

Intervening factors for nursing care in the feeding of hospitalized children undergoing chemotherapy

Fatores intervenientes para o cuidado de enfermagem na alimentação da criança hospitalizada em quimioterapia

Factores intervinientes en el cuidado de enfermería en la alimentación del niño hospitalizado en quimioterapia

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Abstract: Objective: to describe the intervening factors for nursing care in the feeding of hospitalized children undergoing antineoplastic chemotherapy. **Method:** qualitative, descriptive study conducted in a public pediatric university hospital in the state of Rio de Janeiro, from October to December 2015. Seventeen nursing professionals were interviewed, and data were subjected to Thematic Analysis. **Results:** multiprofessional teamwork, understanding of family and interaction, bonding and conversation with the child were considered facilitating factors. In turn, provision of inappropriate food by the family and hospital rules regarding the meal hours of children and caregivers were pointed as difficulties. **Conclusion:** The feeding of children on chemotherapy, as daily and habitual care, is a challenge for nursing professionals due to the limitations imposed by the hospital setting

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and treatment. Nursing care can be facilitated through joint actions with the multidisciplinary health team and the family.

Descriptors: Pediatric nursing; Nursing care; Neoplasms; Feeding

Resumo: Objetivo: descrever os fatores intervenientes para o cuidado de enfermagem na alimentação da criança hospitalizada em quimioterapia antineoplásica. **Método:** estudo qualitativo, descritivo, realizado em um hospital universitário pediátrico público no Estado do Rio de Janeiro, de outubro a dezembro de 2015. Foram entrevistados 17 profissionais de enfermagem, sendo os dados submetidos à Análise Temática. **Resultados:** trabalho em equipe multiprofissional, entendimento da família e convívio, vínculo e conversa com a criança foram considerados fatores facilitadores; enquanto, oferta de alimentos inapropriados pela família e regras hospitalares quanto à refeição de crianças e acompanhantes como dificultadores. **Conclusão:** a alimentação da criança em quimioterapia, enquanto cuidado cotidiano e habitual, é um desafio para os profissionais de enfermagem devido aos limites impostos pelo cenário hospitalar e pelo tratamento. O cuidado de enfermagem pode ser facilitado por meio de ações conjuntas com a equipe multiprofissional de saúde e a família.

Descritores: Enfermagem pediátrica; Cuidados de enfermagem; Neoplasias; Alimentação

Resumen: Objetivo: describir los factores intervinientes en el cuidado de enfermería en la alimentación del niño hospitalizado en quimioterapia antineoplásica. **Método:** estudio cualitativo, descriptivo, realizado en un hospital universitario pediátrico público en el Estado del Río de Janeiro, de octubre a diciembre de 2015. Fueron entrevistados 17 profesionales de enfermería y los datos sometidos al Análisis Temático. **Resultados:** trabajo en equipo multiprofesional, entendimiento de la familia y convivencia, vínculo y conversación con el niño fueron considerados factores facilitadores; mientras, la oferta de alimentos inapropiados por la familia y reglas hospitalarias relacionadas a la comida de niños y acompañantes como dificultadores. **Conclusión:** la alimentación del niño en quimioterapia, bien como el cuidado cotidiano, es un desafío para los profesionales de enfermería debido a los límites impuestos por el escenario hospitalario y del tratamiento. El cuidado de enfermería puede ser facilitado por medio de acciones conjuntas entre el equipo multiprofesional de salud y la familia.

Descriptor: Enfermería pediátrica; Cuidados de enfermería; Neoplasias; Alimentación

Introduction

Cancer is characterized by disordered, and sometimes rapid, aggressive and uncontrolled cell growth, which can spread to other organic structures and thus cause functional problems.¹ Currently, chemotherapy is the systemic treatment that has better results for many cancer types, including those of the pediatric age group, reflecting in increased survival. However, the indication of chemotherapy treatment implies the planning and evaluation of a series of factors such as: age of the patient; nutritional status; renal, hepatic and pulmonary functions; presence of infections; tumor type; presence and extent of metastases; and the condition of life of the patient.¹⁻³

The use of chemotherapy is permeated by the possibility of different adverse effects, including those related to the gastrointestinal system, such as vomiting, nausea, diarrhea, mucositis and constipation.⁴⁻⁵ These effects modify the daily and normal habits of a child, as they impair his quality of life by interfering with food acceptance and tolerance. Thus, differentiated dietary care is necessary, as for example, avoiding offering raw foods to reduce the risk of infection due to neutropenia.⁴⁻⁶

It should be emphasized that food intake is a habit built at the beginning of life and is linked to the rising, customs and culture of each individual and his family. However, this habit changes in the need for chemotherapy, especially because of adverse effects of the treatment.⁷

There is also the hospitalization itself, when the child experiences a significant change in her daily routine; much suffering arises, from the separation, loss of control, bodily injury, pain, stress, and restrictions to play and eat.⁸ These experiences caused by the disease and its treatment may affect the physical, emotional, affective and social spheres of children and their families. In this context, nursing professionals have to deal with situations of risk and vulnerability, which require not only understanding of the disease, but also sensitivity to recognize the particularities of such care for this children.⁹

Researches have pointed to the impact of chemotherapy on the child's diet, including findings of decreased acceptance, weight loss, non-compliance with growth curve percentiles, and difficulties faced by the family when experiencing this process due to one or more side effects.^{6-7,10-11}

The present study was based on the theoretical assumptions of Marie-Françoise Collière, who emphasized that caring is maintaining life through the guarantee of a set of indispensable needs for its sustenance and continuity, which cannot be achieved without an indispensable source of life, i.e. the food. Furthermore, in difficult and complex situations there is a need for people and their families to use more specialized skills to replace daily and ordinary care which

they can no longer guarantee on their own.¹²⁻¹³ This replacement depends directly on nursing care, including during the chemotherapy treatment and hospitalization of the child.

The present study is justified by the understanding that nursing care with the feeding of children on chemotherapy is a life-sustaining care, and therefore essential for the survival of these infants. Thus, the following research question was elaborated: What are the factors that interfere with nursing care in the feeding of children on antineoplastic chemotherapy in the hospital environment?

In this line of argument, the present study aimed to describe the intervening factors for nursing care in the feeding of hospitalized children undergoing antineoplastic chemotherapy.

Method

This is a qualitative descriptive study,¹⁴ in which the Consolidated Criteria for Reporting Qualitative Studies (COREQ) were adopted.

The research scenario was a public pediatric university hospital located in the state of Rio de Janeiro, which assists children with cancer undergoing antineoplastic chemotherapy treatment, by enabling the High Complexity Oncology Care Unit (UNACON) of the Ministry of Health. The pediatric inpatient sector, where the study was conducted, is organized into six wards, with eight beds in each, except for the six-bed hematology ward, thus making a total of 46 beds for the hospitalization of children aged between 29 days and 12 years and presenting different pathologies, including cancer.

All wards have division between the beds, with the partition half tile and half glass, plus a resting armchair for parents or guardians. The team of the sector is multiprofessional, composed of nurses and nursing technicians, physicians, nutritionists, physical therapists and psychologists, as well as students and residents of various courses.

The research participants were 17 professionals from the nursing team who worked in the care of children with cancer for more than three months, which were the inclusion criteria. Nine participants were nursing technicians and eight were nurses. Nursing staff professionals who were on vacation, sick leave or any other type of leave were excluded.

The professionals who met the inclusion criteria were personally approached in the workplace by the first author, who was a nursing resident of the scenario institution at the time of the research, and invited them to participate in the research after explaining its objectives and method. There were no refusals or withdrawals regarding participation during and/or after data collection.

Data production took place from October to December 2015, through a semi-structured interview script whose questions dealt with the performance of nursing professionals in the feeding of children undergoing antineoplastic chemotherapy, as well as the facilitators and difficulties found in this care process.

To ensure the privacy and confidentiality inherent in the research, the meeting between each participant and the researcher for the interviews took place in a private room of the institution at the end of the work shift, so as not to hinder the professional's work activities. The interviews were individual, in a total of 17 (one per participant), recorded on digital media, lasting 20 minutes, on average, and transcribed verbatim shortly after their completion.

As the process of qualitative data analysis is continuous, starting from the beginning of data collection, fieldwork ceased when there was saturation of data,¹⁵ i.e. when it was clear the recurrence and complementarity of statements. Then, the data were subjected to thematic analysis in its three stages: ¹⁴ (a) pre-analysis, with a quick reading of the content of the empirical material generated by the interviews and survey of impressions and directions; (b) exploration of material, with exhaustive reading of the raw data for their transformation into

thematic units; (c) treatment and interpretation of results, with inferences in light of the scientific literature and the theoretical framework.

From the grouping of thematic units, two categories emerged: facilitating factors for nursing care in the feeding of children under antineoplastic chemotherapy; and hindering factors for nursing care in the feeding of children under antineoplastic chemotherapy.

The research was approved by the Research Ethics Committee of the institution where it was conducted on September 22, 2015 (Certificate of Presentation for Ethical Appraisal: 46891715.4.0000.5264/ Opinion: 1.239.259), and respected all ethical aspects contained in Resolution 466/12 of the National Health Council. The professionals contacted were duly informed about the research procedures and about voluntary and anonymous participation, signing the Informed Consent Form. Moreover, the letter T was used for nursing technicians and the letter N for nurses to identify the participants, following the sequential numerical order of the interviews, so as to ensure anonymity.

Results and discussion

Facilitating factors for nursing care in the feeding of children under antineoplastic chemotherapy

The possibilities for nursing care in the feeding of children on antineoplastic chemotherapy in the hospital environment were raised by the study participants through the description of facilitating factors for its implementation. Multiprofessional teamwork mediated by partnerships and respect among health professionals from different categories emerged as an important facilitator for nursing professional performance in this context.

Working together with the medical team, with nutrition team. (N3)

It's the partnership between physicians and nutritionists for sure. (N1)

A close interaction with nutrition facilitates things. (N8)

First we have to give guidance along with nutrition and doctors. (N4)

Doctors accept what we say very often, they have much respect for our opinion. (T4)

Studies point out those health professionals should be prepared to support children, aiming at maintaining their daily life habits, such as feeding. Therefore, in case of changes in the feeding of children on chemotherapy, it is necessary to work together with the multidisciplinary team involved in this care, which includes nursing, medicine, nutrition professionals, among others.^{7,16} This is in line with the findings of the present study, in view of the recurrence of testimonials regarding the importance of multiprofessional teamwork, especially between the nursing and the medical and nutrition team.

Thinking of comprehensive care for these children calls attention to the integration of the health team, recognizing the interdependence of the actors in the production of care.¹⁷ The integrated approach of these professionals is more effective than a succession of isolated interventions in the management of cancer patients.¹

Therefore, it is relevant to consider that multiprofessional teamwork in the hospital environment presupposes the access of children on chemotherapy to the different knowledge sets and practices that facilitate the maintenance of daily and habitual care essential for their survival, i.e. feeding, thus promoting comprehensive and quality care.

Thus, it is evident that the nursing care process, also regarding the feeding of children in antineoplastic chemotherapy, assumes a meeting of actors, based on a system of exchanges between different individuals in which each contributes with their different and complementary competences.¹²⁻¹³

The family's understanding of the child's eating situation, especially regarding the restrictions imposed by chemotherapy treatment, also emerged from the participants' statements as a facilitating element for nursing care.

You only really find it easy when you have the mother's understanding [about the child's dietary restrictions], because other than that I think it's always very difficult. (N3)

Once they believe that this aspect [i.e. the child's dietary restrictions] is important, we are able to do it. (N7)

It is the parents' degree of understanding about this point [i.e. the child's dietary restrictions]. (N1)

After children actually begin the treatment phase, mothers receive so much guidance about this [i.e. the child's dietary restrictions] that it becomes easier for the nursing team. (T2)

Evidence indicates that the inclusion of family caregivers in cancer treatment provides greater support and safety for children.¹⁸ It is known that the impact of the disease leads to the need for the family to develop new skills and tasks. Therefore, when the family has a greater understanding of the necessary care, it becomes an ally of the team, which is fundamental in the care process because the family is the reference of love and trust.¹⁶

Research conducted with family members of children undergoing cancer treatment showed that among family expectations regarding the care of the nursing staff, there are actions that provide comfort, affection and support, in addition to sharing information on the pathology, treatment and care needed through active listening, conversations and explanations.¹⁹

It is reinforced, therefore, that it is necessary to understand what the individuals, in this case the children and their families, experience and express, before deciding on the nursing care to be adopted, because they are the ones that hold the main thread of this process. Therefore, it

is necessary to consider the cultural, social and economic aspects of families in the care process, including eating habits. Thus, it is essential to create links between the various information sets obtained during the conversations and interviews.¹²⁻¹³.

A study found that 38 parents of children with cancer had high levels of stress because of their child's eating and weight loss, as well as feelings of helplessness and conflict with the child. Cancer-related malnutrition is common due to a variety of factors, including poor oral ingestion, abnormal nutrient metabolism, and adverse effects of chemotherapy, including nausea, vomiting, anorexia, and mucositis. Therefore, reducing mortality in children with cancer also depends on nutritional care.¹⁰

Thus, the importance of including family members in the food care of these children is stressed, since the maintenance of this habit despite the changes imposed by the disease directly depends on the family's adherence to the new eating practices.

Still regarding the possibilities of nursing care, the professionals pointed out that daily interaction promotes bonding and knowledge about each child and her preferences, which is also a facilitator in the care process. In addition, proximity can facilitate eating itself, through dialogue and guidance.

I think the facilitator is that we are there every day, so we get to know each child, each preference. And I think that the fact that we interact with the child there every day is a facilitator, [...] creates a bond and this bond is very important. (N6)

If we are around this child the care is ideal, [...] through this conversation, the guidelines to facilitate this diet, we have this as a facilitator. (N7)

The strengthening of the relationship, bond and trust between nursing, family and child generated by the fact that nursing professionals remain full time with the child works as a facilitator of caring for these cancer patients,¹⁶ which corroborates the findings of the study.

Thus, the field of competence of nursing lies precisely in the mobilization and development of the capacities of people, in this case, of the child and those around, the family,

so that, in the face of the disease, they become autonomous to solve eating problems, according to their own affective, physical, social and economic resources.¹²⁻¹³

Hindering factors for nursing care in the feeding of children under antineoplastic chemotherapy

Among the difficulties for nursing care in the feeding of children undergoing chemotherapy in the hospital environment, the provision of inappropriate foods because of the necessary changes in the child's diet, due to the disease and treatment, was mentioned with frequency by the participants.

The family offers a lot of inappropriate things for the child because the child has a hard time eating. And in an attempt to feed the child [...] they bring anything [...] which is not always appropriate. (N4)

The difficulties are many for [...] because parents bring hidden food. (T8)

The family itself wants to give another kind of food that cannot be offered at that time. (E3)

Family caregivers of children undergoing chemotherapy experience a reality permeated by doubts, uncertainties, hopelessness, awe, fear and feelings of incapacity before the many challenges that arise.^{16,18} Studies show that family members may not have the proper understanding; they do not adhere to the guidelines of the health team or interpret them differently. However, the participation of family members in the care of patients with chronic diseases is very important because they can offer the support and strength for coping with the situation they go through.^{16,20}

Therefore, the health team should continually advise parents, before and during treatment, about the changes their children will experience in appetite due to nausea, vomiting and mucositis,⁶ and any dietary restrictions that will be imposed in this process.

It should be noted that eating practices are the source of all life habits and beliefs and are transmitted through cultural heritage. Thus, it is a mistake to propose changes without an adequate understanding of their meaning for the people involved.¹³ If this attitude is not adopted, there is a risk that the guidelines passed on by professionals will not be implemented, as reinforced by the statements of the participants.

Sometimes they show some resistance to avoid things that they know the child cannot eat [...] and when they get home they often keep giving these foods until they finally understand and see that the treatment really is serious. (T2)

The difficult aspect is street food. They want food from outside and never from inside the hospital. It has always been like that. (T3)

Given the need to learn new eating habits, it is necessary to build together a care process based on the exchange of experiences between children, families and health professionals, including nursing professionals. Guidance on new eating practices without prior knowledge of habits, tastes and economic resources of the patients' families should be considered an inappropriate conduct,¹²⁻¹³ as this attitude weakens the adherence to changes imposed by chemotherapy treatment.

Therefore, the effective stance of the health team is essential in order to provide support, follow-up and guidance so that the family caregivers may feel embraced and assisted by all team members.²¹ These instructions not only encourage acceptance and participation, but also reduce the stress of the family in coping with eating difficulties.

On the other hand, the institutional norms that include pre-established hours for eating and the prohibition of external foods were also highlighted by most professionals as limiting factors for nursing care.

The timing issue, I think this is very strict here, I know that food cannot stay out of the fridge for long hours. Anyway, maybe if we had more flexible hours, to try to help the child to eat at the time that she is adapted to eat at home, to see if we can get them to eat better. (T9)

The difficulty is that we can't give them what they want to eat, because sometimes there are things that are not allowed in the hospital. So, sometimes some mothers want to bring food, because they know that the child will eat despite she's under chemotherapy, although she shouldn't. (T6)

We have to obey the protocol, the institution's rule, and there is a detail: we can't allow food from home because we don't know how it was prepared, how it was stored, how it was transported. It is a difficult thing [...] passes and serves what is on the menu for them. (N5)

Hospitalization is a new reality in the child's life that changes their daily and normal habits. The inflexibility of eating hours by the hospital hinders nursing care in this area and also harms the child itself, who often wants to eat at other times.

At home, the child is accustomed to a type of diet, family schedules and having their wishes and desires satisfied by those who care for them. This does not happen in the hospital environment. The hospital routine imposes rules and norms that reduce the autonomy of family members, generating the feeling of powerlessness in the face of usual care previously performed at home, besides hindering the shared care between nursing and family.^{7,22}

It is known that the hospital has rules that must be respected by professionals, patients and caregivers. However, they often become a limiter for individualized care, as stressed by participants in the following excerpts.

Sometimes the child doesn't eat, and this is not even because she's not hungry, it's because she doesn't like the food provided by the hospital. I think that if the mother were allowed to bring the food, [...] the child would get better. Within the diet [...] food with better aspect, the child would eat better too. (T1)

We cannot allow food from home, because we don't know how the food was conserved, so we have to obey. (E5)

In the present study, some professionals expressed willingness to allow the family to provide the child with the food she likes, and to be brought by the family, although others pointed out that it would not be safe because of food management.

This is different from that reported by parents in a study in Australia in which the deponents pointed out the preparation of meals in the hospital by themselves or providing homemade meals as a practice to encourage healthy eating during cancer treatment. Some parents who were not able to cook at home or in the hospital bought healthy foods, tasty for the child, and took them to the hospital. This possibility provided an improvement in the child's food acceptance pattern.⁶

It is emphasized that the care for children and their families cannot be determined solely based on disease and technicism, or by institutional rules. Care must stimulate the continuity of life based on meeting a set of indispensable needs to live with quality. These needs are much broader as they include cultural, social, economic, affective aspects, and other issues.¹²⁻¹³

The hospital diet is important to ensure the supply of necessary nutrients to each patient, and thus deserves consideration because food acceptance and nutritional status are linked to the child's response to treatment.²³ This justifies the importance in the view of professionals of offering only the hospital diet, avoiding food brought in from outside the hospital.

However, the imprisonment of care practices to hospital rules implies even the child's refusal to the offered diet, which can affect the response to cancer treatment and generate a worse prognosis, and even death. Therefore, to reduce the children's refusal to eat, it is important to listen and respect their space, that is, their time, their desire to eat, and their hunger.⁷⁻¹⁰

Thus, the field of competence of nursing should be based on mobilizing the living forces of the patients and of those around them to compensate for the abilities that are affected by the

disease, including support and guidance. Therefore, it is necessary to value the maintenance of daily and usual care, such as nutrition and hydration, as these are the ones that ensure the continuity of life,¹²⁻¹³ which sometimes requires more flexibility in hospital rules.

Still in the context of hindering factors, the separation of mother and child at mealtimes, because the companions are not allowed to have their meal in the ward, was also mentioned.

You cannot eat with your mother. At the time of your feeding, you are trapped at that moment, and your mother has to get up and go to eat, and this separates you both at such an important time, a moment that you want to share with your child. [...] This is difficult, this separation of mother and child even to eat. (T5)

Feeding is considered a central aspect of mother-child interaction from the earliest months and years of life. It is critical that mothers and the family be taken into account in child care. They must be instructed on the importance of this relationship at the time of feeding.²⁴ Therefore, the concern of professionals regarding the separation between mother and child at meal times is justified. It is necessary to seek strategies to overcome this separation or reduce its negative impact in the context of hospitalization.

Therefore, it should be noted that if healing prevails over caring, that is, reparative care, typical of the hospital environment, overrides the daily and usual care such as eating time, there will be a progressive annihilation of all living forces of the person, in this case children on antineoplastic chemotherapy, as their vital energy sources will be depleted.¹²⁻¹³

Conclusion

Teamwork among health professionals, understanding, interaction, bonding and conversation with the children were pointed out as facilitating factors for nursing practice in the feeding of children undergoing antineoplastic chemotherapy in the hospital environment. In

contrast, the provision of inappropriate food by family members and hospital rules regarding the meals to children and caregivers were described as hindering factors.

Given the complex treatment of childhood cancer, the care to be offered by nursing professionals regarding diet has some limitations. In order to provide better possibilities for the maintenance of this daily and habitual care, it is necessary for nursing to advance in research and care strategies that have the child and the family in the center of comprehensive care, with joint actions with the multidisciplinary team.

The limitations of this research are related to the fact that the results were produced in only one single scenario, demonstrating the reality of nursing care in only one hospital institution. Thus, further research on the theme, in different scenarios, participants and methodological approaches, is suggested.

The research contributes to a reflection of professionals of the nursing team about their performance in the feeding of children undergoing chemotherapy. Therefore, it is hoped that by recognizing the factors that interfere with this process, these professionals may be able to rethink their practice and opt for actions that contribute to comprehensive care for children and their families, including the appreciation of their lifestyle in the hospital environment.

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