice sport⁽⁴⁾. Bear in mind that children maintain a desire to participate in group activities, but may feel different and even struggle to fit into their new condition

and they may feel lonely⁽¹⁰⁾. When children are guided by health professionals, they have the opportunity to meet their new needs and understand that those limits prevent complications. Thus, the restrictions are no longer an imposition and begin to happen more naturally as they start to collaborate so that their treatment will be successful⁽⁶⁾.

Regarding the fear of death, according to the participants, the research claims that cancer is still a much stigmatized disease, associated with the idea of death and generating feelings such as fear⁽¹⁹⁾.

A study conducted in the Netherlands with parents of children who died from cancer showed that most of them did not talk to their children about death. Among the reasons they mentioned was the inability of parents to discuss death, the desire to protect their children and the belief that children are not able to understand it⁽²⁰⁾. These data highlight the need for health professionals to intervene approach with the family and children, especially schoolchildren.

Although considered naive, school children are able to understand and assimilate all that is said and presented to them.⁽⁷⁾ Therefore, when they learn of the death of another child, according to the family, they feel insecure about the success of their treatment. Thus, the fear of going through the same situations, with the same illness, and the performance of the same treatment can be minimized if there is room for dialogue and guidance.

When the diagnosis of cancer is confirmed, it is common for parents to receive the news without the presence of the child⁽¹⁹⁾. Insecure, the study participants reported that they could not tell the children their diagnoses.

When children receive guidance in terms of their limitations from their family members,

they often associate it with overprotection and end up not taking the necessary care, but when these guidelines are provided by health professionals, there is greater understanding.

Health professionals, deemed as educators, have the aptitude and should guide the whole family in terms of the disease and its treatment, aiming at the comprehension and participation of children throughout the therapeutic process⁽¹⁾.

The guardians stress that professionals should explain everything to children, using an easy to understand language. Besides dialogue, there are other strategies for carrying out the guidance to children of school age, such as the use of stories, toys, role play, puppets and games^(5,9).

All the mentioned activities are good ways to provide information on the disease and chemotherapy. However, health professionals are not always provided with the necessary tools to perform them. More often these guidelines happen through dialogue - which is not a negative aspect; however, professionals fail to use other resources that are, sometimes, more suitable to children's understanding⁽⁷⁾.

Family members also pointed out that it is important that children start treatment knowing everything that can happen during this process. Therefore, it can be said that the preparation of children is a primary action, which must precede all therapeutic procedures so that children may understand their disease, be aware of what the treatment is, and also its importance and side effects⁽⁹⁾.

Lack of information leads to lack of preparation, low self-esteem, insecurity and fear. Children need to be guided and involved in the therapeutic process so that negative feelings are minimized. This involvement also makes children collaborate with the treatment, and generates a bond and trust in the professionals^(9,16).

CONCLUSION

In the view of family members who participated in the study, it is important that school children with cancer undergoing chemotherapy are told about the disease, the implemented treatment, its side effects, the possibility of changes in terms of body image and the limitations imposed by the treatment (whether related to everyday lifestyle or diet). Death should be seen in a natural way. It is important to highlight the fact that each child reacts differently to treatment, minimizing their fear.

The guidelines should be carried out by health professionals as family members have a hard time approaching them. To that end, professionals need to take on their role as educators, especially nurses, childcare coordinators and the family of the children in everyday care practice. It is up to these professionals to equip themselves in the matters involving the care provided to children with cancer, developing strategies and resources to help their understanding, such as jokes, games, drawings and figures, exercising this role from the time of the children's admission.

We recommend further research aimed at the guidance of children undergoing chemotherapy, since the current studies address guidance which focuses on relatives and research and which addresses guidance strategies aimed at children with cancer undergoing chemotherapy.

REFERENCES

1. Gomes IP, Lima KA, Rodrigues LV, Lima RAG, Collet N. Do diagnóstico à sobrevivência do câncer infantil: perspectiva de crianças. *Texto Contexto Enferm.* 2013; 22(3):671-9.

2. Foster TL, Lafond DA, Reggio C, Hinds OS. Pediatric palliative care in childhood cancer nursing: from diagnosis to cure or end of life. *Seminars in Oncology Nursing*. 2010; 26(4):205-21.
3. Ministério da Saúde (BR). Instituto Nacional do Câncer. Estimativa 2014: incidência de câncer no Brasil. Rio de Janeiro; 2014.
4. Cicogna EC, Nascimento LC, Lima RAG. Children and Adolescents with Cancer: Experiences with Chemotherapy. *Rev. Latino-Am. Enfermagem*. 2010; 18(5):864-72.
5. Gomes IP, Collet N, Reis PED. Ambulatório de quimioterapia pediátrica: a experiência no aquário carioca. *Texto contexto Enferm*. 2011; 20(3):585-91.
6. Nóbrega RD, Collet N, Gomes IP, Holanda ER, Araújo YB. Criança em idade escolar hospitalizada: significado da condição crônica. *Texto contexto Enferm*. 2010; 19(3):425-33.
7. Cruz EF, Silva LF, Goes FGB, Aguiar RCB, Moraes JRMM. Orientações de enfermagem junto às crianças em idade escolar em tratamento quimioterápico antineoplásico. *Rev. Eletr. Enf. [Internet]*. 2014; 16(2):378-85. Disponível em: <http://dx.doi.org/10.5216/ree.v16i2.27009>
8. Jesus IQ, Borges ALV, Pedro ICS, Nascimento LC. Opinion of adults escorting children on an outpatient chemotherapy service about a "Chemoteca" in a municipality of Sao Paulo. *Acta Paulista de Enferm*. 2010; 23(2):175-80.
9. Artilheiro APS; Almeida FA; Chacon JMF. Use of therapeutic play in preparing preschool children for outpatient chemotherapy. *Acta Paulista de Enferme*. 2011; 24(5):611-16.
10. Darcy L, Bjork M, Enskar K, Knutsson S. The process of striving for an ordinary, everyday life, in young children living with cancer, at six months and one year post diagnosis. *European Journal of Oncology Nursing*. 2014; 18:605-12.
11. Silva LF, Cabral IE. As repercussões do câncer sobre o brincar da criança: implicações para o cuidado de enfermagem. *Texto Contexto Enferm*. 2014; 23(4):935-43.
12. Cordeiro FR, Beuter M, Roso CC, Kruse MHL. Pain and the dying process: nurses' perspectives using the creative and sensible method. *Online braz j nurs [Internet]*. 2013; 12(1):106-19. Available from: <http://www.objnursing.uff.br/index.php/nursing/article/view/3989>
13. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DM. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. *Cad Saúde Pública*. 2011; 27(2):389-94.
14. Minayo, MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 12 edição. São Paulo: Hucitec; 2010.
15. Toruner EK, Citak EA. Information-seeking behaviours and decision-making process of parents of children with cancer. *European Journal of Oncology Nursing*. 2013; 17(2): 176-83.
16. Coyne I, Amory A, Kiernan G, Gibson F. Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing*. 2014; 18(3):273-280.
17. Gibson F, Aldiss S, Horstman M, Kumpunen S, Richardson A. Children and young people's experiences of cancer care: a qualitative research study using participatory methods. *International Journal of Nursing Studies*. 2010; 47:1397-407.
18. Pacciullo AM. Estratégias de enfrentamento do tratamento quimioterápico na perspectiva de crianças com câncer hospitalizadas [dissertação]. Ribeirão Preto: Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto; 2012.
19. Silva TCO, Barros VF, Hora EC. Experiência de ser um cuidador familiar no câncer infantil. *Rev. Rene*. 2011; 12(3):526-31.
20. Ivana MMVSG, Marry MVDHE, Liesbeth MVV, Saskia MFP, Isabelle CS, Erna MCM, et al. Talking about Death with Children with Incurable Cancer: Perspectives from Parents. *J Pediatr*. 2015: 1-7.

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