



Original Article

The strength of information on retinoblastoma for the family of the child

A força da informação sobre retinoblastoma para a família da criança
La fuerza de la información sobre retinoblastoma para la familia del niño

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Keywords

Retinoblastoma; Neoplasms; Child; Family; Health communication; Information

Descritores

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Descriptores

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Abstract

Objective: To understand the need for information from the family members of children with retinoblastoma.

Methods: A qualitative study based on the Patient and Family Centered Care Model. Families of children undergoing treatment at a referral institution in pediatric oncology participated. Qualitative content analysis guided the data collection and analysis.

Results: The strength of information on retinoblastoma for the family of these children reveals the value the family assigns to the information about the child's illness during a time of intense suffering; the paths they take to obtain the information; and, the elements considered to be essential to feel fulfilled in their own right.

Conclusion: Provision of information that respects the family's time is essential; it must be honest, and contemplate future perspectives for the child, in a dialogical space. Thus, a practice based on the Patient and Family Centered Care Model is promoted.

Resumo

Objetivo: Compreender a necessidade de informação da família da criança com retinoblastoma.

Métodos: Estudo qualitativo fundamentado no Modelo do Cuidado Centrado no Paciente e na Família. Participaram famílias de crianças em tratamento em uma instituição referência em oncologia pediátrica. A Análise Qualitativa de Conteúdo guiou a coleta e análise dos dados.

Resultados: "A força da informação sobre retinoblastoma para a família da criança" revela o valor que a família atribui à informação sobre a doença da criança, em um tempo de intenso sofrimento; os caminhos que realiza para obter as informações; e os elementos que considera essenciais para se sentir atendida em seu direito.

Conclusão: Torna-se primordial que a oferta de informações respeite o tempo da família, seja honesta, contemple as perspectivas de futuro para a criança, em um espaço dialógico. Dessa maneira, promove-se uma prática fundamentada no Modelo do Cuidado Centrado no Paciente e na Família.

Resumen

Objetivo: Comprender la necesidad de información de la familia del niño con retinoblastoma.

Métodos: Estudio cualitativo, fundamentado en el Modelo de Cuidado Centrado en el Paciente y la Familia. Participaron familias de niños tratados en institución de referencia en oncología pediátrica. Datos recolectados y analizados mediante Análisis Cuantitativo de Contenido.

Resultados: "La fuerza de la información sobre retinoblastoma para la familia del niño" revela el valor que la familia atribuye a la información sobre la enfermedad del niño en un momento de intenso sufrimiento; los caminos que transita para obtener información; y los elementos que considera esenciales para sentirse atendida en su derecho.

Conclusión: Resulta esencial que la oferta de información respete los tiempos familiares, sea honesta, contemple las perspectivas de futuro para el niño, en un espacio dialógico. De ese modo se promueve una práctica fundamentada en el Modelo de Cuidado Centrado en el Paciente y la Familia.

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Introduction

The diagnosis of retinoblastoma, a rare type of intraocular malignant tumor that affects children usually before the age of five, results in intense family emotional distress. As a previously unknown context for the family, important decisions need to be made about how to manage the disease, in a short period of time, considering that early diagnosis increases the chances of cure; however, if delayed it can spread to other parts of the body, with a poor prognosis.⁽¹⁾

Parents need to assimilate, in the short term, the diagnosis, surgery, and treatment needed, which require their understanding of the disease process and they must learn to cope with the rapid changes that occur. A two-way communication with the family members must be provided, providing information and listening to their doubts.⁽²⁾ Shared information with the family members can help them to understand the situation and directly influence their decision-making and skill acquisition. When parents know about their child's illness, they feel more in control of the situation they face, and the feelings of guilt and insecurity decrease.⁽³⁾ Studies have shown that knowledge on the disease is of crucial importance to parents, and that education through provision of information is essential.⁽⁴⁻⁶⁾

The exercise of the right to health information is a precondition for patient and family empowerment, so that they exercise the different possibilities of their health-related choices. In this process, the health professional is essential in the dissemination of information, as an intermediary for communication.⁽⁷⁾

This study is linked to a university extension project,⁽⁸⁾ which aims to bring students closer to the reality experienced by families of children with cancer who are receiving care at a pediatric oncology institute, and to promote the exchange of knowledge among family, students and professionals of the team in order to contribute to better care practices. From the lived experiences in this scenario, it was possible to understand that for the family of a child with retinoblastoma, demands for information are revealed during patient care. So, listening

to the family was considered relevant, as a basis for the proposal of innovative actions for the provision of information.

The objective of the study was to understand the need for information from the family of the child with retinoblastoma.

Methods

An exploratory-descriptive qualitative study designed to understand the phenomena according to the participants' perspective. The philosophy of Patient and Family-Centered Care (PFCC)⁽⁹⁾ was the framework of reference used to understand the need for family information related to the care of child with retinoblastoma.

The *Institute for Patient and Family-Centered Care* (IPFCC) defines PFCC as a partnership-based planning, delivery, and evaluation of health care, grounded in mutual benefits among patients, families and health care providers.⁽⁹⁾ This model advocates including the family members in planning, considering their influence on the patient's health, and as a partner in improving the care practices and the care system. It is a philosophy designed for patients of all ages, and can be practiced in any health service by all health professionals. It is based on four central assumptions:⁽⁹⁾

Dignity and respect: Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

Information shared: Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are useful, and which receive timely, complete and accurate information in order to effectively participate in care and in decision-making.

Participation: Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Collaboration: Patients and families are included as a supporting base for the institution; health care leaders collaborate with patients and families in pol-

icy and program development, implementation and evaluation, and in facilitating health care in professional education and in the delivery of care.

In this sense, information is critical to the child's and the family's care, through which the health team shares its knowledge according to the needs and available time of the family, and families also participate in care and share important information that is included in the planning of care.

The methodological framework that was used was Qualitative Content Analysis,⁽¹⁰⁾ which aims to develop a condensed and broad description of the phenomenon studied, resulting in concepts or categories that describe it.

The study was conducted at a pediatric oncology institute, in the city of São Paulo. It is a non-profit social institution that assists children with cancer, from birth to 18 years of age, derived from several states of Brazil and other Latin American countries. The institution is a reference site in the care of children with retinoblastoma, reaching cure rates of approximately 90% if diagnosed early.

The care provided at the institution is predominantly outpatient. The child with retinoblastoma undergoes consultations with medical professionals and with specialist nurses in the area, as well as being referred to other specialties depending on the demand required.

As inclusion criterion, we defined families of children who had been diagnosed with retinoblastoma for at least one month and who were receiving outpatient treatment, as it is known that a great amount of information is shared with the family during this period, due to the rapidity of events that happens between diagnosis and initiation of treatment. Families of children without the possibility of cure were excluded, in respect for the suffering experienced at that moment.

The study was conducted between April and October of 2014, using semi-structured and individual interviews with each family, whose members could be together and participate at the same time, if desired, in a reserved space in the institution; these were recorded to ensure that no data were lost. At first, the genogram and the ecomap of the family were developed, in order to bring the researcher

closer to the reality of the family.⁽²⁾ Then, the interviews were begun, using the guiding questions: Tell us, how was it for you (family) to receive information on (child's name)'s illness? What do you consider relevant to know about the disease situation and/or treatment in order to be able to take care of your child? Other questions were formulated, as the interview progressed, to provide further clarification and facilitate the researcher's understanding of the need for information perceived by the family in the course of the disease, such as: What information did you consider relevant? How did you find out about the disease? What about the treatment? After each interview, the researcher wrote down his observations and perceptions.

All the narratives were transcribed in their entirety by the researcher, and were later analyzed according to Qualitative Content Analysis.⁽¹⁰⁾ In the categorization stage, the codes were grouped according to their significance and conceptual similarities or divergences, which gave rise to the categories. Finally, common themes between categories and subcategories were chosen, and the relationship between them was identified, based on their agreement, antecedents or consequences.⁽¹⁰⁾

At the beginning of the data collection, participants received information on the purpose of the study, the data collection procedure, and the ethical implications. They also read and signed the Terms of Free and Informed Consent Form. To preserve the anonymity of the participants, the interviews were identified with the letter "E" (Interviewee), followed by an Arabic numeral indicating the sequence of interviews.

Ethical requirements established in Resolution 466/2012 of the National Health Council were fulfilled, and the research was approved by the Ethics Committee on Research Involving Human Beings of the Institution of higher education, under decision number 655.931/2014.

Results

Ten families of ten children diagnosed with retinoblastoma participated in the study, represented by

nine mothers and one grandmother. Although the majority of the participants were the mothers of the child, the focus was on the family as a whole, in order to understand how its members deal with the information they do and do not receive from the professionals. The characteristics of the children and their families are presented in chart 1.

Chart 1. Characteristics of the family, according to the degree of kinship and age and of the children, age and position in the family, diagnosis, diagnosis time, and treatment status at the time of the interview

Family	Family age	Current child age/ position in the family	Diagnosis/time of diagnosis	Treatment status at the time of the interview
E1 (mother)	21 years	4y/1 st child	Unilateral RB/4m	Enucleation + Chemotherapy
E2 (mother)	26 years	3y/1 st child	Unilateral RB/8m	Chemotherapy
E3 (mother)	21 years	2y/1 st child	Unilateral RB /1y	Chemotherapy
E4 (mother)	21 years	1y/1 st child	Unilateral Rb/1m	Enucleation
E5 (mother)	38 years	2y 6m/3 rd child	Bilateral Rb/2y3m	Enucleation
E6 (mother)	45 years	2y 9m/1 st child	Bilateral Rb/2y6m	Chemotherapy
E7 (mother)	28 years	1y/1 st child	Bilateral Rb/5m	Enucleation + Chemotherapy
E8 (mother)	25 years	2y/1 st child	Bilateral Rb/2y	Follow-up
E9 (mother)	29 years	8m/1 st child	Bilateral Rb/7m	Enucleation + Chemotherapy + laser therapy
E10 (grand mother)	45 years	3y/1 st child	Unilateral Rb/3y	Outpatient follow-up

Rb - retinoblastoma; Age in years (y) and months (m)

The analysis enabled the identification of the topic, “The strength of information on retinoblastoma for the family of the child”, which reveals the value that the family attributes to the information about the child’s disease, his/her chances of survival, the therapeutic procedures, the paths they take in order to obtain the information, and the elements considered essential to feel fulfilled in their rights, in a time of intense suffering caused by the discovery of the cancer. This topic is composed of the categories: *suffering intensified by lack of information; searching for their right for information; and, essential elements of information from the perspective of the family*, which are presented below.

Suffering intensified by lack of information

The family members of the child with retinoblastoma experiences intense suffering, from the moment they perceive something different in the child’s eyes and do not know what it is, which triggers restless-

ness in the family which then seeks information from specialists. However, their suffering is intensified when they are referred to other specialist centers without further explanation, and also when the child is subjected to numerous tests without information about what is happening, leading to expectation of the results.

They just kept taking tests, tests, tests, and finally we were sent here (hospital), but they also did not tell me why (E4).

In fact, I did not know what the exam was going to look like, I just learned after they opened it. It has to be done with them (children) sleeping, to take the pictures, and they showed several pictures of how it is inside the eye, but they did not tell me any of this (E1).

With the confirmation of the diagnosis, the fear comes, because they do not understand this disease and the reason for it having affected their child. The despair and panic of losing their child are present; for the family, the word “cancer” is related to death. The unknown scares the family and makes them insecure about what is to come.

It was very difficult; it was a shock for us. Knowing that a tumor like that is in a young child, we were scared (E10).

We did not know, we had never heard of it. Where we live, nobody ever told us about retinoblastoma (E3).

Even when the family receives adequate information, the situation is difficult for them to understand, because they are impacted by the news, fear, and stress. They need some time to process the information so they can understand what is happening.

And even with him (physician) explaining everything to me, the day he (child) had to have the operation, I didn’t want to authorize it, I didn’t want to sign the authorization. It was very painful (E1).

At the time we got very nervous and sometimes it hasn’t hit me completely. At the time it hit me, it happened gradually. As the time was passing, I understood better the situation. At that moment (or right there) we were shocked and didn’t understand what was happening (E5).

Searching for their right for information

In addition to the suffering experienced by the family due to the examinations and the revelation of

the diagnosis, there is a movement to understand the situation in the best possible way. Right then, having access to information is critical. The family members want to know about the illness in order to understand what is really going on with their child, to decide on the best treatment, and to make all necessary efforts to obtain it.

[...] they (professionals) explain everything. When we came here for the first time, he (physician) explained this, that his eyes could be removed. But, because we came at the beginning, it was not necessary, it would be able to be controlled, and thank God, it was. (E10) It is extremely important that you go after, run after this information, no matter where it comes from (E2)

For the family, being able to understand what is happening to the child is paramount, and this knowledge can also come from the interaction with other families who are experiencing the same situation. In this exchange of information, the family members understand that they are not alone.

It's important for us to know about the disease he has. Knowing that several cases like that exist, that he (child) was not the only one, that many children have it (E5).

When the family receives information, whether it is about the disease or about the resources available for diagnosis and treatment, they feel safer and at peace, believing that the child will receive good treatment and a better chance of cure. In his view, knowledge about retinoblastoma is a right that should be guaranteed through media outreach, which would save many lives and reduce the number of children who lose vision, because of delayed diagnosis. However, if the information is not clear, or if the family wants to know more about the disease and its evolution, one of the means that they use to get it is on the internet. However, due to the diversity of content in the digital environment, one is frightened by images seen.

But I think that television should publish more about it, for all, newspapers, it would be important for all children, for everybody, it is our right to know ... It would have helped me to understand and often saved many children who do not have more ways to save the little eye (E3).

I've seen a lot more advanced cases, do you understand me? And his, thank God, it was not like this case

that I saw on the internet, so I preferred not even to have looked, to have just looked at his (E4).

Essential elements of information from the perspective of the family

The family members of the child with retinoblastoma aim to receive information about the disease and treatment; however, they consider it fundamental for their time for information assimilation to be respected, to understand the information that is revealed to them.

At the time the physician speaks we are very nervous, I just cried nonstop, and could not understand many things, sometimes it hasn't hit me, it happened gradually, and as the time was passing, I understood better the situation. At the time we are shocked and don't understand what is happening (E5)

In this sense, the family considers it to be important that professionals open spaces for dialogue, in which there is clarification of their doubts and desires. In addition, the family considers that the honesty of the information, from the beginning, makes the relationship with health professionals more transparent. Thus, the family, empowered with the information, becomes more active and participatory during the treatment.

An interesting thing would be if he (the physician) could be one day here to clear up our doubts [...] It would be great to talk to the person who is dealing exactly with your child's problem (E2)

I think it has to be like that, as we have a problem, we have to talk about it, it does not help to "run over", it has to be the way it is and that's it. There is no sense in picking the words for it ... we have to talk about what it is (E5).

They also consider that it is relevant to know about the future prospects of the child, about everything that can happen to him. This supports them and gives them a sense of security in the moment they are living. The consequences of treatment and prognosis can be understood much more, and help them to maintain hope that their child can have a better future.

The part of the prosthesis (eyepiece), which I found interesting, which I did not know, helps a lot. We have seen some children who have a prosthesis and we do not know

which one is the real eye and which one is the prosthesis. I was very worried at first about this, of it not looking the same. I've found this very important to know (E9).

Discussion

The family of the child with retinoblastoma is composed of young parents with small children, who are in the process of expansion through the birth of children. The discovery of the disease, at that moment, imposes many demands, added to the normal tasks of this phase of family development, triggering a crisis.⁽²⁾

In this study, the family members reveal the strength that information give them to understand what is happening to their child, indicating gaps in communication with professionals and their search for the right to be informed about the disease, its evolution and treatment, as well as the feelings involved in this process. The family members are eager for information, value all aspects related to the health state of the child, and the knowledge of the implications that may influence their future.

However, health professionals are still not very effective in providing for the information needs of the family members, as they appear to have an unclear perspective on what they value, which contributes to increasing parents' anxiety and insecurity.⁽¹¹⁾

Uncertainty about the disease is directly linked to insecurity. In this sense, it is known that sharing information with the family is able to empower them, which is helpful for making decisions.⁽⁹⁾ Empowerment by means of information plays a fundamental role in the process of self-transformation of the person, insofar as which provides an environment of change, with the aim of providing individuals with autonomy.⁽⁷⁾

A study conducted by Israeli authors⁽²⁾ with 12 couples in the management of the diagnosis of a child with retinoblastoma showed that: a) parents who understood their child's current situation better dealt with difficulties and anxieties; b) parents who had more ability to separate rational and emotional elements coped better with the experience; c) the support of the multiprofessional team and of parents who have experienced this situation was relevant to helping them to cope.

Information about the child's cancer is a constant need of the family. It is known that it changes, in terms of content and amount of information, according to the moments experienced by the child and his family. Therefore, it is fundamental to have a communicative exchange between the health professionals and the family, in addition to the subsidy of educational materials and strategies that transmit the information in a clear and objective way.⁽¹²⁾

The professionals who work in the hospital space can and should contribute to the construction of knowledge, sharing information with the family, considering that the hospital is also a pedagogical space. In this sense, educational materials are important allies because they help in cases of doubts and direct care, as well as with standardizing the guidelines to avoid contradictory information.⁽¹³⁾ However, regardless of the information strategy adopted, the health professional needs to manage how the information is given to the family. Parents often feel confused by the available information, and the effort to understand and manage everything is described as being similar to learning a new language.⁽¹²⁾

In a study⁽¹⁴⁾ published in the United States of America, the authors developed a tool to facilitate parents' understanding of the complexity of and risks associated with retinoblastoma, denominated the DePICT (Disease-specific electronic Patient Illustrated Clinical Timeline), which displays real-time information on the full course of treatment in addition to the child's clinical data. The study shows that graphical tools can help with the reasoning and understanding of complex ideas with precision and efficiency. The evaluation of the tool showed its usefulness, which facilitated the understanding by the parents, even those who had difficulties in understanding about the treatment and the prognosis due to educational limitations.

In addition, the family wishes to receive information during all stages of the disease.⁽¹⁵⁾ However, it is necessary to respect the time needed for understanding and comprehending the information. Authors⁽¹⁶⁾ recommend that, in the diagnostic phase, the flow of information should be considered "one-way", that is, of health professionals to parents, so that trust is based on the perception that professionals have the

specialized knowledge to take care of the child. In the learning phase, the flow of information should be considered as a “two-way”, that is, between parents and professionals, in order to know much more about the family’s daily life, care, and abilities to care for the child, developing a mutual trust, a bond and, consequently, improving communication between both, for the family to help and participate with the appropriate care for the child.⁽¹⁶⁾

Thus, it is understood that effective communication between the health professional and the family members provides significant support in the course of the disease. The family members leaves the role of passive subjects and begin to interact with the team to expose their doubts, their anguish, and their feelings during the treatment.⁽¹⁷⁾

Information has been identified to be a crucial element, which needs to be taken into account by the team to provide good care for the family members, who are anxious and often do not understand what they are told, and feel powerless due to events that cannot be predicted. The nursing team should provide information to the family about the health of the child, in order to gain their confidence, because good communication between the nurse and the family reduces anxiety and increases the family’s participation in the care of the child.⁽¹⁸⁾

In this study, individual interviews were used with the family members who had the experience of a child with retinoblastoma. In view of this, broader studies are suggested, including health professionals as participants, in order to deepen the understanding of the need for family information and communication between the family and the professional.

It is hoped that this study will lead to initiatives to assure the family members their right to information. It is recommended to adopt an institutional policy that encourages investments to guarantee the family access to information.

Conclusion

The study showed that sharing information with the family present gaps that compromise the quality of the care provided, since, although there is a commu-

nication between the professionals and the family, the information is not available in a complete and continuous way. The study revealed the value that information has for the family, and the essential elements considered to cope with the situation, such as respect for the time they need, and honesty, including information about the disease, treatment, prognosis and future prospects for the child, in a dialogical space so that they can be received and have their doubts clarified. For information to be effective, it is necessary that it gets to the family and that the family understands it. It is fundamental that the health team recognizes the right of the family members to receive information, and incorporates strategies that promote their involvement and participation, so that the shared information is converted into their knowledge and empowers their decision-making. The development of educational materials is recommended, which should contain information about retinoblastoma, so that the family can use it according to their own time, allied to a continuous space of listening and welcoming, promoting dialogue and clarification of their doubts. It is about guaranteeing their right to information.

Collaborations

Amador DD, Marcílio AC, Soares JS, Marques FRB, Duarte AM e Mandetta MA contributed to the study design, data analysis, article writing, relevant critical review of the intellectual content, and final approval of the version to be published.

References

1. Faranoush M., Hedayati-Asl AA, Mehrvar A, Mehrvar N, Zangoeei R, Abadi E, et al. Consequences of delayed diagnosis in treatment of retinoblastoma. *Iran J Pediatr.* 2014;24(4):381-6.
2. Gedleah A, Lee S, Hill JA, Umukunda Y, Qaiser S, Kabiru J, et al. “Where Does it Come from?” Experiences among survivors and parents of children with retinoblastoma in Kenya. *J Genet Couns.* 2017 Nov 23[Epub ahead of print]
3. Maree JE, Parker S, Kaplan L, Oosthuizen R. The information needs of south african parents of children with cancer. *J Pediatr Oncol Nurs.* 2016;33(1): 9–17.
4. Pinto JP, Mandetta MA, Ribeiro CA. The family living the child recovery process after hospital discharge. *Rev Bras Enferm.* 2015;68(4):594-602.

5. Gibbins J, Steinhardt K, Beinart H. A systematic review of qualitative studies exploring the experience of parents whose child is diagnosed and treated for cancer. *J Pediatr Oncol Nurs*. 2012; 29(5): 253-71.
6. Aburn G, Gott M. Education given to parents of children newly diagnosed with acute lymphoblastic leukemia: A narrative review. *J Pediatr Oncol Nurs*. 2011;28(5):300-5.
7. Leite RA, Brito ES, Silva LM, Palha PF, Ventura CA. Access to healthcare information and comprehensive care: perceptions of users of a public service. *Interface (Botucatu)*. 2014;18(51):661-71.
8. Marques FR, Duarte AM, Ressureição TL, Silva JR, Mandetta MA. Cuidado centrado no paciente e família em oncologia pediátrica: relato de experiência de um projeto de extensão. *Interfaces*. 2014;2(3):95-104.
9. Institute for Family-Centered Care. Partnering with patients and families to design a patient-and family-centered health care system: recommendations and promising practices. Bethesda, MD: Institute for Patient and Family - Centered Care [internet] 2012 [cited 2016 oct 11]. Available from: <http://www.familycenteredcare.org/pdf/PartneringwithPatientsandFamilies.pdf>
10. Morse JM, Field PA. *Qualitative research methods for health professionals*. 2nd ed. Thousand Oaks: Sage; 1995.
11. Melo EM, Ferreira PL, Lima RA, Mello DF. The involvement of parents in the healthcare provided to hospitalized children. *Rev Lat Am Enfermagem*. 2014;22(3):432-9.
12. Ringnér A, Karlsson S, Hällgren Graneheim U. A person-centred intervention for providing information to parents of children with cancer. Experiences and effects. *Eur J Oncol Nurs*. 2014;19(3):318-24.
13. Rodgers CC, Laing CM, Herring RA, Tena N, Leonardelli A, Hockenberry M, Hendricks-Ferguson V. Understanding effective delivery of patient and family education in pediatric oncology: A Systematic Review From the Children's Oncology Group. *J Pediatr Oncol Nurs*. 2016; 33(6):432-46.
14. Panton RL, Downie R, Truong T, MacKeen L, Kabene S, Yi QL, et al. A visual approach to providing prognostic information to parents of children with retinoblastoma. *Psycho-Oncol*. 2009;18(3):300-4.
15. Santos CQ, Figueiredo MCB. Experiências dos familiares no processo de adaptação à doença oncológica na criança. *Rev Enf Ref*. 2013;3(9):55-65.
16. Nuutila L, Salanter S. Children with a long-term illness: parents' experiences of care. *J Pediatr Nurs*. 2006;21(2):153-60.
17. Grant L, Sangha A, Lister S, Wiseman T. Cancer and the family: assessment, communication and brief interventions-the development of an educational programme for healthcare professionals when a parent has cancer. *BMJ Support Palliat Care*. 2016;6(4):493-9.
18. Santos MR, Silva L, Misko MD, Poles K, Bouso RS. Unveiling humanized care: nurses' perceptions in pediatric oncology. *Texto Contexto Enferm*. 2013;22(3):646-53.