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Coping with the diagnosis and hospitalization of a child with childhood cancer

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Coping with the diagnosis and hospitalization of a child with childhood cancer

Objective. Find out how family members cope with hospitalization due to the diagnosis of childhood cancer. **Methodology.** This is a descriptive-exploratory design study with qualitative data analyses, undertaken in the Support Center for Childhood Cancer in Salvador, Bahia, Brazil. 10 members of the families of children with cancer underwent a semi-structured interview as a resource to collect empirical data. Data were submitted to thematic content analysis. Two categories emerged: "family coping with diagnosis" and "family coping with hospitalization." **Results.** It was observed that family members suffer deeply and cope with the diagnosis of cancer in different manners. In addition, psychological stress has a cumulative impact on long periods of hospitalization and occurs in the presence of sadness, anxiety, suffering due to the invasive procedures the children are submitted to, fear and uncertainties related to prognosis. **Conclusion.** The diagnosis of cancer and hospitalization process causes severe impact on family dynamics. A competent nurse must be aware and sensitive to minimize this suffering by listening carefully and providing humanized and comprehensive care to children and their families.

Key words: family; child; diagnosis; cancer; hospitalization.

Afrontamiento del diagnóstico y hospitalización del niño con cáncer infantil

Objetivo. Conocer cómo los miembros de la familia afrontan la hospitalización debido al diagnóstico de cáncer infantil. **Metodología.** Estudio descriptivo, exploratorio, con el análisis de datos cualitativos en un Núcleo de Apoyo para combatir el cáncer infantil en la ciudad de Salvador, Bahía, Brasil. Se practicó una entrevista semi-estructurada a 10 miembros de las familias de niños con cáncer como un recurso para reunir datos empíricos. La información fue sometida a análisis de contenido temático. Emergieron dos categorías: "afrontamiento del diagnóstico por la familia" y "afrontamiento de la hospitalización por la familia". **Resultados.** Los miembros de la familia sufren profundamente

y enfrentan de manera diferente al diagnóstico de cáncer. Además, se produce en ellos un desequilibrio emocional y estrés, que tiene repercusiones acumulativas en los largos períodos de internación donde afloran la tristeza, la ansiedad, el sufrimiento por los procedimientos invasivos realizados a los niños, el miedo y la incertidumbre relacionada con el pronóstico. **Conclusión.** El diagnóstico de cáncer y el proceso de hospitalización producen un grave impacto en la dinámica familiar. La enfermera, además de competente, debe ser consciente y sensible con el fin de minimizar este sufrimiento mediante la escucha y la atención humanizada e integral al niño y su familia.

Palabras clave: familia; niño; diagnóstico; cáncer; hospitalización.

Enfrentamento do diagnóstico e hospitalização do filho com câncer infantojuvenil

Objetivo. Conhecer como os membros da família enfrentam a hospitalização devido a um diagnóstico de câncer infantil. **Metodologia.** Este é um estudo descritivo, exploratório, com análise qualitativa dos dados em um Núcleo de Apoio ao Combate do Câncer Infantil da cidade de Salvador, Bahia, Brasil. 10 familiares de crianças com câncer foram submetidos a uma entrevista semiestruturada como recurso para coleta do material empírico. Os dados foram submetidos à análise de conteúdo temática. Emergiram duas categorias: "enfrentamento do diagnóstico pela família"; e "enfrentamento da hospitalização pela família". **Resultados.** Observou-se que os membros da família sofrem profundamente e enfrentam de diferentes formas o diagnóstico de câncer. Além disso, o estresse emocional e desequilíbrio, que tem impacto cumulativo nos longos períodos de internação ocorrem simultaneamente com tristeza, ansiedade, sofrimento pelos procedimentos invasivos realizados nas crianças, medo e incertezas relacionadas com o prognóstico. **Conclusão.** O diagnóstico de câncer e o processo de hospitalização provocam um forte impacto na dinâmica familiar. O enfermeiro de forma competente deve estar consciente e sensível, a fim de minimizar esse sofrimento, através da escuta atenta e assistência humanizada e integral à criança e sua família.

Palavras chave: família; criança; diagnóstico; câncer; hospitalização.

Introduction

The National Cancer Institute of the United States confirms that, over the past 20 years, the incidence of children diagnosed with all forms of invasive cancers increased from 11.5 cases per 100 000 inhabitants in 1975 to 14.8 cases per 100 000 children in 2012.¹ Childhood cancer (between 0 and 19 years) corresponds to 1% and 3% of all malignant tumors in most populations.² The estimated occurrence of pediatric tumors in Brazil for 2014-2015 is an average percentage of approximately 11 840 new cases of cancer in children and teenagers up to 19 years of age.³ From a clinical point of view, the cancer that afflicts the pediatric population has short latency periods, is more aggressive and grows fast, however, they respond better to treatment and are considered as having a good prognosis.

Despite the gradual and linear increase in the incidence of childhood tumors around the world, it has been observed that, in parallel with such increase, the healing rates of these neoplasms have also increased. Advances in the treatment and early detection methods over the past three decades have made the survival of more than 70% patients possible when the diagnosis is made in an early stage and when the treatment is specialized.^{2,3} Despite the progress made in terms of cure and survival rates, no matter what the treatment and the prognosis are, cancer is an experience that undermines all references of the patient, taking into account their relationship with their bodies, families, society, the roles that they play in society and even their sense of identity, value and confidence in themselves.⁴ In addition,

the childhood cancer diagnosis is one of the most difficult realities that a child or teenager and their families may face.⁴

The revelation of the cancer diagnosis implies in experiencing situations marked by insecurity, danger, suffering and pain and, in the case of childhood cancer, this revelation unfolds into two moments for the parents: the relief in knowing the diagnosis of their child and the fear merged to the sensation that the doctor will seal the their fate. In many cases, it has been observed that the diagnosis of cancer is perceived like receiving a death sentence.⁵ In this context, the child or teenager and their family require a healthcare approach focused on quality of life.⁶ The communication of the diagnosis is a delicate moment for the patient, the family members and the entire multidisciplinary team, as it is related to existential changes that pervade the world of the child, the family and those who professionally care for them. The difficulty of this arduous task lies not only on the verbal formulation of the diagnosis and prognosis from a technical point of view, but above all, on the emotional burden that will be placed on the family and the patient receiving the diagnosis.⁵

Furthermore, the child usually faces prolonged and frequent periods of hospitalization, which have repercussions in their processes of growth and development, since the treatments are long-term, debilitating and intensive processes, resulting in late effects of therapy itself and the course of the disease.⁷ This whole process often culminates in the interruption of everyday activities and social disconnection to the extent that patients are separated from their family centers and friends, resulting in discomfort and strain for both the patient and their family members.^{8,9} In addition to coping with the diagnosis and hospitalization process, many challenges are still present, among which are: the search for quality of life of the children and their families, the search for accurate, fast and efficient treatments, the search for policies that ensure equitable access to therapy and also to the care by health professionals accountable for interpersonal relationships.^{10,11}

The reactions triggered in the families of children with cancer sometimes result in an illness process of one or more of its members during this experience, changing the family's dynamics. This fact must be increasingly considered by health professionals as well as the awareness of the need to take care of both the child diagnosed and their families, because cancer involves high economic and psychosocial burden for those involved. The care of a child or teenager with cancer is an arduous and sometimes painful process for everyone involved. The consideration, welcoming and appreciation of the autonomous and collaborative participation in the decision-making process regarding the care of pediatric oncology patients and their families demand nurses to develop methods of approach that take into account their needs, which must excel at an individualized care according to the specific characteristics of each case.⁶ In addition, the nurse must be adequately prepared to care for children and adolescents with cancer. Many studies emphasize the importance of education of these professionals to improve the quality of their care through a continuous updating of their knowledge and skills for specific programs of permanent education.⁹⁻¹²

Although the national and international scientific production on the impact of childhood cancer is gradually growing, the information on how family members cope with the diagnosis and with the child's hospitalization process is still limited in the Brazilian scenario.¹³ In this context, this study aimed to find out how family members cope with hospitalization due to the diagnosis of childhood cancer. It is expected that this kind of information may contribute to the acceptance of the behavior and reactions of family members who are under this condition. In addition to the provision of resources for nursing care in search of evidence that may help these professionals deal with this problem.

Methodology

This is a descriptive and exploratory study using a qualitative approach of data, undertaken at the

Support Center for Childhood Cancer in the City of Salvador, Bahia, Brazil. The scenario elected for this study guarantees children and adolescents with cancer will receive the attention and support required for their treatment and is aimed at supporting low-income families from Salvador and other cities in the State of Bahia during their rotational hospital stays and during periods they have to stay away from home to accompany their children undergoing cancer treatment. The research project was approved by the Institutional Review Board of "Instituto Mantenedor de Ensino Superior (IMES), under Protocol no. 3 477 and follows the ethics guidelines of Resolution no. 196/1996, of the Brazilian National Health Council (CNS). CNS Resolution 466/2012 which regulates human research in Brazil was recently approved and is in force. The present study followed the ethical principles established by the current norm. Participants who volunteered to participate in the study were informed about its objectives, gave their consent and then signed the Written Informed Consent Form.

Inclusion criteria were: being a family member of a child and/or adolescent hospitalized due to the diagnosis of cancer at the Support Center; being the accompanying person responsible for the child and/or adolescent during hospitalization. The study sample included nine mothers and one father of children or adolescents with a diagnosis of cancer hospitalized at the Support Center in different periods in the course of their disease. We highlight that sample size ($n=10$) was determined due to a saturation of data, i.e., there were no new theoretical insights, nor were there new information on the study object.

Data collection was performed on September 2012, using a semi-structured interview which was recorded and was later fully transcribed. A questionnaire was prepared and divided into two parts. The first one included sociodemographic and clinical questions about the patient: age, gender, place of origin, level of education of the child or adolescent, number of siblings, age at the time of diagnosis of the neoplasia, type of tumor, hospitalization time; the second part

included questions regarding family coping with a diagnosis of cancer and related hospitalizations of the children or adolescent. To guarantee spontaneity and promote a safe and comfortable environment, the interviews were held separately in a reserved room. To preserve the identity of the study subjects, a code was given to each one of them: a word followed by a number following the order of the interviews. For instance: family member 01; family member 02, and so on. To analyze the empirical material, we used a technique for the analysis of content according to its thematic modality. This technique is aimed at describing the content of messages by means of the analyses of communications using systematic procedures.¹⁴ The analysis of content was based on the information collected in the interviews, which were organized to identify common meanings and were later grouped into two categories.¹⁴

Results

Of the 10 family members, nine are mothers and one is the father of a child or adolescent with cancer. Mean age of the family members was 39.9 years, ranging between 20 and 52 years. Most ($n=9$) of the participants were from different cities in the state of Bahia and only one was from the capital city. The time of treatment of the children or adolescents ranged between 2 months and 8 years. The types of neoplasia were: 4 cases of leukemia, one adenocarcinoma, one soft tissue sarcoma, one lymphoma, one osteosarcoma, one hepatoblastoma and one peritoneal tumor. Children's age ranged between 1 year and 11 months to 14 years. Eight of these families had more than one child which made things even more difficult. In order to support the analysis and discussion of the results, two thematic categories emerged from the data: how families coped with the diagnosis and how families coped with hospitalization.

Coping with the diagnosis

The first statements analyzed reveal that, although the parents were concerned with the

symptoms present in the children, they did not expect such impacting bad news. This can be noted in the following statements which were made by family members upon the onset of the disease: *"I was worried during her early signs and symptoms, such as fever, but I didn't think it would be a problem like this, I thought it would be something simple (...)"* (Family Member 02); *"I started to get worried when my son lost weight in the same week he did the required tests. I knew something serious was going on, you know?"* (Family Member 03). During the interviews we observed that cancer is still a term surrounded by several taboos. An interesting fact detected in the statements was that the term "cancer" did not appear in the respondents' speeches: *"When the doctor informed that it was this illness, my reaction was despair, I could not accept it" (...)* (Family Member 07); *"When the doctor informed he had this problem in his liver, it was a shock, I cried a lot at the hospital"* (Family Member 04); *"After the test results, that's when I found out that he had this problem (...), it is very difficult to see your son well and, all of a sudden, with this problem"* (Family Member 02).

The family members reported that the confirmation of the child's cancer diagnosis was the most intense moment of suffering due to the fear of the unknown. This entails a very large impact, both on the children and their families: *"It was such a blow when I found out, a very big shock. The doctors didn't know if they should attend me or my daughter at the time"* (Family Member 09). Reactions of shock, despair, crying, denial and fear were highlighted along with the emotions present at the time of the interviews. This can be observed from some family members' testimonials when they received the diagnosis: *"I shook so much, I couldn't think straight. I have been crying since the day I found out, I couldn't think. It feels like you are out of your mind and I could not believe that it was happening (...); I was shocked and very scared. At first, I had the feeling that it was a lie, that he was not sick, the exam must be wrong"* (Family Member 03); *"The moment I got the diagnosis I didn't believe it. You know the feeling of suffering a blow to the heart?"*

I thought my son was death sentenced already, because I didn't know there was a cure, I was even giving up on my boy (...)" (Familial 06); *"I couldn't understanding anything, I was in shock because I have 10 children and none of them have this problem (...); For us mothers who aren't familiar with the disease, finding this out is as if the world had collapsed on top of me, it's like I don't have the ground underneath me. I even thought it could be contagious, because I didn't have a lot of information. It was a terrible fight, he (referring to her son) was very weak and I was devastated"* (Family Member 08).

Coping with the hospitalization

The process of hospitalization is seen as a critical and delicate situation for both the children and their families. To have a relative hospitalized, especially if it is a child, carries a great psychological stress and emotional disparity, which has cumulative effects in long periods of hospitalization due to the peculiarities of the unfamiliar surroundings and to feelings like sadness, anxiety, suffering due to invasive procedures performed in the children, fear and uncertainties in relation to the prognosis: *"the most intense moment was my sons' hospitalization for a month. I needed my mother to come from the country side to stay with me there because I was so devastated (...)* it was shocking to stay there in the Pediatric Oncology, it's horrible and agonizing to stay there in that hospital and see other children suffering and dying, you end up thinking the worst, you know? I kept praying to get out of there and, thank God, he responded well to chemotherapy" (Family Member 04). Some families with children bearing this pathology had to experience seeking treatment in different cities. In these cases it becomes necessary to build another life routine, as well re-evaluate the roles and tasks of the family members: *"what makes me nervous is that nobody ever tells you when you can go home. I never know when the treatment may end (...)"* (Family Member 07); *"I was shaking all over when I saw my daughter going to surgery"* (Family Member 09); *"The saddest and scariest moment was when I saw my daughter intubated in the ICU of Martagão"* (Family Member 10).

Discussion

Parents believe that the signs and symptoms presented in the beginning reflect “the pains of growing” or that they are associated to a problem that might be easily solved. However, the definition of the diagnosis is more difficult if the child does not have severe limitations resulting from the disease. It was observed that in the beginning the similarities between the signs and symptoms of cancer with other more common diseases in children make an early diagnosis more difficult. Families maintain their responsibilities and function and having cancer is still confounded as a “normal” disease in children.¹⁵ When they talk about cancer, family members use the word “disease” or “problem”, indicating how difficult it is for them to accept the diagnosis of cancer of their child. Often times, this leads family members to use defense mechanisms such as denial. However, this type of behaviour associated to other emotional reactions may interfere with the level of understanding of the parents, with treatment compliance and also have a negative impact on the behavior of the child.¹⁶

Communicating bad news about children to them and their families, as it is the case with cancer, is very complex and involves different professionals of the multiprofessional healthcare team, in addition to the children and adolescents themselves, their parents and other family members and caregivers and is also influenced by the development and cognitive level of the patient. Furthermore, it includes the family interaction dynamics and the different needs of parents and children.¹⁷ Parents, main stakeholders in the lives of children with a chronic disease, such as cancer.¹³ Concomitantly, parents experience a feeling of oppression by the amount of technical information and they also have to cope with their fears and anxiety about the disease to make decisions about treatment.¹⁸ Many parents report having difficulty to deal with the emotional resources required to prepare their children adequately to struggle with cancer. In addition, parents have difficulties expressing their feelings and tend to internalize their negative emotions. This is invariably manifested as somatic

complaints and a feeling of emotional burden caused by their child's disease.¹⁸

Even though the family is considered as a support pillar, usually in situations like this they experience a feeling of hopelessness and inability in face of the difficulties related to the healthcare of the child diagnosed with cancer as well as in maintaining a balanced family life.¹⁹ The reaction of the child in face of this disease is directly related to multiple factors such as: age, immediate stress represented by physical pain triggered by the disease, personality traits, experiences and the quality of parental relationships. In some cases, the child is separated from the family and start living at an institution which will become a part of their lives. New persons will become a part of their lives with whom they will develop long-lasting relationships: healthcare professionals.⁵ The family is surprised by the diagnosis of cancer and when it is confirmed, the family is shaken and in some situations this creates an anticipated mourning. In this period there are characteristic emotional reactions such as guilt, loneliness, fear, disappointment, rage and despair.²⁰

The universe of suffering includes different causal elements which have a different nature, such as mood changes, feeling of loss of control and hope, as well as dreams and the need to find themselves.²¹ Pain and suffering are triggered by different realities and have converging concepts which are somehow converging and overlapping. Suffering is a broader and more complex concept and may be characterized, in the case of disease, as anguish, vulnerability, loss of control, threat to the integrity of self.²¹ It is observed that often times, unsolved issues which last from the time of treatment and remain in some aspects of the lives patients and their families, producing negative and visible or latent effects. Nurses must pay close attention to the signs of psychic suffering throughout the process and propose prevention interventions and treatment of psychological sequelae, to provide a better balance of the existential dynamics between patients and family

members. However, pediatric oncology nurses need to improve their attention and qualified listening provided to patients and family members, to support them and encourage their autonomous and collaborative participation in the decision-making process and care.²²

Cancer requires patients and families to change their routine, attitudes and behavior, from the first signs and symptoms, from the confirmation of the disease to the hospitalization.¹⁶ Hospitalization of children is an experience filled with suffering followed by disruption of the family routine and life routine, including other responsibilities, concerns and financial demands. All of these problems lead to an explosion of feelings, actions and thoughts which changes behaviors and has an impact on how they deal with the situation.¹⁹

Cancer treatment is a major challenge for the family which takes over the responsibility to help the child overcome physical suffering and the limitations imposed by the disease, in addition to emotional suffering and the difficulty to maintain a healthy interaction of all family members.¹⁹ The main limitations of this study are the sample size which could be expanded and improve the findings, however, it was observed that the number of patients was enough to analyze the content and meet the study endpoint.

The conclusion of this study is that most family members were women and that for them, the most difficult moment was the confirmation of the diagnosis. It caused shock, surprise and denial, since they were not prepared to receive this kind of bad news, followed by sadness, despair, anger and even depression triggered by suffering, insecurity and fear of death. During the study we observed that the consequences of childhood cancer reached the whole family structure, in special of the accompanying person who plays the role of main caregiver. Furthermore, the reality of a child with cancer causes significant changes in the family dynamics and carries intensive reactions in face of the socioeconomic and psychological burden they have to cope with.

The findings of this study may be useful for healthcare teams, especially nurses who are in the front line of healthcare. When caring for oncology patients, professionals should exercise careful scientific and technical skills, competence and interpersonal relations, providing qualified listening to the healthcare needs of patients and family. It should always be taken into account that the patient's family has to face intensive emotional burden when coping with cancer. It is essential that nursing care, as well as the whole healthcare team knows how to properly support the family so that this system is preserved and strengthened aiming at the treatment and cure of the child. The emotional support for the difficulties that will arise during this process is essential and may tremendously decrease the impact of the diagnosis and alleviate the reactions to treatment and hospitalization.

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