

THE VIEW OF FAMILY MEMBERS REGARDING GUIDANCE PROVIDED TO THE CHILD UNDERGOING ANTI-NEOPLASTIC CHEMOTHERAPY

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ABSTRACT: This study aimed to describe family members' view of the guidance provided to school-age children undergoing antineoplastic chemotherapy treatment, and to discuss the strategies for providing these children with guidance. It is a qualitative and descriptive study, with semistructured interviews held with 10 families of children undergoing chemotherapy treatment in a public hospital in Rio de Janeiro, in March 2013 – June 2014, using thematic analysis of the information. The data showed that most of the children began chemotherapy treatment without receiving guidance, and that it is the family which is mainly responsible for the guidance. For the family members, the child must be given guidance in relation to the disease, treatment, care with hand and food hygiene, and possible reactions from the chemotherapy. Play resources, such as play, pictures and illustrated books can be used as strategies for providing guidance. It is important to provide guidance to children undergoing chemotherapy treatment using resources which make it possible for them to understand.

DESCRIPTORS: Pediatric nursing; Chemotherapy; Oncology nursing; Information.

A VISÃO DOS FAMILIARES QUANTO ÀS ORIENTAÇÕES REALIZADAS JUNTO À CRIANÇA EM QUIMIOTERAPIA ANTINEOPLÁSICA

RESUMO: O objetivo deste estudo foi descrever a visão dos familiares quanto às orientações realizadas junto às crianças em idade escolar em tratamento quimioterápico antineoplásico, e discutir as estratégias para orientação junto a essas crianças. Trata-se de um estudo qualitativo descritivo, com entrevistas semiestruturadas em 10 familiares de crianças em tratamento quimioterápico, num hospital público do Rio de Janeiro, no período de março de 2013 a junho de 2014, por análise temática das informações. Os dados mostraram que a maioria das crianças inicia o tratamento quimioterápico sem receber orientação e que a família é a principal responsável pela orientação. Para os familiares, a criança deve ser orientada quanto à doença, tratamento, cuidados com a higiene das mãos, alimentos e possíveis reações da quimioterapia. Recursos lúdicos, como brincadeira, desenhos e livros ilustrativos podem ser usados como estratégias para a realização das orientações. É importante a orientação das crianças em tratamento quimioterápico com uso de recursos que possibilitem sua compreensão.

DESCRIPTORIOS: Enfermagem pediátrica; Quimioterapia; Enfermagem oncológica; Informação.

LA VISIÓN DE LOS FAMILIARES ACERCA DE LAS ORIENTACIONES REALIZADAS CON NIÑOS EN QUIMIOTERAPIA ANTINEOPLÁSICA

RESUMEN: El objetivo de este estudio fue describir la visión de los familiares acerca de la orientaciones realizadas con niños en edad escolar en tratamiento quimioterápico antineoplásico, así como discutir las estrategias para orientación con esos niños. Es un estudio cualitativo descriptivo, con entrevistas semiestruturadas con 10 familiares de niños en tratamiento quimioterápico, en un hospital público de Rio de Janeiro, en periodo de marzo de 2013 a junio de 2014, por análisis temático de las informaciones. Los datos evidenciaron que la mayoría de los niños empieza el tratamiento quimioterápico sin orientaciones y que la familia es la principal responsable por la orientación. Para los familiares, el niño debe ser orientado cuanto a la enfermedad, tratamiento, cuidados con higiene de las manos, alimentos y posibles reacciones de la quimioterapia. Recursos lúdicos, como juegos, dibujos y libros ilustrativos pueden ser usados como estrategias para la realización de las orientaciones. Es importante la orientación de los niños en tratamiento quimioterápico con uso de recursos que posibiliten su comprensión.

DESCRIPTORIOS: Enfermería pediátrica; Quimioterapia; Enfermería oncológica; Información.

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● INTRODUCTION

Cancer is considered to be a global public health problem, as it covers 13% of causes of death worldwide. It is calculated that in 2020, there will be approximately 15 million new cases per year. In Brazil, cancer is in second place among the diseases which kill the most, following diseases of the circulatory apparatus⁽¹⁾.

Childhood cancer corresponds to a group of diseases which present, as a common characteristic, the accelerated growth of abnormal cells, these possibly occurring in different places in the organism. Their prevention is a challenge - as there is no evidence associating their appearance with environmental factors. In addition to this, from the clinical point of view, they present a shorter latency period and – although generally more invasive and of faster growth – respond better to the treatment, and are considered to have a good prognosis^(2,3).

After diagnosis, the treatment must be begun as soon as possible. Although there are various therapeutic modalities for treating cancer, chemotherapy, in the pediatric population, is the modality used most. It consists of the administration of antineoplastic drugs, generally orally or endovenously, which harm tumor cells – but which also damage benign cells^(2,3).

In recent decades, with the technological evolution of the antineoplastic therapies, a proportion of the treatment of the cancer is undertaken at an outpatient level, favoring the child's living at home with her family⁽¹⁾. As a result, the chemotherapy's side effects, such as fatigue, anorexia, nausea, vomiting, diarrhea, mucositis, dysuria, weight loss and alopecia⁽⁴⁾, appear at home, and cause stress for the child and her family⁽⁵⁾. In this regard, it is important that family members and children should receive guidance regarding the care measures which must be adopted in relation to these possible side effects.

As the individual is most familiar with what she needs for her own well-being, she is important and must be listened to. The health professionals must understand the experience of cancer from the perspective of the person experiencing it; and in this way help her to find ways of promoting quality of life. Thus, the child, with her family members, must be the source of information which the health professionals need in order to plan their actions⁽⁶⁾. For the appropriate inclusion of the child in the guidance and in the planning of the care during the treatment, it is necessary for the professional to know the characteristics of the phase of child development.

This study addressed the phase of child development known as school age, which covers children between 6 and 12 years old. In this phase, the children are capable of classifying, selecting, ordering and organizing the facts regarding the world for resolving problems, as well as developing the ability to read, one of the instruments which are most important for their independence⁽⁷⁾. In this way, they are able to understand what is happening around them, and when they lack access to the guidance, or do not find a space to be heard, they can react negatively to the treatment.

It was identified in one study⁽⁷⁾ that the children, due to lacking knowledge regarding chemotherapy treatment, feel fear, insecurity and hopelessness. In addition to this, chemotherapy is remembered for its side effects, which makes fear stand out.

The challenges present in the routine of the treatment of children with cancer increasingly require greater qualification on the part of the nurses, and improvement for dealing with demands. Caring in pediatric oncology is challenging, given that it requires, besides specific material and therapeutic resources, professionals who understand the specific characteristics permeating the child universe⁽¹⁾.

One Brazilian study, which had as one of its objectives to identify the guidance provided by nurses to school-age children regarding antineoplastic chemotherapy, provided evidence that a proportion of the professionals direct the guidance provided to the parents rather than to the children, although they show that they understand that the children, particularly those of school age, are already able to understand their condition and treatment, and often know more about their health situation than do their parents⁽⁸⁾.

In the international ambit, one study undertaken in three main centers of oncological treatment in the United Kingdom showed that children with cancer have concerns about the symptoms, and are

upset by the fact that communication regarding their illness and treatment takes place between their parents and the health professionals, without including them⁽⁹⁾.

Based in the above, the need is evidenced to guide the child, particularly that of school age, given that these are already able to understand the events around them. It is believed that when the children are instructed, together with their family members, in relation to the disease, treatment and necessary care, they present greater adherence to the therapy implemented and to the continuity of the care in the extra-hospital environment.

Due to the fact that the parents are the children's direct caregivers, and live together with them, one must consider their opinion regarding the guidance to be undertaken. It is therefore important that the team listens to the parents and asks them questions regarding what they consider to be important for the knowledge of the child undergoing chemotherapy treatment.

Hence, this study had as its study object: the family members' view of the guidance provided by the professionals to the children with cancer regarding the chemotherapy. The objectives were: to describe the family member's view in relation to the guidance to be undertaken with the school-age child undergoing antineoplastic chemotherapy treatment; and to discuss the strategies for providing guidance to the children undergoing antineoplastic chemotherapy treatment.

● METHOD

Qualitative descriptive research⁽¹⁰⁾. The scenario was the chemotherapy outpatient unit of a public pediatric hospital located in the State of Rio de Janeiro, which attends children receiving oncological treatment during the chemotherapy cycles.

A total of 10 family members of children undergoing chemotherapy treatment participated. The criteria for the participants' inclusion were: a) to be aged 18 years old or over; and b) family members responsible for the direct care of children receiving chemotherapy treatment. The exclusion criteria were: a) family members of children who needed to be accompanied full-time, making it impossible for the family member to be temporarily separated from the child in order to participate in the study; and b) family members who presented psychological changes which made their participation in the study impossible.

The number of participants was defined during the study, as the criteria for ceasing data collection was data saturation, defined as the suspension of the inclusion of new participants from the moment in which the data come to present a certain redundancy⁽¹¹⁾.

Data collection was undertaken in February – March 2014, through semistructured interviews with open and closed questions. The closed questions were crucial for the identification of the participants. The open questions aimed to meet this study's objectives, these being: What information regarding the chemotherapy treatment do you think is important for the child to have prior to starting chemotherapy? How do you think the professionals can guide these children? Following the participants' authorization, the interviews were recorded using an MP3 device.

The accounts were transcribed in full and following the three phases of thematic analysis⁽¹⁰⁾: (a) pre-analysis, with skim reading for investigating the content of the empirical material generated by the interviews; (b) the phase of exploring the material, when the raw data were transformed into units representing meanings, and then aggregated into the categories; (c) the phase of the treatment and interpretation of the results, when it was possible to make inferences in the light of the scientific literature regarding the guidance provided to children undergoing chemotherapy treatment.

The study was approved by the Research Ethics Committee of the institution in which it was undertaken (CAAE: 23092913.7.0000.5264/ Opinion: 520.619), and respected all the aspects found in Resolution 466/12 of the Brazilian National Health Council⁽¹²⁾.

In this regard, the study participants signed two copies of the Terms of Free and Informed Consent, one of which remained with the researcher and the other with the volunteer. The participants' anonymity was ensured through their classification by numerical order preceded by the term "volunteer".

● RESULTS

The data from the interviews were grouped into three categories referring to the guidance provided to the children and their family members, the importance of providing this guidance to the children, and the content and strategies for providing the guidance.

Providing the guidance regarding the cancer and its treatment directed towards the children and their family members

In some cases, the children began treatment without receiving any type of guidance, whether in relation to the process of becoming ill, the treatment, or the side effects:

As far as I remember, nothing was said to him before he started the treatment [...]no information was passed on about the disease or about the side effects. I was informed about what he might feel, how it would be [...]. They warned me, but they did not warn him. (Volunteer 1)

There are situations in which the child is present when this guidance is provided to the parents and, even so, no guidance is provided to her:

He [the child] was near, so she [the professional] spoke to me, but the conversation was not directed to him. (Volunteer 10)

No information was passed directly to him [the child]. The guidance was provided to us [family members]. Sometimes there were certain conversations with the doctors in which he was present and, after the doctors had left, he would even ask "what is this?" (Volunteer 4)

There are children who do not receive guidance from the professionals, as a result of which their family members take on an active role in the guidance, providing clarification regarding the disease, reactions to the treatment, and some of the necessary care:

By what little I passed on to my grandson, it was me who provided guidance to him about it being necessary to take the medicine, I spoke about the disease, but he has no notion yet about its seriousness. (Volunteer 9)

It wasn't the team, it was me that gave the guidance about his hair falling out. He knows that he has leukemia, but he doesn't know what it is. (Volunteer 7)

In some cases, it was the professionals who gave the child the information, providing guidance about the possibility of a cure and explaining the procedures to be undertaken:

We provide him with guidance, both us and the nurse. He pays attention and tells us about anything which feels different. He really takes care of himself! (Volunteer 4)

They spoke with him a lot, when he had the catheter [long-term]they explained it to him [...].It was passed on well. (Volunteer 6)

The importance of the provision of guidance by the professionals, regarding cancer and its treatment, to the children

The family members reported that they think it important for the guidance to be undertaken by the professionals, as these have more knowledge and use an appropriate language for facilitating understanding on the part of the child, as well as having greater credibility:

I think that the professional has studied more to talk about it, for passing it on in the child's language, do you know what I mean? (Volunteer 4)

I think that providing guidance is very important. Because when I talk about the things with her [child], I don't know if she believes me, or if she thinks that I am hiding something. It is better for her [the professional] to speak than me, she has greater credibility.(Volunteer 3)

For the family members, with access to information, the child can be capable of passing information on to other people, such as visitors, friends and the parents themselves. This also allows more positive behaviors for coping with the disease and the treatment:

The child has to know about the care measures if he is to explain things to people who visit and to other people one meets in the day-to-day [...] We often explain, but people don't like it, you know? They don't understand. (Volunteer 6)

So, I think it helps in the treatment [...].I think it is great that he learns about the treatment, because he is interested in knowing, he has already asked to learn about the medicine, and he explained about the disease to his friends. (Volunteer 8)

I think that the guidance helps him to understand and accept it better. (Volunteer 6)

The family members reported expectations of change following the guidance – in the case of children who have not yet been given guidance – and changes in the behavior of the children who had already been given guidance by the health professionals:

While he did not know about the disease, he remained silent, he didn't want to talk, he gave way to his feelings[...].After the doctor talked with him and explained everything, he cheered up[...]I think that he understands it better and feels better. He knows what he has to do and is calmer. (Volunteer 8)

If they explained everything about the care which he needs to have, he would help himself more. This happened when the doctor spoke about the care to be taken with foods. Now he goes to the supermarket and looks at the expiry date on things, he takes care of himself! (Volunteer 4)

Strategies for providing the children with guidance regarding cancer and its treatment

While the interviews were being held, the family members reported the information provided to the children prior to starting the chemotherapy treatment, and listed the content of the guidance which they think is important to provide.

In relation to the content, they spoke about the disease, hand hygiene care, food hygiene care, and regarding the possibility of the disease being cured; in addition to this, some mentioned the guidance related to the treatment's side effects, such as hair falling out:

I think that the team has to speak about what the disease is, how the treatment is going to be, because I can't talk about this, because I don't know. (Volunteer 10)

Explaining to them the risk which they run, explaining that if they cooperate, you can get on with it, you can treat, cure, do you know what I mean?(Volunteer 4)

You have to tell them to wash their hands, use alcohol gel, take care with the catheter, and with food [...]. All of this is important for the child to understand. The main thing is to tell them about the care. (Volunteer 6)

I think it would be important to provide guidance about hair falling out. (Volunteer 7)

The family members also pointed out that this guidance could be undertaken through conversations, with tenderness, as well as through using other resources, such as explanations, play and pictures:

Ah, if I were the nurse I would provide guidance in the best way possible, with words, with tenderness [...]. I think that by talking together, you can also explain. (Volunteer 3)

Ah, I think that you can do it through play. You can even do it by explaining, drawing, playing with paper, you can show what you have to do, how you have to clean. (Volunteer 6)

He even has a little book about chemotherapy. The book is great, it speaks in their language, and explains about the chemotherapy, about hair falling out [...]it involves the child [...].I think it is a way of helping the child to understand, because it is written in children's language and tells the story of a child his age. (Volunteer 10)

In relation to the resources used for providing this guidance, the family members indicated sensitive conversation, with tenderness, as well as the use of illustrated books, games and pictures which are able to show the procedure to be undertaken with the child. According to them, through these means of guidance, the child can better understand her process of illness, as these resources are associated with her ability to understand.

● DISCUSSION

The study data indicated that, in some cases, the children began the antineoplastic chemotherapy without understanding about their disease, its treatment or side effects, with the fact that the child was the main person involved in the chemotherapy treatment not being considered.

Hence, there is a tendency to consider the pediatric patient as a passive receptor, instead of seeing her as an active user of the health services. In this regard, the studies on childhood cancer have progressed in the absence of the opinion of the children themselves, without there being interest in researching whether the services provided by the health team correspond to their needs⁽⁹⁾. It is only recently that health professionals have come to understand that children want to receive detailed information about their illness⁽⁶⁾.

The study data indicated that the professionals provided the guidance to the family members, even when the child was close by, and that it remains the responsibility of the family to pass the information on. In this same regard, it was seen in another study that the children report receiving information about their disease and treatment directly from their parents, and did not report a single example in which they were provided with guidance by the health professionals. When questioned regarding how they would like to be advised, they said that they would like to be advised directly by the health professionals, before their parents received this information⁽⁹⁾.

In relation to the content of the guidance provided to the children, the family members indicated that they speak about the disease and the possibility of cure. However, in relation to the possible reactions to the treatment, the children are provided with guidance after presenting these. In relation to this, the literature emphasizes that, due to the lack of guidance about possible reactions to the treatment, the children may think that the reactions which they are experiencing may be permanent⁽⁹⁾.

When the children are provided with guidance, they pay attention, and communicate to the professional team anything that they feel which is different. This being the case, the guidance directed towards the child is important, as – particularly at school age – the child presents understanding of the disease itself, as well as the factors involved, according to her understanding. The children are able to understand and perceive any indication which is recognized as not normal, at an early stage⁽¹³⁾.

In the view of the family members, the health professionals have greater skill and credibility for informing the children, and use language which is compatible with the level of child development.

The form of the adaptation of the guidance to the child's age range is a delicate question. This is because the method used for guiding these children determines how the child perceives and interprets the situation and, as she matures, acquires greater skill and ability for understanding concepts related to the disease; and this influences how she can respond to the treatment⁽¹⁴⁾.

The literature shows that the children would like the health professionals to use words which they understand. In addition to this, they would like to be advised directly, clearly and specifically⁽⁹⁾.

The family members revealed that access to the information can cause positive changes in inappropriate habits which they had prior to starting the treatment. This issue has been addressed in the literature by a study undertaken with children and adolescents undergoing chemotherapy treatment, which evidence that prior to the chemotherapy, they did not take care of hygiene with their hands and foods, consuming these without washing first. After starting treatment, due to the need to wash and cook the foods, they understood that they are exposed to bacteria, and reported changing habits⁽⁶⁾.

The results also indicated the need to use creativity and resources such as play, drawing, and the use of educational materials with playful language in order to facilitate the child's understanding regarding the disease and its treatment.

It is possible to insert the child into the hospital world, and familiarize her with the procedures undertaken, through letting the child play with hospital instruments⁽¹⁵⁾. This is because play activities facilitate the acceptance of the procedures, mitigate pain, increase the child's understanding in relation to the treatment, and facilitate the bond between the child and the professional^(9,16). In the opinion of those accompanying the child undergoing chemotherapy, play activities, the availability of toys and a colored physical environment positively influence the quality of the treatment and well-being, mainly contributing to forgetting the pain and the fact of the hospitalization, as well as encouraging the continuing of the treatment⁽¹⁷⁾.

It is also emphasized that the use of pictures, storybooks and metaphors can favor the understanding of some concepts. In older children, the child can be encouraged to produce drawings about her perception in relation to the treatment and the disease, this method also being possible to be used by adults in order to facilitate explaining aspects of the treatment and disease⁽¹⁴⁾.

For the family members who participated in this study, the guidance helps the child to accept and understand the disease better, to have willpower, and to avoid possible situations of sadness and depression. That is, it increases the personal resources such that the coping may be more positive.

The use of strategies for encouraging positive coping on the part of the child and her family has been addressed in studies which emphasize the need to humanize the care provided by the health professionals. These must provide psychological support such that this involvement and emotional support may function as facilitators of the care provided to the child. This is possible through active listening, encouragement, manifestation of support and understanding, solidarity, and the ability to put oneself in the place of the other; through the sum of these practices, it is possible to obtain an efficacious affective bond, which tends to bring benefits for the treatment^(17,18).

In addition to this, other practices which optimize the child's coping are games and play activities. If added to the daily care practices, these resources favor relaxation and allow positive coping with the situation of hospitalization, given that the child both wants and needs to play^(17,18).

In addition to the resources mentioned, in the family members' view, the professionals' approach must be tender, which facilitates the child's understanding regarding her situation, minimizing the negative effects of hospitalization, based on the premise that the hospital environment triggers psychic suffering for both the patient and her family members⁽¹⁸⁾.

The results of a study which aimed to report the perception of children with cancer in relation to the care provided showed that, when questioned regarding what they thought of the nurses, the children classified them as cool, funny and helpful, also reporting their satisfaction in playing and conversing with these professionals. As well as these facts, it is possible to observe that the children reported getting to know the nurses better, and feeling more relaxed talking with them, because of the fact that the nurses spent more time with them⁽⁹⁾.

It is important to emphasize that welcoming the child with empathy, with a smile or the simple squeeze of her hand, being in a good mood and transmitting happiness and support to the patient helps both the child to establish a bond of trust with the nurse, and for this professional to feel satisfaction through providing quality work⁽¹⁹⁾.

Although not all the children were appropriately advised, the family members reported appreciating that the children received information about their disease and treatment, in particular when this was from the health professionals, as these had greater credibility.

● CONCLUSIONS

It is possible to perceive that many children begin chemotherapy treatment without receiving any information about their disease or treatment, guidance on these issues being directed to their family members. In some cases, the parents took on the role of providers of guidance, while in others, the health professionals themselves provided this guidance. Although not all the children were appropriately advised, the family members reported appreciating that the children receive information about their disease and treatment, particularly from the health professionals, as these have greater credibility.

In relation to the content of the guidance provided to the children undergoing chemotherapy treatment, the family members reported the need to hide nothing from the child, as well as to clarify the children's doubts about the disease and treatment. In addition to this, their discourses evidenced the importance of guidance regarding care with food, washing hands and foods, as well as in relation to the possible adverse reactions to the treatment.

Regarding the resources to be used for providing this guidance, some family members reported that conversation was enough. In contrast, most of the family members mention the use of resources which ensure the child's understanding, based on means and language which are suited to the child's ability to understand. This being the case, the resources mentioned by family members were the inclusion of play, through games, drawings and illustrated books, as well as a tender and humanized approach on the part of the health professionals.

As a result, one can conclude that the family members who care for children undergoing chemotherapy treatment consider it to be important for the health professionals to provide guidance to the children prior to the start of the chemotherapy treatment. Furthermore, they report the importance of the use of resources which allow this information to be understood by the children, in order to facilitate their understanding and minimize the negative effects of the treatment of the disease as – when they are not provided with guidance – the children can be overtaken by a feeling of fear, having a poor experience in relation to the treatment process.

Based on this study, one can perceive that gaps in the care still exist, which need to be filled, in relation to the provision of guidance to the child with cancer, undergoing chemotherapy treatment. It is necessary for the nurse to create strategies for sharing the information and guidance regarding the therapy implemented with the child, particularly when the child is of school age, as children at this age already have the skills and abilities to be active subjects in their care.

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