







THE PERMANENCE OF THE FAMILY IN THE CENTER OF INTENSIVE ONCOLOGICAL PEDIATRIC THERAPY: NURSING PERCEPTION

A PERMANÊNCIA DA FAMÍLIA NO CENTRO DE TERAPIA INTENSIVA PEDIÁTRICA ONCOLÓGICA: PERCEPÇÃO DA ENFERMAGEM

LA PERMANENCIA DE LA FAMILIA EN LA UNIDAD DE CUIDADOS INTENSIVOS PEDIÁTRICOS ONCOLÓGICOS: PERCEPCIÓN DE ENFERMERÍA

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ABSTRACT

Objective: to identify the perception of the nursing team about the limits and possibilities of the presence of the family member in the care of the child in an intensive pediatric oncology center. **Method:** this is a qualitative, case-study conducted between September and November 2014, with 25 Nursing members, through a semi-structured interview at a pediatric oncology intensive care unit of a public hospital in Rio de Janeiro. Data were submitted to categorical content analysis. **Results:** the team realizes that in some situations, the family member's permanence causes difficulties for their work. However, it understands that it is also essential for care because it offers companionship and conveys confidence to the child. **Conclusion:** shared care between the nursing team and the family represents continuous negotiation, exchange of experiences and enables the care of the child with cancer in the intensive care unit.

Keywords: Family; Oncology Nursing; Child; Neoplasms; Intensive Care Units.

RESUMO

Objetivo: identificar a percepção da equipe de Enfermagem a respeito dos limites e possibilidades da presença do familiar no cuidado à criança em centro de terapia intensiva pediátrica oncológica. **Método:** estudo qualitativo, do tipo estudo de caso, realizado entre setembro e novembro de 2014, com 25 membros da Enfermagem, por meio de entrevista semiestruturada em um centro de terapia intensiva pediátrica oncológica de um hospital público do Rio de Janeiro. Dados submetidos à análise de conteúdo categorial. **Resultados:** a equipe percebe que, em algumas situações, a permanência do familiar traz dificuldades para o seu trabalho, porém, entende que também é essencial para o cuidado, pois oferece companhia e transmite confiança para a criança. **Conclusão:** o cuidado compartilhado entre a equipe de Enfermagem e a família representa contínua negociação, troca de experiências e viabiliza o cuidado à criança com câncer no centro de terapia intensiva.

Palavras-chave: Família; Enfermagem Oncológica; Criança; Neoplasias; Unidade de Terapia Intensiva.

RESUMEN

Objetivo: identificar la percepción del personal de enfermería sobre los límites y posibilidades de la presencia del familiar en la atención del niño en cuidados intensivos pediátricos oncológicos. **Método:** estudio cualitativo, tipo estudio de caso, realizado entre septiembre y noviembre de 2014, con 25 miembros de enfermería, por medio de entrevistas semiestructuradas, en una unidad de cuidados intensivos pediátricos oncológicos de un hospital público de Rio de Janeiro. Los datos fueron sometidos al análisis de contenido categorial. **Resultados:** el personal percibe que, en algunas situaciones, la permanencia del familiar perjudica sus tareas, aunque también entiende que es esencial para el cuidado al ofrecerle compañía y transmitirle confianza al niño. **Conclusión:** el cuidado compartido entre el personal de enfermería y la familia significa negociación continua, intercambio de experiencias y permite cuidar al niño con cáncer en la unidad de cuidados intensivos.

Palabras clave: Familia; Enfermería Oncológica; Niño; Neoplasias; Unidades de Cuidados Intensivos.

INTRODUCTION

Childhood cancer is considered a disease increasing in the age group from zero to 19 years old, with repercussions in the life of the child and the family, who are largely not prepared to deal with this diagnosis. It is the second cause of death in children and adolescents, estimated to be 420,000 new cases of cancer by 2018/2019.¹ When diagnosed early, good chances of cure can be obtained.

Besides modifying the routine, the diagnosis of cancer in the children and their hospitalization generate psycho-emotional changes in the family and interfere in the family dynamics. This is because the confrontation of the diagnostic revelation causes pain and suffering due to the lack of knowledge about cancer, as well as the stigma of the disease and the changes that family members must make to adapt to the new situation.²

When facing the unknown, the family experiences a series of feelings, such as fear, which is characterized by a feeling of insecurity about routine change and the consequences of treatment. Each family has its own characteristics, its ways of acting and facing the discovery of cancer and the hospitalization of the child, since they are unique beings, and must be respected and understood in their way of being.³

The illness confirmation and the need for hospitalization of the child cause difficulties in the reorganization of family roles and social functions, such as work, study, and leisure, which often need to be interrupted by the situation, causing instability in the family dynamics.⁴ The situation may become more painful when there is a need for intensive care unit admission.

An intensive care unit is characterized as a place with continuous monitoring that allows potentially severe or decompensated patients of one or more organ systems. The treatment proposes continuous monitoring, specific equipment, the technologies necessary for diagnosis and treatments, aiming to ease the suffering, regardless of the patient's prognosis.⁵ However, some people think that the patient's admission to this unit is associated with death.

Thus, when the child is admitted to the intensive care unit, the relatives, especially the mothers, who are the main companions, experience moments of suffering with fear of the possibility of the loss of the beloved child, of the uncertainty of return to the home, the separation of the children that are not under their care, the confrontation of the unknown environment and the contact with professionals who see them only as the accompanying mother of the hospitalized child, that is, is not included in the care.⁶

The inclusion of the family in the hospital to accompany the child and the adolescent is guaranteed by the *Estatuto da Criança e do Adolescente* that states: "a responsible person is guaranteed during hospitalization." It also establishes that "hospitals must provide conditions for the full-time stay of a parent or guardian in cases of admissions of children and adolescents."⁷

The presence of the family facilitates the adaptation of the child during the hospitalization and reduces the impact of the separation of his routine. This also provides comprehensive care by the multi-professional team, increasing adherence to treatment, which results in a better therapeutic response to the disease.

There are several studies in the scientific literature that highlight the benefits of family participation in hospitalized child care.^{6,7} However, the context of family presence and their permanence in the oncology intensive care center has not yet gained visibility in the literature.

Therefore, the question is: how does the Nursing team perceive the presence of the accompanying family member in the pediatric oncology intensive care center? Thus, this study aimed to identify the perception of the Nursing team regarding the limits and possibilities of the family member's presence in the child's care in the center of pediatric intensive care oncology.

METHODOLOGY

This is a research with a qualitative approach⁸ of the single case study type, described as the research that provides an overview of a particular case.⁹ The study scenario was the *Centro de Terapia Intensiva Pediátrica Oncológica (CTIPO) of a public hospital in Rio de Janeiro*.

Twenty-five members of the Nursing team participated in the research, ten of them were nurses and 15 were nursing technicians. The participants were selected with the following inclusion criteria: be working in the sector for at least two months, any gender. Nursing professionals who were absent and/or away from the sector during the period of data collection were excluded. The following codes were assigned to identify the members of the Nursing team: nurses - Nur (1-10) and Nursing technicians - Nur Tec (1-15).

The data production was held from October to November 2014 through a semi-structured interview with a script that contained the following questions: how do you see the presence of the accompanying family member in the CTIPO? What are the advantages and disadvantages of the child's accompanying family member in care? The interviews were recorded in the digital mp4 device, to preserve the integrity of the speeches.

The interviews were performed according to the participants' availability, in the morning, afternoon and evening, in the Nursing break room, seeking to preserve a space that had few interferences. The average duration of the interviews was 10 minutes.

After the transcription of the interviews, the empirical material was completely read and the data were submitted to categorical content analysis following the steps: pre-analysis; exploitation of the material; treatment of results, inference and interpretation.¹⁰ Following the steps of pre-analysis and exploration of the material, it was possible to organize and repeat the research data.

The following strategies were used to maintain rigor in the study: the interviews were available after transcription, for all the participants to verify if they were represented in the way the data were being analyzed and consolidated criteria were used for Reporting Qualitative Research (COREQ) as a support tool. It consists of a list of 32 verification items of the research team, the research project and data analysis for qualitative research methods.¹¹

After that, the treatment and interpretation of the obtained results were held and, after the analysis of the data and identification of the themes, the codified data were grouped by similarity. Each category was considered saturated when it was not possible to add new data. The following categories emerged after this procedure: limits of the family member's presence in child care at the pediatric oncology therapy center; the permanence of the relative facilitating the sharing of child care in the pediatric oncology intensive care center.

At all stages of the research, it was sought to meet national and international standards of research ethics involving human beings. As recommended in Resolution 466/12 of the *Conselho Nacional de Saúde* (CNS),¹² the research was submitted and approved by the *Comitê de Ética em Pesquisa* of the Antônio Pedro University Hospital (CEP/HUAP/UFF) under number 826.222/10/2014 and by the *Comitê de Ética em Pesquisa* of the hospital scenario study. In this sense, all participants signed an consent form: *Termo de Consentimento Livre e Esclarecido* (TCLE). The interviewees could listen to the testimonies soon after the recording and may add or cancel some information.

RESULTS

Twenty-two (88%) of the 25 nursing professionals were female and three (12%) were male; 10 (40%) were nurses and 15 (60%) were Nursing technicians; all nurses were specialists, two (8%) were specialized in the area of Oncology and nine (82%) in intensive care. Nine (36%) of the 15 (60%) nursing technicians were also Nursing graduates, and four of them (16%) had specialization in intensive care.

Regarding the time of professional training, 10 (40%) nurses interviewed had about 10 years and 15 (60%) technicians ranged from 10 to 20 years. Regarding the performance in the pediatric intensive care center, the time of performance was the same around four years for both nurses and nursing technicians.

LIMITS OF THE FAMILY MEMBER'S PRESENCE IN CHILD CARE AT THE PEDIATRIC ONCOLOGY THERAPY CENTER

In the perception of the Nursing team, in some situations, the permanence of the family member brings difficulties to their work, as well as the interaction of both. For them, some

parents feel angry about the disease and seek a guilty one, they tend not to value nursing care, and they classify professionals as good, bad, dry, cold. In short, professionals are labeled according to the feeling of the parents.

[...] only in the moment of anger, by the illness (Nur Tec 10).

[...] they find us very cold and with little sensitivity to the suffering of the child and their suffering (Nur 3).

On the other hand, some relatives for the Nursing team see the care provided with distrust and restrictions. The family shows apprehension, anxiety, and fear and at certain moments they question about some nursing practices.

There are some family members you see they are suspicious [...] it depends a lot on the approach and the way you talk. We have had experience of professionals [...] who will be questioned and treated even with certain harshness (Nur 5).

One family or another that does not accept much the issue of diagnosis, treatment, that they are very anxious, very insecure, they do not want to lose and ends up disturbing us a bit (Nur Tec 5).

And maybe it's a procedure that we have to do that the relatives do not accept, I believe that is it (Nur Tec 9).

Nursing professionals understand that the diagnosis of cancer, the child going to the CTIPO, as well as the accomplishment of several medical procedures and Nursing, create different types of feelings in the parents and should be the reasoning.

Nevertheless, for some professionals, the care is exclusive to the Nursing team, and should not be shared with the family. They also affirm that the companion can only observe and entertain the child.

No, I do not think it's up to family nursing care (Nur Tec 7).

If he is a companion he is here to follow up, so all the care of the child belongs to the multidisciplinary team [...] (Nur Tec 3).

I think the companion has to observe the child and be on the child's the entire time [...] (Nur 4).

Corroborating these testimonies, the Nursing team still proposes that the family should only act in the child's entertain-

ment. Activities such as putting a DVD, stimulating to see cartoons, draw and paint are activities that can be performed by the family member.

That child who interacts, the mother puts a DVD [...] a child who is already in the schoolhouse who likes to draw, the mother is always there helping to draw and paint (Nut Tec 7).

Well, I think she can interact well with the child, trying to put a DVD that we have here [...] And for those who write we also have paper sheets, we print pictures for them so they interact more with the child (Nur Tec.11).

Regarding the family's participation in child care, the interviewees stressed that when the child is hemodynamically unstable, the family member's participation in the care is not allowed. Situations such as the child being intubated, using mechanical ventilation, vasoactive medications, hemodialysis, among other devices, are factors that prevent parents' collaboration in care.

If you are intubated, we will not want you to accompany or change a diaper. Their help is just that, to observe some change and to be helping us in that way, calling us (Nur 9).

I think this will all vary according to the severity of the child, the procedures such as diaper change, bath assistance are difficult to do (Nur 4).

Do you want help? Do you want to do something? Then you can't. The child is intubated. [...] if the family helps and something happens, the responsibility is ours. So I do not allow it! (Nur Tec 3).

Some professionals perceive the interference of the family in the routine of intensive care as a limit to care. This interference varies from family to family and is directly related to the procedure in which the child was submitted. It can be seen in the following statements:

[...] it is interfering yes. Most of the time, he does not like that, for example, you will get peripheral venous access and you can't do it the first time, so you already get "faces and mouths" looking at you with an ugly face (Nur 8).

It depends, there are some that interfere, [...] they think the child will feel pain [...]. Interfering in terms of everything, for example, you will puncture a vein and the

child will become very angry, tearful, sometimes even in diaper change (Nur Tec 3).

One way to minimize family member interference is to explain about the behaviors performed in the hospitalized child that promotes a relationship of trust. This fact was observed in the following report.

How can I explain? You're saying the following: Look, this is the medication, I'm going to need to suction your son, [...]. Then, I realized that the mother liked me to say that. I think it pleases you to give a satisfaction of what you are doing with the child (Nur 4).

Providing information about all the procedures and behaviors performed in the child allows the family to feel more secure with the Nursing team. This also humanizes the care provided to the child as well as the accompanying family member.

THE PERMANENCE OF THE RELATIVE FACILITATING THE SHARING OF CHILD CARE IN THE PEDIATRIC ONCOLOGY INTENSIVE CARE CENTER

During the hospitalization of the child with cancer in the CTIPO, there are procedures that can be shared with the relatives, since they are care that by nature are already common in the practice of families in the home environment. One of the facilitators that the participants of the Nursing team emphasized was the presence of the accompanying family member as a welcome.

That's what I said. There are companions and companions. There are those who help. They are there supporting the child at the time of the procedure, at the time you make a medication (Nur 3).

I try to let them participate in the care process. So they end up interacting with us, they end up helping a lot (Nur Tec 4).

They help people in the care (Nur Tec 5).

The family is considered an essential element in the recovery of the health of the child with cancer. With the family's permanence to accompany it, it was necessary to insert it in some activities related to the child, promoting the narrowing of affective bonds, as well as bonds with the Nursing team. This interaction was evidenced in the following reports:

Helping us in the shower (Nur 1).

They help in the hygiene, they help in changing diapers, sometimes they check the temperature, but otherwise, it would not fit them anymore (Nur Tec 13).

I try to stimulate like this, the mother exchanges her son, change a diaper, passes a moisturizer, because it is the contact, the handling, helping in the bath (Nur Tec 10).

The bath! The bath is a very intimate part of the child, the patient. The family member being there on the side helping, doing the hygiene is important (Nur Tec 12).

Thus, the Nursing team understands that the presence of the family contributes to some care in the child, such as: assisting in bathing, feeding, changing diapers, putting the thermometer and passing moisturizer. With this, an interaction between the family member and the Nursing team was established, providing safety and support to the child.

Also, some professionals feel more secure in providing care to the child when the parents are present. The interaction resulting from the family/nursing team coexistence in the CTIPO is reflected in the flexibility of the care performed with the child.

I always liked the parents present in the treatment of the children. I think it's good for the child and for the team as well. (Nur Tec 8).

I even feel a little dependent when the companion is there, not for him to take care of me, but for him to be able to follow this process, you know? (Nur 5).

I think it's important for us to reach out to this child in a more sensitive way, not so gross, and a way for us to be close to that father (Nur 3).

The CTIPO Nursing team also pointed out that, upon imminent discharge from the child to the infirmary, it prepares/teaches the family to perform certain procedures, such as tracheostomy suctioning, in case the child is tracheostomy.

[...] when they are going to be discharged, because in the ward the parents do some procedures, such as suctioning the tracheostomy, bathing in the bed, diaper changing, teaching them to suction is our behavior, but everything should know as Nursing [...] (Nur 10).

The proposal of the CTIPO Nursing team in training the family to perform procedures such as suctioning of the child's

tracheostomy is due to the fact that children often after discharge to the infirmary and consequently discharge from hospital can go home in possession of devices such as a tracheal cannula, nasoenteral catheter, and venous catheters. The goal is to prepare them to know how to manipulate these devices, since, in the domicile scope, the care of the child happens to be carried out by the family.

DISCUSSION

During the development of this study, the child and the family experience varied difficulties during the hospitalization period, either due to the separation of family members during hospitalizations or due to the profound changes in their daily activities or, by fear of the unknown and of death.¹³

Conflicting feelings emerged in the parents, such as anger, fear, impotence and, therefore, in the hospital, the family maintains constant vigilance, controlling the care provided to the child, being available to her, being a source of support. Most of the time, however, the relative can be interpreted as inflexible, invasive and even undesirable by the team, for questioning about the situation of their child.

Although there is recognition of the importance of the family in the therapeutic process and to improve the child well-being, there are situations in which this relationship is not established in a quiet way and in which there is no acceptance of the family member in care. The first contact between the family and the nursing team is almost always negatively addressed, due to factors such as fear, anxiety, anguish, lack of knowledge about the procedures to be performed with the child and lack of trust in interpersonal relationships.¹⁵

It is understandable that the professionals experience moments of intimate conflicts regarding the permanence of the parents in the ICU since the inclusion of this new element (the parents) in the care and inside the ICUs is something new and incipient, that needs to be worked with the team.¹⁶

In this sense, the family maintains constant vigilance, controlling the care provided to the child, being available, being a source of support. However, most of the time the family member can be interpreted as inflexible, invasive, and even undesirable by the team for questioning about the situation of their child.¹⁴ This situation can trigger instability among these characters. One way to handle the situation is to gradually break down the barriers that surround professional care and family care.

Engaging the family in the care of the hospitalized child implies reviewing the ways in which Nursing has outlined this process since the incongruity between the actual participation and the participation desired by them can cause parental difficulties. Pediatric nurses need to remember that parental preferences for participation vary and need to be prepared to sup-

port family participation at the level at which their members choose, contributing to a satisfactory experience.¹⁷

Thus, the need to establish bonds, trust and accountability appeared to ensure integral care. An expanded look and act for the family, making it part of the process, in the scope of care for the hospitalized child, attributing respect to the uniqueness of the child-family binomial.¹⁸

One way of establishing links is to inform the family member about the treatment and the performance of procedures and examinations, as well as to clarify the doubts they have, and this, in turn, conveys safety and tranquility, providing a sense of respect and appreciation as a co-participant not care. The relationship established between the nursing professional and the family should appreciate the knowledge expressed by the family caregiver, since, from it, it becomes possible to pay attention to the specificities of each child and family.¹⁹

Also, in addition to providing more satisfactory emotional conditions for both, the family presence has a number of other advantages: it creates a closer and more intense relationship with the team, it is a direct source of information about the evolution of the disease, it prevents accidents with the child, it is a source of affection, security and mediates and facilitates the child's adaptation to the hospital.²⁰

Thus, in the hospitalization of the child, from the interactions with the health-nursing professionals working in the sector, the family is able to reorganize and act. There is a need to rethink the role of the family as a caregiver and our role in interacting with it during the relationship of care, considering the meanings attributed to the lived experience. It is necessary to create spaces of freedom so the family can establish as such in the hospital environment.²¹

The insertion of the family in the care of the hospitalized child triggers a new way of organizing the work of Nursing, considering that the mother starts to carry out a lot of care for the child, which was previously Nursing competence, especially those related to hygiene, feeding and emotional support to the child.²²

From the statements, it was verified that, in the care of the children hospitalized in the CTIPO, the interaction between the participants involved in the care is necessary so that the assistance to the child is effective and satisfactory, both for caregivers and for those who are cared for.

Thus, interaction and bonding can be important tools in strengthening human relationships in pediatric hospitalization units, just as close listening and empathy attitudes toward the child and family can make care humanized.²³

Therefore, shared care becomes a perspective, in which both professionals and family caregivers act in the construction of shared responsibility for care, in which each one benefits the child with the specificity of his care, negotiating strate-

gic actions capable of propitiating him/it provides comprehensive and humanized care.²¹

Considering that the hospitalization of the child can lead to changes in the routine and in the family relationship, the family often gives the role of reference and support to the Nursing, including associating it with the family figure. Thus, Nursing professionals are in a privileged place to transform care, valuing the protagonism of family members and contributing to the shared care between Nursing and family in a respectable, responsible and ethical manner.¹⁹

In this way, the care provided by the family as well as the safety they are executed, depending on the guidance and support of the health team, not only teaching, but considering the difficulties that the family may present to prevent them. In this case, the term "difficulties" is not limited only to those found in the practice of care, but also the family's wear and tear on living with cancer, the patient's weaknesses arising from the disease, and the fragility of health services in the preparation for discharge.²⁴

Besides providing more satisfactory emotional conditions for the family and the child, the presence of the family has a number of other advantages: it creates a closer and more intense relationship with the team, it is a direct source of information about the evolution of the disease, it prevents accidents with the child, it is source of affection, safety and serves as mediator and facilitator of the child's adaptation to the hospital.¹⁷

Thus, in the hospitalization of the child from the interactions with the health-nursing professionals working in the sector, the family is able to reorganize and act. There is a need to rethink the role of the family as a caregiver and our role in interacting with it during the relationship of care, considering the meanings attributed to the lived experience. It is necessary to create spaces of freedom so the family can establish itself as such in the hospital environment.²¹

CONCLUSION

Within the area of the CTIPO, the Nursing team feels some difficulties related to family reactions, such as feelings of fear and anger, as well as sharing care with the family, especially when the child is with hemodynamically unstable health. On the other hand, there are procedures that can be shared with family members, such as those related to hygiene, food and emotional support, since they are cares that by nature are already common in the practice of families in the home environment. Thus, as nursing interaction with the family is established and caregiving actions are shared in this scenario.

The care shared between the Nursing team and the accompanying family member represents a continuous negotiation, an exchange of experiences that favors the coexistence of both

and enables the care of the child with cancer in the CTIPO. It is of fundamental importance that the Nursing team appropriate changes and new knowledge, aiming at actions that promote the involvement of parents in health care for the sick child.

Therefore, the Unit's nursing team, on to technical and scientific knowledge, skills such as attentive listening, sensitivity and qualified care for both the child and his/her family are important for a safe and humane environment, providing the necessary conditions for child-centered care.

In this way, in addition to sharing care within the reference of the CTIPO, Nursing prepares the family to perform certain procedures on the child, on the imminence of discharge to the ward, as well as hospital discharge.

This study intends in the area of Pediatric Oncology to awaken reflections of the Nursing team on the importance of the accompanying family member in the care of children with cancer hospitalized in the CTIPO, preparing them to insert the accompanying family member as care subject, conditions that this relative has to continue the treatment of the child at home.

One of the limitations of the research was the reality of an institution in *Rio de Janeiro*. Thus, it is suggested to carry out new research, in other regions, to broaden the discussion and compare this research with others.

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