THE PERCEPTION OF NURSING STAFF ABOUT THE PARTICIPATION OF FAMILY IN CARE FOR CHILD WITH CANCER

A PERCEPÇÃO DA ENFERMAGEM ACERCA DA PARTICIPAÇÃO DA FAMÍLIA NA ASSISTÊNCIA À CRIANÇA COM CÂNCER

LA PERCEPCIÓN DE EQUIPO DE ENFERMERÍA SOBRE LA PARTICIPACIÓN EN EL CUIDADO DE NIÑOS CON CÁNCER

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ABSTRACT

Objective: to understand the perception of the nursing staff about the family participation in care for child with cancer. Methodology: exploratory descriptive study in the qualitative approach, developed with 13 members of the nursing staff in Pediatric Oncology Department of Policlínica, Liga Norte-Rio-Grandense Contra o Câncer, in Natal/RN. After transcription, data from the interviews was analyzed by content analysis, in the form of thematic analysis. As pseudonyms, we used names of children's characters. The project was approved by the Ethics Committee of the LNRC, embodied by the opinion paragraph, 099/099/2011. All participants signed a consent form. Results: the achievement of excellence in nursing care in pediatric oncology arises of the family’s participation in care provided to these patients, it is essential to include the family on treatment and consider all the feelings that surround the impact of illness of caregivers’ lives. Conclusion: the perception of the nursing team on the participation of families of children with cancer concluded that it should provide a better service, always trying to include family members in care provided, contributing to a comprehensive care. Descriptors: nursing; oncology; pediatrics; family.

RESUMO


RESUMEN

Objetivo: comprender la percepción del equipo de enfermería acerca de la participación familiar en el cuidado de los niños con cáncer. Metodología: estudio exploratorio descriptivo, cualitativo, realizado con 13 miembros del equipo de enfermería, en el Departamento de Oncología Pediátrica de la Policlinica, de la Liga Norte-Rio-Grandense Contra o Cáncer, Natal/RN. Los datos de las entrevistas, después de la transcripción, fueron examinados a partir del análisis de contenido temático. Como seudónimos, fueron utilizados nombres de personajes infantiles. El proyecto fue aprobado por el Comité de Ética en Pesquisa de la LNRC, por medio del dictamen nº. 099/099/2011. Resultados: el alcance de la excelencia en la asistencia de enfermería en oncología pediátrica, parte de la participación de la familia en el cuidado prestado a estos pacientes, siendo indispensable incluirla en la realización del tratamiento y considerar todos los sentimientos que envuelven la repercusión de la enfermedad en la vida de los cuidadores. Conclusión: la percepción del equipo de enfermería sobre la participación de la familia de los niños con cáncer concluyó que es necesario proporcionar una mejor asistencia, siempre tratando de incluir los miembros de la familia en el cuidado realizado, contribuyendo para una atención integral. Descriptores: enfermería; oncología, pediatria, familia.

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INTRODUCTION

Cancer is currently one of the biggest health problems affecting Brazil and the world. Globally, studies show that cancer represents 0.5% to 3% of prevalence among children, compared with the general population. In Brazil, data from the cancer registry of population-based, it was found that childhood cancer ranges from 1% to 4.6%.¹ In developed countries, cancer is ranked as the leading cause of death by disease in children from 01 to 14 years.²

In Brazil, in 2005, cancer mortality in children and adolescents aged between 1 and 19 years comprised 8% of all deaths, representing the second leading cause of death in this age group. Given that the first cause of mortality by external causes such as accidents and violence, it can be seen that the mortality from childhood cancer is currently the leading cause of death by disease in this age group.³

The earliest pediatric population (0-4 years) are more predisposed to develop cancer, with the exception of lymphomas, carcinomas and bone tumors that usually affect children and adolescents between 10 and 14 years. Before analyzing the clinical point of view-rolling, it is known that tumors have a lower latency for children, often grow quickly, are aggressively invasive and best respond to chemotherapy.⁴

Because of the complexity of cancer, the treatment should be comprehensive, deserving attention to the physical, psychological and social, with particular emphasis on family. To adopt prevention and protection, to promote early diagnosis, to institute appropriate treatment with the lowest risk of sequelae, to implement decent conditions for the child or adolescent in palliative care, to include physical, psychological and social rehabilitation should be essential goals for the health care.⁵

About the complexity and difficulty of the situations that children face, they are listed: changes in the body and general health, pain, side effects due to treatment which they are being submitted, and changes of interaction, psychological and affective. Among the many problems which affect the children, they try to be strong and overcome these moments, seeking support from the people, such as family, friends and health professionals.⁶

When dealing with the children it is paramount to enter in their world, understanding their circumstances and stages of childhood in an integral way in covering children and their families, trying to meet their needs, regardless of their current condition. The nursing staff and interdisciplinary team can and should develop activities with the children and their families, seeking to promote the well-being.⁷

In the care of oncology child nurses and all nursing staff have a crucial role, because the assistance in pediatric should be linked to their families and their needs.⁸

Given all the problems of cancer in childhood and all that it has lead in the affected children's lives and how it has been held to support pediatric cancer, we reflect on the perception of the nursing staff about the importance of the presence of families during the whole process of the disease ranging from diagnosis to treatment, and it is responsibility of nursing staff at the time of care to respect and encourage such participation.

With this research, we believe that there will be a contribution to improve the care provided to children, because from the moment that the nursing team reflects on the perception, we can find a way to act contributing to an improvement in care provided.

OBJECTIVE

- To understand the nursing staff's perception about the families' participation in the care of child who has cancer.

METHODOLOGY

This is an exploratory descriptive study with qualitative approach conducted in Natal/RN, in the sector of pediatric oncology of Policlinica, a general hospital with a variety of specialties, ranging from the pediatric oncology to aesthetics. Policlinica provides care to the pediatric and to the intensive care unit of Liga Norte-Rio-Grandense Contra o Câncer (LNRC).

The criteria for inclusion of subjects in the sample were: to participate in the nursing team and have at least three months of occupation in the area of Pediatric Oncology at the Policlinica of LNRC in Natal/RN, as well as wish to participate in the study voluntarily. Thus, 13 subjects agreed to participate in the study, 10 nursing technicians and three nurses. Data collection was performed in August 2011.

To conduct the study we used as a tool the semi-structured interview. All interviews were
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At the moment which a child or teen gets a serious illness when it is necessary a complex treatment, the whole family structure, in terms of physical, psychological and social, is affected. With changes in their structure that vary with the severity levels, depending on the child’s illness, the clinical and support of other family members. 

When the disease is cancer, the situation worsens, because it is a stigmatized disease and feared by the population for all the suffering it causes to the patient and the whole family. The diagnosis of cancer affects not only the individual but also family members and significant people, especially when a lot of care are necessary.

Childhood cancer is a disease which is more complicated for a family to understand and accept, because the child or adolescent are still in early life. Moreover, the possibility of cure are very uncertain, depending on the type of cancer and the time between diagnosis and treatment. The family, most often, does not have an explanation of how those children have acquired this kind of disease, its severity and concern or uncertainty about a possible death of the child.

Due to the analysis of interviews with the nursing staff, we realize the importance of this first contact with the families of children in order to guide them and enlighten them about the treatment process by which these children will pass.

When we start to live with them, we realize that they [parents] come very disoriented: What world is this? What will happen to my child? What will happen to my family? Because it is not only the child, it involves parents, staff, neighbors... It involves a lot of people, right? (Tinkerbell).

It should be emphasized repeatedly the importance of information and guidance to caregivers in an attempt to alleviate these feelings may lead the caregiver to have problems as tension due to the role of caregiver. “When the family is included in the care and has knowledge about the evolution of their child, and the guidance they receive, it is safe enough to believe that they can participate in their care.

Due to the presence of many variations in health of child with cancer because of treatment, there are the ups and downs in the emotional state of family members, causing an even greater weakness. At times they can see the hope in each one of them, but they may find themselves sad and shaken with uncertainty that the disease brings. Thus, it is less painful.

The family as the primary unit of care is a social space in which the members interact, exchange information and identify health problems, support each other, joining forces to find solutions. For the child, the parents’ presence brings security, since any process that involves a disease generate in children feelings of pain and suffering, and then the family support is necessary and indispensable to the continuity of care, making it milder and
obey the rules imposed by the team at the time of initiation of treatment and hospitalizations, if necessary covenants, and sometimes even the interference of a multidisciplinary team to deal with these issues.

Sometimes when they are difficult to work with, we sit in the ward and we call them to talk, to pass some information. (...) We have a very large opening to the family, sometimes the family deny some things, which is normal. They think we’re boring, they do not care about us, but by the time everyone is a family. It is the family of pediatrics. (Strawberry).

Actually in the beginning they arrive without knowing, without knowing what can do and what can not, and little by little we organize them. There are some people who are more difficult that we can’t work easily, we fight all the time. For example: we say they can not do some things and they do, but eventually we won (Tinkerbell).

In oncology disease, attention and support that health professionals can give these families are crucial, because it can be an emotional support for parents, family and the child. It may still represent a collaborative unit of the clinical team, which inures to the effectiveness and efficiency of care.

The establishment of an ongoing dialogue aimed at clarifying questions, sharing experiences and in joint participation in care allows informal caregivers have the essential tools for care at home. 13

Here you do a job on the ward which it is all perfect, hand washing, care, feeding, but if you do a work with parents or caregivers, they won’t continue the work. So you have to work very closely with the family too. Each arrival brings a lot of information, every day you have to go reinforcing what you said on the first day, so we have a very large opening to the family. Sometimes, the family deny some things, they do not care about us, but by the time everyone turns a large family of Pediatrics (Strawberry).

Considering the implications of the biopsychosocial disease and the complex demands of therapy, the inclusion of parents in the treatment of childhood cancer is essential. To assume their duties collaborators, parents need to be fully able to engage in the process, which it is long and includes intrusive procedures such as surgery and chemotherapy sessions and radiation, and it can leave children even more vulnerable and weak.14

Nursing care in pediatric oncology has been growing every day, specializing and changing over time. Previously, the family did not participate in the process of hospital care of the child because she could not accompany
her/him in the process of hospitalization. Nowadays, the family is present and they are very important at this critical moment in which the child is.\textsuperscript{15}

In general it can be noticed in the speech of the nursing staff the need to follow the family with the child, according to the professionals they are extremely important because they act with the support of these children, contributing to the treatment has better results and be more effective.

We do our part which is of technician in nursing, but if the family is not with us, it doesn't work. If children do not feel the warmth of the family, they leave, there is no reason to continue that treatment, especially teenagers who need much more support from family, they know they can not do everything a teenager does without cancer (The Little Mermaid).

And beyond they are this emotional support for these patients, the parents share child care with the team helping to promote better care.

The family has to be helping, because the cancer is complicated, but if there isn't love of parents and family, the child surrenders to the disease (Barbie). It is very important when parents participate. For example, there is control of diuresis: we talk to them and train them to collect urine to measure and record. So they have an obligation with us and they feel useful. This is not taking our responsibility, but it is to have that technical contact with the patient, family and nurses. It is very important to involve the family's attention because if a parent fails to come to the hospital, the child thinks he/she is abandoned (Emilia).

They are very dedicated, they are often overlooked with something, they often realize, mothers help us very much, because there are things we do not see, because they really lives with their children. So I just think they help the staff very much. Sometimes the staff knows that there is a bit of excess, which can be a fear of the disease (Little Red Riding Hood).

Another aspect related with the participation of the family on this assistance was how much they seek to be informed about everything that happens during the treatment of children, after passing through the shock of the diagnosis and accept the disease they become active participants in the care provided to patients.

You see that the family of pediatric cancer patients is very informed, very informed, they know the medications, they may not know the name but they know that if it is out of the vein it will hurt. There are mothers who give a lecture about the disease. I think it is a differential in the treatment for them to be so long in the hospital, there is a lot. Even we can see with the families, with mothers who can not read, though it may be humble in the sense of knowledge, they can do everything well right. This part is very rewarding (Snow White).

In terms of presence of parents, professionals report that most of the time, almost always, the participation of mothers is higher as carers of these children, as well as the team recognizes the need for these mothers to be present and active in treatments working as an assistant with this service and playing a major role.

If the family does not care, the treatment does not go on. I like that mother who is well oriented (...), it is good because sometimes when there is so much medication that sometimes we get a new medication that I do not know, it is prescribed, then the mother asks and I'll seek to know what it is (Monica).

The mother is usually the balance of the children, I understand. When a mother is more humorous, more firm, she passes it to the child and she can have the strength to live winning little by little. I compare the parents to the child (Tinkerbell).

With the presence of parents, the child feels more secure, since the hospitalization process can generate ambiguous feelings related to pain and healing, and the hospital is seen as a venue of painful experiences. The presence of the mother during the admission and treatment alleviates the suffering of children, allowing her to have a reference of life outside the hospital.

The children are the mirror of a family and when they are abruptly removed from the living, it can generate conflict and disruption. A child is considered as a being whose physical health conditions, mental and social health are directly related to the characteristics of the family in which he/she lives.\textsuperscript{16}

In talking about the question of the presence of mothers and demands that they make in relation to care, the professionals show how much they understand these requirements and they still say that at the time that presence of the mother is active for a direct influence on quality of care provided by nursing team.

Who is the mother who likes to see their child with cancer? You have to give greater attention and charge enough, then the mother wants to know everything, participates and asks everything. If they were my children, I think I would have the same position (Sleeping Beauty).

They even say that the technician “A” didn’t pass the alcohol swab in gear before making medication, and they call attention at time: have you washed your hands? Are you...
forgetting the mask with a neutropenic patient? And when they are more demanding, it is better for us, because it improves the quality of nursing care. When you have parents more demanding, the team also has the most competent care. Then we end up having that involvement with the family. When children die, mothers come back here, by calling and asking, until they follow their lives (Snow White).

There is really a responsibility of the family in the welfare and development of care, the participation of all of them is effective and important in order that they seek knowledge about everything that involves the child's illness and thus they're co-authors of care performed.

Nursing thus plays a major role in including families in providing care. Thus the communication of nursing allows through conversations, explanations, guidelines that are geared for the family to understand the importance of their participation in care. In the statements below it is possible to identify the link between work, family and care.

Everything will be done before we talk, explain, there is dynamic, there is a unique moment[...] Mothers who arrive sometimes are very poor, they do not understand what cancer is, do not know what that child is doing there, why hair falls out, because that remedy gives that effect[...] So we try to do this kind of humanization, this type of approach to see the understanding that mother and child, because otherwise the mother will not help with the treatment that it is consuming and painful (Minnie).

It is clear that experiencing cancer is a difficult time for both the patient and for family members, it is common that the presence of this disease can bring all these painful and negative feelings. Also because the family is dealing with a situation full of uncertainty and the expectation of death.

It is natural that the family of the patient with cancer has these feelings, but it is important to verbalize them, in order to minimize the stress that causes the disease. Seeking to understand the feelings of the family is important to maintain a good standard of communication and contributes to the quality of life for all, since cancer is extremely sensitive and emotional.17

When asked about the difficulties and challenges encountered to a better work with these patients, the interviewees cite some studies that could be performed not only with children but with parents and family caregivers in an attempt to relieve stress and seeking measures to give a higher quality treatment for children.

In the case of parents and relatives, it is important that the work involved, and in which they could even show their feelings and experiences, share those experiences with parents of other children and, especially, might take a little time. Activities of this size would help family members to disregard the suffering and entertain them with other situations.

For this, the staff talks about the participation of volunteer work that aims to involve these families and may contribute to the long hard living with cancer treatment.

A key point that I think is still missing here in pediatrics It is the issue of volunteering for a greater humanization. As much as the nursing staff try, it is always little because they spend a lot of down time especially mothers. Then: Mother is idle, idle children, or someone is just thinking in stupid things, or just talking about one, taking care of the life of another, thinking that treatment does not work[...]. If you bring a volunteer staff, mothers occupy the minds (Strawberry).

I think I need to have a greater assistance in terms of reception, the mothers have a good monitoring, because I think it must have both the mother and the child, or treatment with a psychologist would help to deal with grief. My greatest difficulty is to give assistance to the caregiver as to the child (Sleeping Beauty).

The acting as a staff member in the nursing care of a child with cancer and dealing with their family it is beyond all the theoretical and practical knowledge of a professional's lifetime. Dealing with different charges and fears requires that all professional psychological support and human, making them able to adapt care assistance to the patients and their families.

It requires, above all, the ability to deal, with feelings, dribbling challenges and difficulties in daily care to develop the care with excellence and responsibility. In the development of the profession, it is the work process of nursing staff in order to provide safe care and free from risk or harm to costumers.18

The integration model proposed by Dungan identifies individuals fitted with three-dimensional body, mind and spirit, the experiences are integrated in these three dimensions and maintain harmony with the environment and can help to optimize the processing of any situation.19

CONCLUSION

Nursing, among many assignments that there are, is responsible for the care of these children and their families at the time of impact with the discovery of the disease that brings so many fears, anxieties and doubts...
both in children and their parents, who see the possibility of not accompany growth and development of their children.

The alleviation of suffering, making hospitalization less traumatic, is one of the main tasks of nursing that should promote quality care that meets physiological, psychological and social difficulties. The union between technique and sensitivity allows the actions of the team can achieve efficiency and humanization necessary in pediatric oncology.

With the family it was suggested a social work or voluntary, which could allow them to expose their feelings and difficulties with the team and / or with other parents and caregivers. This could alleviate the problems resulting from disease, providing a moment of abstraction that suffering.

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