Themes for the Construction of Educational Material about Feeding Children with Leukemia

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Temas para Construção de Material Educativo sobre Alimentação da Criança com Leucemia

Temas para la Construcción de Material Educativo sobre Alimentación de Niños con Leucemia

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ABSTRACT

Introduction: Food is a theme that raises many doubts in family members of children with leukemia and educational materials are essential to prepare and guide these caregivers for home care. **Objective**: To identify the topics on feeding children with leukemia from the perspective of nurses and family caregivers for the construction of educational material. **Method**: Qualitative participatory research conducted in 2018 through discussion circles, in an oncology hospital in Rio de Janeiro-RJ, with 6 family members and 6 nurses, after approval by the Institutional Review Board. The data were analyzed using the content analysis method in the thematic-categorical modality. **Results**: The narratives of family members and nurses were utilized to elaborate the content for the construction of educational materials such as primes, pointing out the need for guidance on food offered to the child, focusing on the following themes: normal immunity; neutropenia; nausea and vomiting; mucositis; dysgeusia; constipation; diarrhea; hygiene and food preparation. **Conclusion**: The construction of educational material for family members of children with leukemia may help to respond to their doubts, since it will enable nurses to guide them during the hospitalization, and later working as a guide for the development of their child's home care.
Key words: leukemia/diet therapy; diet; caregivers; child; educational and promotional materials.

RESUMO

Introdução: A alimentação é um tema que gera muitas dúvidas nos familiares de crianças com leucemia, e os materiais educativos são fundamentais para preparar e orientar esses cuidadores para o cuidado domiciliar. **Objetivo:** Identificar os temas sobre a alimentação da criança com leucemia sob a ótica de enfermeiros e familiares cuidadores para construção de material educativo. **Método:** Pesquisa qualitativa participativa realizada em 2018 por meio de círculos de discussão, em um hospital oncológico no Rio de Janeiro-RJ, com seis familiares e seis enfermeiros, após aprovação dos Comitês de Ética em Pesquisa. Os dados foram analisados pelo método da análise de conteúdo na modalidade temático-categorial. **Resultados:** As falas dos familiares e enfermeiros subsidiaram o conteúdo para construção de materiais educativos, como cartilha, apontando a necessidade de orientações sobre alimentação oferecida à criança, destacando os seguintes temas: imunidade normal; neutropenia; náuseas e vômitos; mucosite; disgeusia; constipação; diarreia; higiene e forma de preparo dos alimentos. **Conclusão:** A construção de material educativo para familiares de crianças com leucemia poderá contribuir para sanar as dúvidas dos familiares, uma vez que permitirá aos enfermeiros orientá-los durante a internação de sua criança, servindo posteriormente como um guia para o desenvolvimento dos cuidados de sua criança no domicílio.
Palavras-chave: leucemia/dietoterapia; dieta; cuidadores; criança; materiais educativos e de divulgação.

RESUMEN

Introducción: La alimentación es un tema que genera muchas dudas en los familiares de los niños con leucemia y los materiales educativos son fundamentales para preparar y orientar a estos cuidadores para el cuidado domiciliario. **Objetivo:** Identificar los temas de alimentación infantil con leucemia desde la perspectiva de enfermeras y cuidadores familiares para la construcción de material educativo. **Método**: Investigación cualitativa participativa realizada en 2018 a través de círculos de discusión, en un hospital oncológico de Rio de Janeiro-RJ, con seis familiares y seis enfermeros, previa aprobación de los Comités de Ética en Investigación. Los datos fueron analizados mediante el método de análisis de contenido en la modalidad temática-categórica. **Resultados**: Los discursos de familiares y enfermeras fueron utilizados para elaborar contenido para la construcción de materiales educativos como el cuadernillo, señalando la necesidad de orientación sobre la alimentación ofrecida al niño, centrándose en los siguientes temas: inmunidad normal; neutropenia náuseas y vómitos; mucositis; disgeusia; constipación; diarrea; higiene y forma de preparación de los alimentos. **Conclusión**: La construcción de material educativo para familiares de niños con leucemia puede ayudar a resolver las dudas, ya que permitirá al enfermero orientarlos durante la hospitalización de su hijo, sirviendo posteriormente como guía para el desarrollo del cuidado en el domicilio.
Palabras clave: leucemia/dietoterapia; dieta; cuidadores; niño; materiales educativos y de divulgación.

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INTRODUCTION

Childhood cancer (between 0 and 19 years of age) includes several diseases having in common the uncontrolled growth of abnormal cells. It is mostly embryonic affecting the cells of the blood system and supportive tissues, accounting for 1% to 4% of all neoplasms; leukemia (28%) is the most predominant pediatric cancer[1].

The treatment of leukemia involves chemotherapy drugs with or without cranial irradiation and develops in four phases: induction therapy whose aim is complete remission with restoration of normal hematopoiesis and disappearance of disease-associated signs and symptoms; prophylaxis of the Central Nervous System (CNS) to prevent relapse; intensification therapy to maximize early destruction of neoplastic cells; and maintenance therapy to keep the organism disease-free[2].

However, chemotherapy has also toxic effect in the organisms, provoking gastrointestinal symptoms that are able to promote poor absorption of nutrients and malnutrition[3]. As part of the chemotherapy cycles are in outpatient mode and most of the children admitted for chemotherapy are discharged after completing the treatment block, the families face challenging health situations at home caused by demands of care imposed by the disease and treatment of the children[4].

The family needs to prepare themselves to deal with a new scenario of the child's health as Basic Attention mostly within Family Health Strategy[5] is frail.

Food is one of the major claims falling upon the family while caring for children at home[6]. The investigators, for that matter, strengthen the competence of the nurse in nutritional counseling and the importance of education in health to elaborate good clinical childhood food practices[7]. In addition, caretakers need to be instructed and coached for home-based care because of procedures and skills they need to develop[8].

In this scenario, educative materials gain relevance across every levels of care, nevertheless, they are biomedical-centered where health caretakers determine how the patients and families must act in certain situations[9].

This study attempts to change the current model and introduce a new format with the participation of patients and their families in choosing the themes and developing the material to make them knowledgeable, skilled and protagonists of their reality.

After searching the Latin American and Caribbean Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE) and "*Base de Dados em Enfermagem*" (BDENF) databases with the descriptors "child", "health education", "programmed instruction", "teaching material", "promotional and educative material", "neoplasia" and "chronic diseases", no studies with the participation of nurses and patients' families about educative materials on food for home-based care to children with leukemia were found.

The objective of the study was to identify the themes about food for children with leukemia in the perspective of nurses and family caretakers to construct educative material as easy-to-access primers.

METHOD

Qualitative and participative study based in the Consolidated Criteria for Reporting Qualitative Research (COREQ)[10] conducted in an oncologic hospital in the municipality of Rio de Janeiro with 12 pediatric hematology beds. The children hospitalized were cared by a multiprofessional team, in addition to attending residents and fellows.

The methodology of participative research was the method adopted to investigate the social reality where the individuals live in a dialectic perspective for better awareness and potential transformation of the reality through the reciprocity between subject and object[11].

The sample consisted of 12 individuals, six attending nurses and six family members of children with leukemia (the most incident in children with cancer) randomly selected in the days the investigators were at the clinic to collect the data. The family members were invited to join the study in the working days from 10 A.M. to 16 P.M., however, three refused and four were unable to participate of the discussion groups due to the severity and/or complications with the child.

The inclusion criteria were family/caretakers of children with leukemia in treatment and nurses who provided care to these children and their families for more than one year (one per child). Fellow, residents, routine-attending nurses, visitors were excluded.

Data were collected in June and July 2018 through discussion groups, qualitative approach technique with opinions, beliefs and priorities of the participants about a certain theme[12].

The research question was: What do you believe an educative material should address for the family member to provide better care to the child with leukemia at home?

The discussion groups met three times in three phases each, totaling 9 encounters: the first with nurses, the second with the family and the third with nurses and family together. In the first two phases, it was attempted to know what the participants thought it was important for the educative material about themes as food,

chemotherapy, immunity, contamination/infection and central venous catheter.

The third phase comprehended the themes obtained in the previous phases for the participants to choose those to be included in the educative material. During the debates, it was understood that food, chemotherapy, immunity, contamination/infection were interconnected and converged to the main doubt of the family: which food can be offered to the child? Eventually, it was decided that the focus would be feeding the child with leukemia.

The discussion group was arranged with the participant seating at the left of the principal investigator to start the debate and whomever wished to speak, raised the hand and waited its turn while any other participant was talking. The sessions lasted 60 minutes in average and were fully audio-recorded.

During the group discussions in the third phase and supported by scientific literature, the content of the educative material was defined. Upon extensive debate, the themes about which food would be offered to the children and when were: regular immunity, neutropenia; nausea and vomit; mucositis; dysgeusia; constipation; diarrhea; hygiene and how food was prepared. The criteria to complete data collection was saturation because the second and third cycles produced quite similar results to the first.

The material resulting from the discussion groups with nurses and family was reviewed in order to systematize theme-category-based content analysis, an array of techniques to obtain indicators of communication to allow the inference of facts related to the reception of these messages[13].

To organize, analyze, interpret and categorize the material, the following stages were followed: (a) audio transcription; (b) comprehensive reading to design the study *corpus*; (c) codification of the *corpus* in registers; (d) identification of the subjective meaning of fragments of the participants' narratives by similarity or proximity; (e) interpretation of ideas and meanings extracted from each thematic group; (f) discussion of the results of the scientific literature about the theme.

All the investigators participated of the process of treatment and analysis of the data. The audios were fully transcribed and the field notes were evaluated and validated individually by the authors.

The Institutional Review Board of the proposing and co-participant institutions approved the study, report number 2.549.848 (CAAE 81885817.4.0000.5282) and report number 2.627.369 (CAAE 81885817.4.3001.5274), respectively. Data were collected after the participants signed the Informed Consent Form. Alphanumeric codes were utilized – *Enf* for nurses and *Fam* for family according to the order the participants joined the study.

RESULTS AND DISCUSSION

The age-range of the family (five mothers and one grandmother) was between 22 and 61 years and education, from elementary to university. Five were relatives of children with acute lymphoid leukemia and one, acute myeloid leukemia. Time of treatment was from two months to four years. As the children were in different treatment phases, it was possible to have a comprehensive and consistent content able to be shared by all.

The nurse's age were from 33 to 58 years, average professional experience of six years in pediatric oncology and all were graduated in oncology and/or pediatrics.

Feeding the child with leukemia is matched to the evolution of the disease and/or treatment, thus it was not realistic to discuss a single diet, but a set of patient-centered diets to be offered at different timepoints considering the child's clinical status[14]. The educative material would preferentially reflect the treatment phases because food is critical to provide the required nutrients for their development.

The themes nurses and family concluded that were important to include in the educative materials were divided in eight groups, addressing the food the child can eat, hygiene and preparation.

Feeding the child with regular immunity

It is possible that even sick, the child's immunity and gastrointestinal function are regular without food restriction. As the narratives show, the child can have a healthy and age-compatible nourishment[14].

> I think it has to talk about the importance of a healthy feeding (*Enf*1).
> Need to talk about fruits, which one he can eat. Fruits, vegetables (*Fam*3).

While the nurse is concerned with healthy food, the family is focused to what the child can eat. If the immunity is regular, no food restrictions are required, it is recommended to eat healthy food as grains, flour, legumes, vegetables, milk, eggs, poultry, fishes, meats, beans and rice. In addition, oils, fat, salt and sugar in small quantity and restriction of processed food. It is necessary to evaluate the child's clinical conditions because of treatment-related adverse events[14].

Feeding the child with neutropenia

Chemotherapy is essential to treat leukemia but causes unexpected reactions that the child will need to make adjustment in its life habits, among them, feeding. The narratives below portray these aspects:

> Just completed one CT cycle, going home, knows it will be neutropenic and won't be able to eat anything raw [...] no raw food, only cooked (*Enf*4).
> In this phase (neutropenia), watch fruits and vegetables because of intestinal infection (*Enf*2).
> Recently, I found that you can't eat fruit with low immunity [...] regular fruit (can't eat) (*Fam*5).

Neutropenia, a common post-chemotherapy condition, as these narratives show, makes the child susceptible to infections[15], a concern for nurses and family who attempt to adopt infection preventive measures. Food requires special attention to prevent being carriers of microorganisms that may compromise the child's health condition and its life.

Chemotherapics reduce the child's immunity, known as neutropenia, needing attention to avoid infections. Neutropenic diets can diminish the incidence of infections, minimizing the exposure of the patient to bacterial agents. The basic recommendations are: hygiene and food preparation should be kept to avoid contamination, avoid eating meat, fish or raw eggs, eat pasteurized products, packaged and whenever possible, avoid raw vegetables[15].

Quite often, the child with leukemia is discharged with the immunity system still in recovery and needs home-based care, for instance, neutropenic diet[16].

This diet consists in cooking or baking food at high temperatures to significantly reduce the number of bacteria and other microorganisms to protect the immunosuppressed patient. However, clean fresh fruits and vegetables have compatible microbiologic profile with the Brazilian legislation for neutropenic patients[17].

Although some authors recommend the neutropenic diet[14-16], there is no evidence in the national and international literature that it is effective in preventing infections. A Brazilian study concluded that patients receiving neutropenic diet had higher infection rates when compared with those with unrestricted diet[18].

Even without scientific-based evidence of the efficacy of neutropenic diet, there is consensus adopted by most health institutions about oncologic nutrition in Brazil recommending its use, considering the reality of many Brazilian children who have poor food hygiene and diet[14].

Feeding the child with nausea and vomits

Nausea and vomits are the most common reactions occurring during the chemotherapy[19] treatment and mostly they don't compromise the child's health but are great obstacles in accepting the diet, being necessary to change food, schedule and portions offered as the narrative demonstrates:

> Whenever he does CT, he is sick and retching [...] can't see food (*Fam*3).
> It is good to offer cold and odorless things after CT, otherwise, he will throw up [...] quite often we tell them to suck ice (*Enf*3).

Gastrointestinal problems are chemotherapy's side effects because of the drug toxicity and its impact in the overall status of the patients' health whose more frequent complaints are nausea and vomits, responsible for poor food acceptance[19]. In addition, damages may occur, affecting the digestion and absorption of nutrients and making these patients more propense to abdominal distention, loss of appetite and secondary reduction of food intake[20].

Feeding the child with mucositis

Mucositis is an inflammation of the mucosa caused by chemotherapy, it can onset all through the gastrointestinal tube, however, oral mucositis is more common. Causes severe limitations in feeding because of the pain, possibly leading to changes in food consistency, acidity, temperature and spices utilized[21]. The narratives reveal the nurses' and family's concerns with the child with mucositis:

> Instruct them to drink water because dry mouth can cause bruises, mainly if mucositis is present (*Enf*2).
> His feeding worries me [...] don't know what can or cannot (eat), most of all when there are mouth wounds (*Fam*5).

Investigators concluded that mucositis is one of the most common toxicities of the gastrointestinal tract, but quite often, it is detected only at home. It is important to guide parents and children to watch the hygiene and frequent checking the oral cavity to identify possible early lesions and bleeding and seek medical care[21].

The degree of mucositis requires food consistency adjustment of the child's intake, who must understand how nourishment is relevant. Liquid and pureed should be preferred over dry, solid or spicy food, at room temperature, cold or icy, adding less salt to the preparations, avoiding raw fresh vegetables, acid or sour food and abrasive spices[22].

Feeding the child with dysgeusia

Dysgeusia is another complication of chemotherapics and is usually associated with xerostomia, negatively impacting the diet acceptance by the child because it can't feel the food taste:

> Sometimes, he says the food is tasteless and doesn't want to eat (*Fam*4).

> We want to prepare the food, but we don't know because for her everything is tasteless (*Fam*1).

Family members reported dysgeusia as an obstacle for food acceptance. It is caused by the chemotherapic which compromises the integrity of the oral epithelium, reducing gustative receptors and/or cell changes at the surface of the receptors' membranes leading to complete taste loss, reduced sensitivity, taste distortion or perception of tastelessness[23].

It is recommended a diet with smaller volumes, offering six to eight meals per day, encourage the intake of comfort food, modify the consistency according to the acceptance, visually, colorful pleasant meals, food with strong tastes, herbs and spices to add flavor[14,24].

Feeding the child with constipation

Constipation is common in children with cancer associated more with the continuous use of morphine rather than chemotherapics[14]. However, the family has concerns as the narrative below shows:

> Need to guide the child to drink water most of all when morphine is being used because of intestinal constipation (*Enf*3).
> Sometimes, the child did not defecate for several days, then we feed them papaya, but we are worried because of low immunity (*Fam*2).

It is necessary to replace processed food for fiber-rich food together with hydration. Fruits, legumes, oats, barley, beans, lentil, chickpeas, wheat bran and vegetables[25] are recommended.

Possibly, the child is neutropenic too and may need specific dietary care.

Feeding the child with diarrhea

Diarrhea is another complication for the child with cancer and may be related to intestinal infection.

> Once in a while, I listen a mother saying the child has diarrhea [...] I don't know if it was the food there or if from other place (*Fam* 3).
> Has to tell about the risks of intaking raw food [...] risk of intestinal infection and diarrhea (*Enf* 1).

Diarrhea causes loss of fluids, electrolytes and poor absorption of nutrients, can be the consequence of certain chemotherapics, primary and secondary infections, antibiotics and stress[26]. Patients with diarrhea should have food in portions, light and easy to digest as purée, cornstarch porridge and cooked fruits, rice, noodles, banana, peeled boiled potato, skinless chicken and fish, grilled or baked, chicken, legumes or meat broth, oral hydration beverages, decaffeinated tea, sieved fruit juices and water[17,24].

Hygiene and preparation of food

The participants were concerned with hygiene and how food was prepared in addition to what the child is able to eat because of chemotherapy-related adverse events, neutropenia and mucositis, for instance, as the narratives show:

> Has to tell that everything must be cooked, including fruits, vegetables, salads, [...] avoid eating out (*Enf* 3).
> Started to offer cooked food (*Fam* 5).
> I believe it needs to stress the importance of food hygiene [...]. Fruits and legumes have to be wiped clean and peeled (*Enf* 1).
> You may even mash the fruits, it is not the same thing, but it is the ideal (*Enf* 4).

As the interviewees made clear, guidelines about neutropenic diet to prevent infections should be included in the educative material.

The literature addresses hygiene and ways to prepare the food to prevent infections possibly caused by microorganisms carried in them. Fruits and vegetables should be washed with water immediately before eating in addition to care while peeling and chopping due to potential contamination; apples and potatoes must be scrubbed with a clean brush to ensure effective disinfection. Eventually, should be wiped with clean cloth or disposable paper towel[27].

Baked or cooked portions should be preferred over raw food, prioritizing individual packages, avoiding food where hygiene standards are not clearly guaranteed and pasteurized dairy. Drink only bottled water, however, drinking water must be boiled, preferentially. Food, utensils and the room must be spotless to prepare the food[14,28].

Microorganisms-free diet must be ensured through strict hygiene and food preparation because of potential diseases since at home the caretaker will not have access to hospital lab tests to detect neutropenia.

These thematic groups can be the subtitles of the sections and in each one, list foods that can be offered to the child.

The involvement of the participants in defining the themes of the educative material to be constructed is important because their role moves from mere reporters and addressees of conclusions towards an effective participation in the production of knowledge about their

realities, further to bringing closer the scholar researches to healthcare practice[29].

The limitation of the study is that the participants were enrolled in only one Brazilian oncologic institution. New studies about educative materials are necessary involving other oncologic institutions across the country and different types of childhood cancer.

CONCLUSION

To identify educative themes/contents about feeding children with leukemia in the perspective of nurses and caretakers/family to construct educative materials has become a relevant activity because it opened the dialogue among nurses and family; it broadened the potential of action of the educative material as it brought together the nurse's experience and the necessities the family expressed about feeding, increasing the possibility of promoting the health of the child with leukemia at home.

The participation of the family in discussion groups led to the necessity of disclosing information about feeding the child with leukemia in the eight thematic groups proposed: regular immunity, neutropenia, mucositis, nausea and vomits, constipation, diarrhea and hygiene and how food is prepared.

The educative action pursed with the collective search of themes to construct educative material for parents of the children with leukemia occurred when family/caretakers realized they are able to take the front in producing the material both in the selection and adjustment of the themes.

It is anticipated that the current study encourages the construction of educative materials in several formats to meet the family demands of feeding the child with leukemia at home.

CONTRIBUTIONS

Cicero Ivan Alcantara Costa and Sandra Teixeira de Araújo Pacheco contributed for the study conception and/or design, acquisition, analysis and interpretation of the data, wording and critical review. Gabriella Soeiro, Michelle Darezzo Rodrigues Nunes, Liliane Faria da Silva and Patrícia Lima Pereira Peres contributed for the study conception and/or design, acquisition, analysis and interpretation of the data. All the authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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