



SPACE AND PRACTICES IN HEALTH / NURSING IN PERCEPTION OF MOTHERS OF CHILDREN WITH CANCER

ESPAÇO E PRÁTICAS EM SAÚDE/ENFERMAGEM NA PERCEPÇÃO DE MÃES DE CRIANÇAS COM CÂNCER

EL ESPACIO Y LAS PRÁCTICAS DE LA SALUD / ENFERMERÍA EN LA PERCEPCIÓN DE LAS MADRES DE NIÑOS CON CÁNCER

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ABSTRACT

Objective: to understand the perceptions of mothers about the space of care and practice in health, in particular nursing, in a pediatric oncology service. **Method:** this was a qualitative research conducted with ten caregivers of children in ambulatory cancer treatment using the focus group and interview approach. The collected data were transcribed and analyzed for the construction of categories expressing the perceptions of mothers about the space and current practices in the service. The study was submitted to the Committee of Ethics in Research (CEP/UERN) and approved under protocol CAAE. 3104.0.000.428-10. **Results:** the following categories emerged from the caregivers reports: "Access to cancer care, "Physical space at the COHM" and "Human resources and patient care in pediatric oncology at the COHM". The rapid diagnosis and access to care were reported; however, despite the support and care provided by professionals, the physical structure characterized as not welcoming for prolonged stays during treatments, was considered a limiting aspect of this practice. **Conclusion:** to discuss the outpatient cancer care in this institution it is necessary to articulate physical, functional, and structural aspects as the conditions that act positively or not on the experience of cancer in families. **Descriptors:** humanization in assistance; hospital oncology service; nursing care.

RESUMO

Objetivo: apreender as percepções das mães acerca do espaço assistencial e das práticas em saúde, em particular da enfermagem, em um serviço oncológico pediátrico. **Método:** pesquisa qualitativa realizada com dez cuidadoras de crianças em tratamento oncológico ambulatorial utilizando o grupo focal e a entrevista. Os dados coletados foram transcritos e analisados para a construção de categorias que expressassem as percepções maternas acerca do espaço e das práticas vigentes no serviço. A pesquisa foi submetida ao Comitê de Ética em Pesquisa (CEP/UERN) e aprovada sob CAAE n.º 3104.0.000.428-10. **Resultados:** a partir dos relatos das cuidadoras emergiram as seguintes categorias: "Acesso ao atendimento oncológico", "Espaço físico do COHM" e "Recursos humanos e assistência aos pacientes oncológicos pediátricos no COHM". Foi relatada a rapidez no diagnóstico e no acesso a assistência e apesar do apoio e do acolhimento prestado pelos profissionais, a estrutura física, caracterizada como pouco acolhedora para a permanência durante o tratamento, foi considerada um aspecto limitador das práticas. **Conclusão:** para discutir a assistência oncológica ambulatorial nessa instituição é preciso articular os aspectos, físicos, funcionais e estruturais como condições que atuam, de forma positiva ou não, na vivência do câncer nas famílias. **Descritores:** humanização da assistência; serviço hospitalar de oncologia; cuidados de enfermagem.

RESUMEN

Objetivo: conocer las percepciones de las madres sobre el espacio asistencial y de las prácticas en salud, en particular de enfermería, en un servicio de oncología pediátrica. **Método:** investigación cualitativa realizada con diez cuidadoras de niños en tratamiento ambulatorio de oncología utilizando el grupo focal y la entrevista. Los datos obtenidos fueron transcritos y analizados para la construcción de categorías que expresasen las percepciones de las madres sobre el espacio y las prácticas actuales en el servicio. La investigación fue presentada al Comité de Ética en la Investigación (CEP/UERN) y aprobada bajo CAAE n.º 3104.0.000.428-10. **Resultados:** de los informes de las cuidadoras surgieron las siguientes categorías: "Acceso a la atención oncológica", "Espacio físico del COHM" y "Recursos humanos y asistencia a los pacientes de oncología pediátrica en el COHM". Fue reportada la rapidez en el diagnóstico y el acceso a la asistencia y a pesar del apoyo y acogimiento dado por los profesionales, la estructura física caracterizada como poco acogedora para la permanencia durante el tratamiento fue considerada un aspecto limitador de las prácticas. **Conclusión:** para discutir la asistencia oncológica ambulatoria en esta institución es necesario unir los aspectos físicos, funcionales y estructurales como condiciones que actúan, de forma positiva o no, en la experiencia del cáncer en las familias. **Descriptores:** humanización de la atención; servicio de oncología en hospital; atención de enfermería.

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INTRODUCTION

The term cancer is generally used to represent a diverse set of more than 100 illnesses, including malignant tumors in different locations.¹ Despite the scientific and technological advances in treatments, there is still a remarkable association between morbidity, mortality, and cancer, which makes cancer one of the world's leading public health problems.²

When it comes to pediatric cancer, the anguish of parents and relatives facing a disease that carries difficult monitoring is commonly evidenced, especially by the stigmas and taboos related to the healing process. This condition can generate anxieties related to live or die because of the meaning of the problem, for the child and family, potentiating the inherent psychological and social aspects, which may hamper the treatment. In addition, the possibility of death lurking these people since the discovery of the disease is daunting and tends to make them more susceptible to magnify feelings in the face of the difficulties experienced.³⁻⁵

The fact of being a stigmatized health problem emphasizes the need to develop embracing and supporting practices during the child's treatment, with a view to integral assistance to the needs of the group. In this case, it is important that the multidisciplinary team know the nuances of child development and the impact of this problematic in the social insertion space of these individuals.^{3,4}

Thus, the caregiver in the pediatric assistance must be capable to deal not only with the disease and its treatment, but also with the child and family. Furthermore, in the context of pediatric oncology and therapeutic characteristics, it is possible to observe irritated children as the result of successive admissions and immobility during treatments. This situation is further aggravated by the distance from their own known and safe space, limitation of activities proper for their age, and procedures and interventions, which invasive or not, often causes pain.⁶

In this dimension, it is possible to state that it is the nursing staff that more commonly embraces and establishes a dialogue with these people, especially by being more present during the entire treatment. In fact, it is necessary that these workers be trained to act in a more comprehensive fashion, developing skills and technical/scientific competencies exercised with embracement, and seeking to understand wishes and needs.⁶ Therefore, the nursing professionals who provide pediatric care,

particularly during oncological treatment, should thrive to understand the children in their life context, especially by involving parents and other close relatives or people who can act contributing to the daily work.

It is possible to suggest that the family plays a decisive role in the treatment and recovery of the child because they share fears and routines inherent to the disease. In addition, the partnership established between mothers and health professionals is characterized as fundamental to facilitate the involvement and acceptance from the child facing the disease and treatment.⁵ This relational dynamic must be the most fruitful possible, especially for the mothers to understand the problems and treatment and still be able to embrace and support the child at this time drawing from the support received. These people should be considered agents participating in the treatment, attentive to the care provided and having the discernment of the possible needs that arise during the process.⁷

Accordingly, the family and especially the mother can be characterized as primary tools of perception and evaluation of the assisting space and health practices provided by the various professionals. Thus, an evaluative relationship of reciprocity must be established with the health staff, encouraging the discussion of actions and assistance dynamics, which could contribute to the treatment and the reorganization of health practices.⁵

In the face of this dimension, this study aims to understand the perceptions of mothers about the assisting space and health practices, particularly provided by the nursing staff. It is expected that this evaluation will allow the reflection on the structural and assisting conditions that interfere with the daily assistance by providing possibilities to seizure other aspects beyond the technical dynamics.

METHOD

This was a qualitative research conducted with mothers of children undergoing oncologic treatment at the Hematology Oncology Center (COHM) in Mossoró-RN. The listed criteria for the mother and child for acceptance of participation in the study were to be in ambulatory monitoring the child for at least one year, and the child under the care and oncology treatment to be at least twelve years old.

The delimitation of this treatment time was due to the need to have mothers who knew the service and health practices

developed in this sector in order to be able to reflect about the institutional context and the assistance. The child age criterion is related with the characterization of adolescence because individuals older than twelve years are no longer considered a child. The study sample size was delimited to ten mothers regardless of the number of mothers with children in oncological treatment, however, according to their acceptance to participate in the study.

Initially, the focal group approach was used for data collection, which provided subsidies for the reconstruction of the script of interviews to be used in the second step of the research process. Two focus groups were performed. The first one discussed the experiences with pediatric cancer, treatment and difficulties/non-difficulties in that context; the second one discussed the nursing practice with the children and families in the assisting space of the COHM.

The interview script guide was elaborated after this first round of data collection addressing gaps identified in the focus groups about space, health practices used by the nursing staff, and the limits and possibilities of assistance within this institutional context. The interviews were subsequently conducted with all participating mothers.

The data collected through these two approaches were successively read in order to identify the categories of meanings related to the object of investigation. After the definition of categories, the data were analyzed in the light of a theoretical referential that was the foundation for the construction of this study guided by the context as the key aspect that interferes in satisfaction with the assistance.³

This study was submitted to the Ethics in Research Committee from the Rio Grande do Norte State University (CEP/UERN) under CAAE No. 3104.0.000.428-10 and approved under the embodied protocol No. 080/10.

RESULTS AND DISCUSSION

Categories of meanings were defined using the analyzed data from the focal groups and individual interviews to discuss the assisting space and the mothers' perceptions about the health practices used in the COHM. The categories were labeled as "Access to oncologic care", "Physical space at the COHM", and "Human Resources and assistance to cancer pediatric patients at the COHM".

● Access to oncologic care:

The COHM was founded in 1995 and is currently the Reference Unit for Cancer

Treatment in the West Potiguar region in Brazil. It is characterized as a service of high complexity and, despite its private operation it is the only institution in the region accredited by the Single Health System (SUS) to meet the needs of the local and neighboring population in hematology and oncology.

Regardless of the difficulties related to access, particularly to the pediatric oncology service, the maternal discourses showed no pilgrimage in search of assistance. No problems related to health assistance were reported, from the final diagnosis to the beginning of treatment, during the research at the institution or by the surveyed mothers:

She started running a fever. I took her to the doctor and the diagnosis was quick. The doctor sent her soon to the pediatrician who forwarded her to the doctor who was an expert on this disease. With the exam results they diagnosed her disease. (Mother 1)

She had an inflated belly, fever, and spots on the leg, and then I looked for a pediatrician. This was on Friday. The doctor requested some exams and had her taken to the oncologist pediatrician on Monday for the evaluation of the exams' results. I was promptly serviced. (Mother 7)

The early initiation of treatment in cancer, including in children, is one of the aspects that tends to contribute to the healing of the disease. However, the situation highlighted in this service does not necessarily characterize the national parameters; in such cases, the diagnostics and treatments tend to have a late onset, which depends on aspects that are external to the patient. In Brazil, these differences are evidenced according to economic and social conditions, and geographical issues. The proximity to major centers and access to financial resources facilitate the search for assistance and early assistance.⁸

A study conducted to identify children and adolescents with cancer in the municipality of Jundiaí and surrounding regions showed that 67.6% of the study sample was forwarded to the hospital and, on average, it took less than a month between the discovery of the disease and the onset of treatment in 50% of these patients.⁹ Also in this case, there were no difficulties in accessing assistance. However, the fact that a large proportion of patients seen in cancer services are referred from a hospital network must be considered, which may be representative of failures in the basic health assistance network.

The functioning of the reference system for basic assistance must be highlighted because

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despite being the "gateway" for the preliminary assistance to users, in the case of cancer, the referral from other basic services to hematological services seems to be common. Probably, the existing shortcomings in the basic health systems create difficulties toward referrals or early diagnosis necessary for proper and important procedures and decisions.

Early diagnosis is further affected when it comes to children because the signs and symptoms of infantile cancer significantly resemble some from frequent childhood diseases. This condition tends to delay the search for health services, which in addition to the precariousness of the system, eventually magnifies the inherent difficulties in the diagnosis and treatment.¹⁰

This aspect is exacerbated by the fact that the instruments for tracing cancer, particularly in the early stages, are precarious and the diagnostic exams are costly, indicating the lack of public resources for health actions in the country. In this situation, there is a tendency to late diagnosis among patients suffering with cancer and users of the Single Health System (SUS).¹¹

However, despite these obstacles, the improvement in survival rates and healing of the childhood neoplasias is visible, which are reflections of an early diagnosis and advances in anti-neoplastic drugs. Changes in the evolution behavior of tumors have been reported recently with an increase in the rate of healing of most cases. Currently, two thirds of cancers might have an excellent prognosis if the diagnosis is early and appropriate therapy is instituted. Although the causes are still somewhat unknown and the tumors differ from the adults with respect to histological types, biological behavior, and clinical presentation, the therapeutic response in the child is in most cases better than in adults.¹²

Even though, it is necessary to reflect the routine of public policies and health practices regarding the knowledge of the institutions and their needs articulating these dimensions with the different contexts of life in the society. To think locally means to consider the diversity and specificities of pressing demands and the necessity to articulate the needs that arise in each space in order to assist the various subjects involved in this dynamic.

● Physical space at the COHM:

According to the National Policy of Attention in Oncology, an Assistance Unit of High Complexity in Oncology is defined as a hospital that possesses technical conditions, physical facilities, equipments, and adequate

human resources to provide specialized assistance of high complexity for the definitive diagnosis and treatment of the most prevalent types of cancers in Brazil.¹³

Among these, the ambulatory chemotherapy is highlighted, as a new trend that allows the child to return to their family environment. In this modality, the hospitalization only happens in the face of possible complications from the treatment, enabling a reduction in stress caused by the absence of the familiar environment.¹⁴

Despite the ambulatory treatment provided by the unit, with short stay in the service, some speeches still emphasized the difficulties related to the physical structure for the care of children during oncological treatment. In general, the physical space was considered insufficient for the demand evidenced by the lack of beds for accommodation of the child during the chemotherapy session. In these cases, the discomfort was caused by the improvisation needed for assistance at that time.

I would just change the space with the chairs in the chemotherapy room because it is too conjugated. It is very tight, the space is small. It should be a larger room but since it can't be, it has to be this way. One day we will have a hospital, which we should already have a long time ago. (Mother 2)

The space should be bigger, right? It lacks comfort. The chemotherapy room needs to have more seats because sometimes when everyone arrives it is crowded. Thus, some children sit on chairs in the chemotherapy room, others at the reception all day long. Sometimes for more than six hours. (Mother 4)

In this standpoint, the physical dimension is characterized as a primordial aspect for the adequate assistance because an appropriate institutional environment contributes to the improvement of treatment and experience through this situation. The precarious physical conditions have an ultimate impact on the professional performance making the proper assistance and children's comfort difficult to achieve.¹⁵

The absence of entertainment during the treatment is another aspect related to the physical structure of the service. Despite being a pediatric sector, and the chemotherapy a time-consuming procedure, there is almost no entertainment geared towards the children. In one of the chemotherapy rooms there are only two televisions, and some toys at the reception. In another room there are no sources of entertainment for the children.

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There are some days when she (the daughter) is located in the room without a television, because there is only one room with a television and sometimes it is crowded; then she complains to me because she doesn't like to stay there without doing anything, she wants at least to watch TV all day. She does not want that I come here to the room that has nothing for entertainment. (Mother 7)

In this sense, the importance of pediatric hospital institutions in having the architecture that is pleasing to the child's eye must be reinforced. The space should be colorful and with stimuli capable of facilitating the child's development, including architectural aspects related to lighting and ambiance. In fact, when reflecting on a pediatric environment and humanized assistance, it is imperative to understand the different needs of each other and the development of the child undergoing oncological treatment.³ In addition, it is essential to consider spaces that promote interaction because the contact with others value ludic elements facilitating the establishment of connections and trust, which are aspects that support the adherence to any health treatment.¹⁵

Studies point to the importance of an environment that fosters playing activities because it is characterized as a significant tool to discuss issues such as wholeness of assistance and adherence to treatment. Playing tend to facilitate communication between children, health professionals, and accompanying persons assisting with the reassessment of the disease and preservation of the child's rights.¹⁶

In this study, the issues highlighted by the mothers do not differ from the national panorama regarding difficulties in public services and the need for further investments in health care. This situation becomes even more critical when the family of the child suffering with cancer present precarious social, economic, and cultural conditions expanding the vulnerability that the disease imposes. Therefore, the allocation of more resources to public services would contribute to the child's treatment and, consequently, to improve the quality of the assistance provided.¹⁷

● Human Resources and assistance to pediatric cancer patients at the COHM

In relation to the human resources present in this pediatric oncology assistance, the mothers emphasized the absence of an exclusive nurse in the sector. In this service, up until the period of this study, the pediatric section counted only and in special situations,

with the nurse assigned at the adult ambulatory chemotherapy sector.

In relation to the staff, so I think, there should be a nurse, I do not know now, but at the time when she was receiving chemotherapy treatment there were no nurse directly assigned here in the sector, and I think it should have one. (Mother 2)

There is no set nurse here, huh? The nurses are in the area of adult chemotherapy and only when needed, they are called to come to this sector. This need to be improved, but I heard that in the hospital, there will be a nurse in each sector. (Mother 5)

The role of nurses in the oncology sector includes the care related to the promotion and prevention, utilization of adequate assistance to the client and families using the acquired knowledge, and seizing from the actions of the interdisciplinary team.¹⁴ In addition, the importance of the practice of health education in pediatric oncology assistance is emphasized because information/orientation is essential for parents to adapt and best experience the changes that occur in their daily lives when facing a disease.¹⁸ However, the absence of a specific nurse in the sector may result in disruptions in the routine assistance by not allowing the performance of specific actions in this category.

The presence of only one nursing technician per shift was also reported by the interviewed mothers in combination to the lack of nurses exclusively assigned to the sector. This question was commented considering that the workload is exhausting to just one person on the ward due to the demand and specific needs of each child.

The sector needs more nurses here in the pediatrics because there are too many children for the care of only one nurse who cannot perform properly; I think it would be better to have one more nurse. (Mother 1)

There are many responsibilities here for the nurses, there are days with too many children for the care of one nurse ... The children need to be medicated, measured, weighed. It is a lot of work to do! To get the medication from the other side of the hospital and deliver to different patients. I think it's very tiring; the sector should have at least two nursing technicians to facilitate the assistance. (Mother 2)

There is one nursing technician to assist all the children so I think the sector needs to increase the number of professionals. (Mother 3)

Even pointing these negative aspects, the parents highlighted the qualities inherent to the routine assistance service, stressing that the healthcare medical and nursing staff

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present knowledge and skills in practice with children.

I think that they are well prepared, well aware, I haven't seen flaws. They are here all the time, they have so much patience. (Mother 5)

They are always great, I love all of them. There are no flaws! They are very careful. We don't even need to call because they are always attentive. (Mother 3)

When I have questions, depending on the situation, the doctor is not always present. When the doctor is present I reach out to her, but if she is not present I reach out to the nurses. They work along with the doctor and know all the occurrences from the chemotherapy and treatment. (Mother 2)

The humanization in the practice, fairness, and dedication on the part of the professional team are essential in this type of service. They are characterized as another level of support allowing the family to feel supported to bring their anguish, requiring the active interest from the professionals aiming at improving the care and their sensitivity through the mechanisms of listening. This allows the approximation to find in the other, the forces to overcome the disease and challenges, such as the process of adaption to new situations when facing health/disease processes.⁶

Both doctors and nurses demonstrate a lot of interest in the patients. This is very important, both for the child and the mother or father who is following up on the situation. It's very interesting to feel that there are more people interested in your problem than you, I find it very important. (Mother 6)

The need for empathy and embracement is essential for the establishment of a safe and calm relationship among the family, child, and multidisciplinary team. That relationship must be based on meeting the physical, psychological, and social needs of users, and seeking to facilitate the patients' knowledge about the diagnosis and treatment.⁶

The existence of a good relationship between workers and users was observed from the obtained speeches, which can facilitate the identification of needs for care and clarifications, as well as, the acceptance of the chemotherapy treatment based on technical actions and guidance in the overall process that the child is going through:

All in the team are excellent. Their professional and human sides because I think both sides need to be present. It has been very calm for me since I came, with understanding and information that are very important to us who are experiencing this! It is very important, especially when the

person arrives to begin treatment. (Mother 3)

I think that the nurses are friends, companions beyond being nurses, I have nothing against them. They are all good, even the housekeeping staff. They are all great! The nurses treat all children equally. No one is considered better than the other! I think that the way they work is beautiful. (Mother 6)

There are studies that discuss the importance of the health team to relate well with users; this can be characterized as a differentiator in the experience of the illness process and effectiveness of assistance.¹⁹ Helpful and involved workers are able to interfere significantly in the adaptation of families and children to the disease.²⁰ The diagnosis of cancer in the family brings numerous implications for everyone, not just for the child, but for parents, siblings, relatives and friends, the people who tend to be under strong pressure as the result of the diagnosis. The changes occur in the domestic routines, professional and financial life, and absences because of hospitalizations; the support provided by the healthcare team to ease anxieties and frustrations is essential.¹⁸

When there is a close relationship established with the use of appropriate language performed through the sharing of information by the multiprofessional team, this need can be minimized.²¹ Furthermore, an adequate relationship between the child, family, and healthcare professionals facilitates the awareness of the extent and severity of the disease, adherence to treatment, and trust on all involved.²⁰

In this case, it is possible to suggest that, despite all the existing functional and physical limitations, the practices developed by the workers have contributed in a singular way to the establishment of good relationships, which can stimulate the best experience and acceptance of the disease.

Even understanding the positive characterization developed in this space, it is necessary to reflect on aspects related to the knowledge of the users regarding the assistance as a right and not as a favor. It is possible that the parameter for evaluating the rendered care as good is related to the perception that the professionals providing the care are doing it as a favor. For many users of the services, and in many spaces, the work on health is still not understood as a professional activity, which characterizes the offered assistance more as a good deed than as a practice that should be developed in the best possible way. In these cases, whosoever

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does this way is perceived as good, disregarding all other aspects that interact in providing quality assistance.

Furthermore, many of these mothers have no comparison parameters regarding the offered assistance in cancer services; because of the absence of other assistance contexts for comparison, this assistance tends to be qualified as the best.

CONCLUSION

With respect to the nursing healthcare provided to the oncological child in ambulatory treatment, it was possible to grasp that the nursing staff requires offering ongoing support to children and families beyond a high-quality technical assistance to help them cope with this condition in a humanized and complete fashion.

In this studied site, it was observed, in general, that the mothers are satisfied with the attention given to their child and family with regards to access to the service, interactions, guidance, and clarifications when needed. However, there is no reflection on the patterns characterized as qualifiers of assistance; this dimension might have a direct relation to the breach of knowledge related to practices in other areas of healthcare.

The physical and functional aspects and the need for strategies for better procedures and solutions were reflected when listing the negative points made by the mothers. This dimension can be minimized in the physical space related issues and on the basis of the construction of a new hospital for oncological care. Nonetheless, it is still necessary to reflect the functional dynamics in order to generate greater safeness and satisfaction with the assisting process in health/nursing.

The development of this study provided subsidies and reflections for the improvement of the assistance provided by the whole nursing team in the pediatric oncology sector. In addition, the study contributed to the academic area, mainly toward the professionals interested in this specialty, both with regard to the development of research and reflection and reorganization of the technical assistance dynamics.

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