ORIGINAL
ARTICLE

How an Educational Material Would Be Like? Perceptions of Relatives of Children with Leukemia

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Como Deve Ser um Material Educativo? Percepção dos Familiares de Crianças com Leucemia
¿Cómo Debe Ser un Material Educativo? Percepciones de los Familiares de Niños con Leucemia

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ABSTRACT

Introduction: The child with leukemia, when at home, requires special care. In this context, family members are faced with care-related demands that need to be learned due to their child´s clinical condition. This article is part of the research "The learning demands of family members of children with leukemia for home care". **Objective:** To know the perceptions of family members of children with leukemia about the proposal to build education materials for home care and describe the themes that family members considered significant in the composition of these materials. **Method:** Participatory study developed in a children's hematology ward in Rio de Janeiro. Paulo Freire´s problematizing education was the theory utilized to support the study. Data were collected through three discussion circles, and subsequently examined using Bardin´s content analysis. **Results:** Eight family members of children with leukemia participated in the study. Two categories emerged: The proposal for the construction of education materials for home care and relevant themes to compose the educational materials. **Conclusion:** Considering the perception of family members in the construction of educational material can make an assertive contribution in choosing content, and how to approach them, and be a more effective strategy in this continuous process of health education for relatives of children with leukemias.

Key words: educational and promotional materials; child; leukemia; pediatric nursing.

RESUMO

Introdução: A criança com leucemia, quando no domicílio, requer cuidados especiais. Nesse contexto, os familiares deparam-se com demandas de cuidados que precisam ser aprendidas em função da condição clínica de sua criança. Este artigo é um recorte da pesquisa "As demandas de aprendizagem dos familiares de crianças com leucemia para o cuidado domiciliar". **Objetivo:** Conhecer as percepções de familiares de crianças com leucemia sobre a proposta de construção de materiais educativos para o cuidado domiciliar e descrever os temas que os familiares julgarem significativos na composição desses materiais. **Método:** Estudo participativo desenvolvido em uma enfermaria de hematologia infantil no Rio de Janeiro. A teoria utilizada para fundamentar o estudo foi a educação problematizadora de Paulo Freire. Os dados foram coletados por meio de três círculos de discussão e, posteriormente, examinados a partir da análise de conteúdo de Bardin. **Resultados:** Oito familiares de crianças com leucemia participaram do estudo. Duas categorias emergiram: "a proposta de construção de materiais educativos para o cuidado domiciliar" e "temas relevantes para compor os materiais educativos". **Conclusão:** Considerar a percepção dos familiares na construção de material educativo pode contribuir de maneira assertiva na escolha de conteúdos e na forma de abordá-los, e ser uma estratégia mais eficaz nesse processo contínuo da educação em saúde dos familiares das crianças com leucemias.

Palavras-chave: materiais educativos e de divulgação; criança; leucemia; enfermagem pediátrica.

RESUMEN

Introducción: El niño con leucemia, cuando está en casa, requiere cuidados especiales. En este contexto, los familiares se enfrentan a demandas de cuidado que necesitan ser aprendidas debido a la condición clínica de su hijo. Este artículo forma parte de la investigación "Las demandas de aprendizaje de los familiares de niños con leucemia para el cuidado domiciliario". **Objetivo:** Conocer las percepciones de los familiares de niños con leucemia sobre la propuesta de elaboración de materiales educativos para el cuidado domiciliario y describir los temas que los familiares consideraron significativos en la composición de materiales educativos. **Método:** Estudio participativo desarrollado en una sala de hematología infantil de Río de Janeiro, teniendo como base la teoría de la educación problematizadora de Paulo Freire. Los datos fueron recolectados a través de tres círculos de discusión y, posteriormente, analizados mediante el análisis de contenido de Bardin. **Resultados:** Participaron del estudio ocho familiares de niños con leucemia. Emergieron dos categorías: La propuesta de construcción de materiales educativos para la atencíon domiciliaria y temas relevantes para componer los materiales educativos. **Conclusión:** Considerar la percepción de los familiares en la construcción del material educativo puede contribuir asertivamente en la elección de los contenidos, en la forma de abordarlos, y ser una estrategia más efectiva en este proceso continuo de educación en salud para los familiares de niños con leucemia.

Palabras clave: materiales educativos y de divulgacíon; niño; leucemia; enfermería pediátrica.

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INTRODUCTION

Pediatric cancer (leukemias and lymphomas) is the leading cause of death in childhood[1]. Introduction: Children with leukemia, when at home, require special care. In this context, family members facing this chronic disease face dietary changes, the presence of a venous catheter (semi-implanted or fully implanted), continuous use drugs that need to be administered for their survival and modified usual care. This care needs to be learned by family members and nursing can assist in the transition phase from hospital to home.

Therefore, in this context, it is important for the nursing team to use health education strategies to better equip these families to prepare them for home care. This instrumentalization can occur in different ways, including through the implementation of educational health technologies.

These technologies have been increasingly used in nursing teaching and practice as a facilitating resource for the learning process. However, like the educational material, they are excellent resources when adopted as a complementary tool to health educational actions and not just as an isolated part of the process[2].

In this study, the conceptions of Paulo Freire were used, whose objectives are social transformation, exchange of experiences, questioning, individualization, and humanization[3]. The involvement of the clientele in educational actions, by health professionals, through empathy and active listening, is of great value for them to feel important in the care process. In addition, it is relevant to have a relationship of trust between nurses and family members, allowing the exchange of experiences and mutual learning. That is, both the professional and the user can teach, and both learn[3].

Thus, understanding that, in the construction of an educational technology, the needs and care demands of individuals must be considered, in this study, the family members of children with leukemia who experience their care in the hospital and/or home environment were given a voice. Thus, we sought to express the learning demands for home care, with a view to future construction of educational materials.

Based on this context, it is clear that educational technology can be one of the best ways to guide the family of children with leukemia who need to receive guidance on the best care to be performed with the child in the different phases of their treatment.

It is noteworthy that children with leukemia have special health needs, requiring multidisciplinary monitoring and often depend on modified usual care (dependence on adaptive technologies in daily care to move around, eat or others), technological (use of semi-implanted or fully implanted catheters) and medication, whose knowledge needs to be taught to family members during hospitalization, so that they can continue to meet the demands at home[4].

Thus, when the child starts treatment, health professionals, especially nurses in hospital units, should guide family members regarding the care they will need during the therapeutic process, preparing them for the transition from the hospital environment to home[5].

This article is an excerpt from the research "The learning demands of family members of children with leukemia for home care" which aims to give voice to family members of children with leukemia, aiming to know the perceptions of these family members about the proposal to build educational materials for the care of their children at home and describe the themes that the family members considered significant in the composition of educational materials.

Knowledge of family members' perceptions will provide the construction of materials more appropriate to their questions. It is expected that this will allow greater security in the home care of children with leukemia.

METHOD

This article is an excerpt from the research "The learning demands of family members of children with leukemia for home care".

This is a qualitative study of the participant type, carried out in a child hematology ward of a federal hospital of reference in oncological and hematological diseases in Rio de Janeiro-RJ, Brazil.

Paulo Freire's conceptions of education (problematizing education) were used to support this study. According to the author's pedagogical assumptions[3], education is a mediating activity between the individual and society, between theory and practice that is built on the relationship of dialogue. Therefore, education has the role of developing active subjects and participants in social transformation.

In problem-based education, the relationship between educators (nurses) and students (family members of children with leukemia) cannot be based on isolation, but on solidarity between both. In this way, it is impossible to occur antagonistic relations, in which the first would be the oppressors and the second, the oppressed.

The basis of problem-based education has been shown to be adequate in the development of health education by enabling actions related to the participation of the individual in the construction of their knowledge in a critical and reflective way.

This research was approved by the Research Ethics Committee (CEP) of the proposing institution under opinion number 2,549,848 and of the co-participant, number 2,627,369 (CAAE: 818858817.4.0000.5282), and all aspects contained in Resolution No. 466/2012[6] of the National Health Council of Brazil were respected. After approval by the CEP, nurses with experience in pediatrics, researchers 1 and 3, who, at the time of data collection, were master's students at the State University of Rio de Janeiro (UERJ) – one female and the other male – contacted the medical and nursing leadership to explain the objectives and methodology of the research. Then, there was a previous reading of the electronic medical records to identify children with leukemia and their family caregivers.

Inclusion criteria were family members responsible for the care of hospitalized children with leukemia. Family members who visited the hospitalized child or did not actively participate in his/her care were excluded.

Subsequently, they invited family members to participate in the research in the reception room, explaining the objectives of the research, as well as the aspects contained in the Informed Consent Form (ICF).

Twelve family members were invited, eight agreed to participate and four refused because the child was presenting, at the time of data collection, reactions to chemotherapy or because she was undergoing some procedure. The acceptance was formalized with the signature of the TCLE.

Data collection took place between May and June 2018 through three discussion circles lasting approximately 60 minutes, which were held in a private room at the hospital to preserve the privacy of participants and researchers. Each participated once in the discussion circle.

The first and second circles were performed with three family members and the third with two. In this discussion space, they were asked to express their opinion on the proposal to develop educational materials that would help them care for their child with leukemia after hospital discharge, that is, when they were at home.

In addition, family members were asked to express their opinion on what they considered important in an educational material to care for children with leukemia at home.

Discussion circles are practices in which participants, through dialogue, build relationships and can be carried out in various environments, such as health services and schools, recognizing their difficulties and developing new skills that make it possible to overcome obstacles and challenge them to build a better world[7].

In this discussion space, the proposal was presented by the trained researchers to different family members, no minimum and maximum number of participants were established, and the ICF was read.

In practice, the discussion circles took place as follows: there was a moment of presentation of the research proposal, the participants, and the operationalization of the circle, followed by the reading, clarification, and signature of the ICF. Subsequently, family members were asked to sit in circles. In the center of the circle, a basket was placed with different images of food, children with semi-implanted and implanted catheters, patients with nose bleeds, medications, alopecia (hair loss) and children with fever. Then, the questions for discussion were: "what do you think of the idea of developing educational materials that help them care for their child with leukemia after hospital discharge? And what do you consider important to contain in this educational material?"

An order of debate was established (object of the word), which was through the removal of an image from the basket, respecting the speech of each of the participants.

At the end of all the circles, there was a closing ceremony with thanks to the participants.

In each circle, the same theme was used, and, after the authorization of the family members, the speeches were recorded using a voice recorder, of the MP3 type, and later transcribed in full for analysis. There was no need to return the transcripts to the participants for corrections because the audio of the recordings was in great quality.

The criterion for the end of the fieldwork was saturation (redundancy or repetition), which occurred after the transcription of the speeches of the relatives of the discussion circles, conference of linguistic materiality and exhaustive reading of the generated empirical material.

After data collection and transcription of the dialogues, the material was analyzed using the content analysis method proposed by Bardin[8] in the thematic modality, in three stages: pre-analysis: floating reading stage in which the researcher is impressed with the theme; exploration of the material or coding: the raw data are systematically transformed and aggregated into units; and treatment of the results: inference and interpretation in the light of the scientific literature on the studied theme[8].

The family members were identified during the study with the code F1, F2, F3, F4, F5, F6, F7 and F8 in order to preserve the anonymity of the participants.

RESULTS

At first, the characterization of children and family members was conducted. As for the child, we sought to know the age, diagnosis, and time of treatment. As for family members: the degree of kinship, education, age, and their origin.

Of the eight family caregivers participating, all were female, seven mothers and one grandmother. F1 is the mother of an 8-year-old boy, diagnosed with acute lymphoblastic leukemia (all), with a treatment time of five months; F2 is the mother of a 2-year-old girl, diagnosed with all, with a treatment time of two months; F3 is the mother of a 9-year-old boy, diagnosed with all, with a treatment time of three months; F4 is the mother of a 9-year-old girl, diagnosed with all, with a treatment time of four years; F5 is the mother of a 5-year-old girl, diagnosed with all, with a treatment time of two months; F6 is the grandmother of a 10-year-old boy, diagnosed with all, with a treatment time of four months; F7 is the mother of a 5-year-old boy, diagnosed with all, with seven months of treatment, and F8 is the mother of a 10-year-old boy, with a treatment time of three years and diagnosed with chronic myeloid leukemia (AML). It is noted that most are male, diagnosed with all, and started treatment recently, ranging from two to five months, under the age of 9 years.

All children were dependent on chemotherapeutics, presented modified habitual care demand and technological dependence. Thus, when children start treatment for leukemia, they become dependent on the care provided by health professionals and their families.

Regarding the characterization of family members: F1 is 30 years old, high school and lives in São Gonçalo; F2 is 22 years old, elementary school 1 and lives in São Gonçalo; F3 is 29 years old, elementary school 2 and lives in São João de Meriti; F4 is 34 years old, higher education and lives in Boa Vista; F5 is 22 years old, high school and lives in São João de Meriti; F6 is 61 years old, illiterate and lives in Duque de Caxias; F7 is 28 years old, incomplete elementary school 2 and lives in Campo de Goytacazes and F8 is 40 years old, higher education and lives in Rio de Janeiro. It can be seen that most belong to the maternal group, in the age group of 22 to 30 years, and come from municipalities in Rio de Janeiro; in addition, all are female.

After the discussion circles were completed, the speeches were transcribed. After this moment, exhaustive readings were carried out, which allowed the coding, unfolding, grouping and synthesis of the testimonies, resulting in two categories: the proposal to build educational materials for home care and relevant themes to compose the educational materials. No *software* was used to analyze the data and the researchers provided the study results to the participants.

CATEGORY 1: THE PROPOSAL TO BUILD EDUCATIONAL MATERIALS FOR HOME CARE

When talking about the proposal to create an educational material with a view to caring for the child at home, family members reported:

> I think it's cool because here we are not 100% educated as it is and as it is not at home with the child [...] I think it's very positive. [...] It's true because we leave here with very little education. [...] We don't know. So, he gets home, we don't know what to do (F1).

> Pretty good. Because we will look at what you need and what you don't. What's picking up the most is this. If I stayed with someone else, I didn't understand, I would see it (F2).

> Critical. There are many mothers who are laywomen. [...] We don't always have this knowledge. [...] I think this material is important for those who are starting now there is a lot of doubt. I have already been treating my daughter for four years and I am full of doubts, especially those who are starting now (F4).

Another aspect pointed out by the family member was the importance of educational material as an instrument that can enable the assessment of the child's needs at home and, thus, reduce expenses with unnecessary travel to the hospital institution.

> It's interesting because you have to know what to do inside the house, because any little thing that the child has, we think it's an emergency thing. Then, if we can do it at home, we don't need to bring it to the hospital. Because it can be a small thing that we can solve at home, you don't have to come (to the hospital). Spend a lot of money to bring to the hospital (F6).

Participant F7 believes that the preparation of the educational material will allow her to spend more time at home with her children:

> For me, it would be much better. To take care at home because we would have more time to stay at home with our children (F7).

Another relevant point mentioned by F8 concerns educational material as a means of providing security in the provision of care to the child:

> I find it very interesting. I think it's fundamental. I think it's too much support. Too much security. [...] This is a good idea from you (F8).

The family members elucidated, through the testimonies, the need to contain images or illustrations and texts in the educational materials so that they feel stimulated to read:

> I think with images it gives more lightness. I think it is more accessible for certain parents, for certain families, and it is lighter [...] than you take a material full of letters that you end up shelving on a daily basis. Not looking or leaving it for later and ends up not seeing. I think the drawing is more attractive and unfortunately, nowadays, people prefer it (F8).
>
> Thus, it could be with texts or images (F3).

In addition, the family member F4 mentioned the difficulty in understanding the vocabulary of health professionals, emphasizing that if the language were simple, it would facilitate the understanding of all family members, since many are lay people.

> There are a lot of lay people. With your vocabulary totally different from us. It is too complicated. [...] Your hospital vocabulary is one and ours is another. It's complicated if it was that easy even in the vocabulary, I think it would be better for us (F4).

At the end of the discussion circle, there was a closing ceremony with thanks to the participants.

CATEGORY 2: RELEVANT TOPICS TO COMPOSE THE EDUCATIONAL MATERIALS

This category expresses the themes that family members would like to have contained in the educational materials. The following were mentioned: doubts about food; care with catheters; and difficulties in understanding medical prescriptions.

Regarding issues related to food, doubts were expressed about what to offer the child during cancer treatment when they are at home.

> Especially in relation to food, we are very doubtful about certain things. [...] His food is something that usually worries me because I don't know what he can and can't do, if he can do everything, if he can't do everything the same (F1).
>
> The nutrition. Me too (I have doubts with food). At home I don't know what happens. I don't know if you can or not. Then it's getting difficult for me. Do you get it? She squeaks. Then it's getting complicated, I don't know if you can, if you can't, it's just the food or what he drinks, these things. Mine is very fond of fruit (F2).

Also, during the speeches, the participants associated their concerns with the low immunity of the child and his/her diet.

> I feel when she goes home that her immunity drops very quickly. I don't know what to eat. What gets me is this [...] Food raises many doubts, especially fruits, the type of food (F2).
>
> Mine is very fond of a lettuce salad. Then you are: my God, will he be able to eat? Is his immunity good? I wonder if he's not. You get a little lost (F3).

One of the participants revealed having doubts about how to feed her child already in a period of remission and, therefore, she believed it was essential that these guidelines were included in the educational material.

> Food is also lost to us. In fact, we go to the nutritionist, but there is still a time when he has a little party. Then, wow, can you ever eat a brigadier? Can you have a cake? [...] This question is how the post-treatment life actually remains, even in remission. Even if we talk to the nutritionist, that's it. Won't he be able to lead a normal life? Will he spend the rest of his life with these restrictions, these limitations, because for a child it is always more difficult. We can go to a party, eat a brigadeiro, have a soda. Got it? I think it is essential to give a reinforced one (F8).

The participants also pointed out the care related to the use of the catheter as important aspects to be included in the educational materials.

> And the catheter because it is there doing maintenance every week, because it has already happened at once that it gets wet, and I don't know what to do. If I came to the emergency room with him, or if I changed the bandage at home? How should I change it? If I could change or if I couldn't change, you know? And I've always been insecure about that. He had an allergy. You ran out of the movie. Then I had to do the catheter care, cleaning, and everything every two days at home. I was pretty insecure about it. I'm afraid of infection, contagion, and everything (F8).
>
> And the catheter part as well. Yeah... Semi-implantation is easier, isn't it? No, harder. At bath time, you have to roll it up and not at all, it's easier, you don't need to put any plastic. It is necessary to be very careful, the semi is more difficult (F7).

Furthermore, in this research, the importance of explanations about the prescription of medicines that the child should take at home was also pointed out.

> [...] On the way out of the hospital, the prescriptions bothered me. That lot of medicine, the schedule

> practically the same, a lot of pills all at that time, in relation to some medicine, has to be fasted, but how does it have to be fasted if you have already dined? Got it? The recipes don't always come well explained, it's complicated, the granulokine we get lost. Those who do not work in the area do not know (F4).

In addition, another family member also mentioned that, although in medical prescriptions, the dosages of the drugs are in milligrams, which made it difficult to understand the dose to be administered, making it return to the hospital for another doctor to transcribe the prescription.

> They put their milligrams; they don't put what they have to aspirate with the syringe. I've been back several times in the emergency room to ask to fix it because I didn't know. I do, but I don't have to calculate that there. It's not my job. The more chewed the better. [...] On that day, we debated about it at the Ronald house. It was 0.2 ml (medicine) and the girl was saying it was 20 ml (medicine) there. Then there is that doubt, more chewed would be better for us. There are some people who understand, there are others who have a lesser degree of difficulty. Others, higher (F4).

At the end of each discussion circle, there was a closing ceremony with thanks to the participants.

DISCUSSION

The family members expressed, in their speeches, the importance of building an educational material as a resource that will help to take care of the child at home. In this sense, they mention the relevance of the material as a tool for learning and clarifying doubts.

Similar to the findings of this study, research that dealt with the production of educational technology for patients with HIV/AIDS served to clarify doubts, exchange knowledge and experiences for those living with HIV/AIDS and their family circle about questions regarding the disease[9].

It is worth mentioning that the relationship between educators (nurses) and students (family members of children with leukemia) should not be based on isolation, but on solidarity between the parties. Therefore, the presence of a new tool would be to improve the exchange of knowledge between them[3].

In addition, it is through dialogue that men recognize the other and recognize themselves and can transform the environment in which they live[2]. Thus, health professionals should consider family members as equals, valuing their knowledge, since there are no "empty consciences"[3].

However, educators (nurses and other health professionals) must recognize the reality in which family members are inserted, actively listen to them, and encourage them to understand their history and not just transmit information[3].

Thus, educational material can have a positive impact on health education for family caregivers of children with leukemia, in order to help them answer questions that may occur when their children are no longer hospitalized.

The participants saw the educational material as a way to remedy the little information received by them during the hospitalization of their children. Therefore, for these caregivers, the educational material can make it possible to understand and enrich their fragile knowledge about how to take care of their child at home.

It is known that caring for a child with special health needs in the home context is a challenge for family members/caregivers. This is a clientele that lives with numerous difficulties related to health services, the distant relationship with professionals and the lack of knowledge about the rights of children[10].

Thus, nurses should discuss with family members their doubts regarding the care of their children in order to clarify them. In this health education process, when the printed didactic and instructional materials are able to motivate reading, arouse the interest of the target audience and resolve their doubts about the procedure that will be done, value is added to the clinical practice of the pediatric nurse, promoting a care without trauma for the child, qualified, safe and respectful in the hospital[2].

Regarding the importance of educational material as an instrument that can enable the evaluation of the child at home, the early recognition of warning signs in the health status of children with leukemia, such as fever, persistent bleeding, shortness of breath, pain and the appearance of dark spots on the body (ecchymosis), the appearance of spots at the site of chemotherapy application with pain and burning, and pain in the belly or diarrhea, are particularly relevant in the context of homecare[11].

Therefore, educational materials should enable the family member to detect early signs of aggravation and be allies in the home care guidelines of family members of children with leukemia, but health professionals should emphasize in the health education process the signs and symptoms that indicate the need to seek care from a health service.

Another relevant point mentioned by concerns of educational material as a way of providing security in the provision of care to the child: In line with this discourse, educational material, when well applied by health professionals, can offer support for patients and families to perform care safely, whether at the hospital, outpatient, or home level[12].

Participants also emphasized the need to contain images or illustrations and texts in educational materials. The reports converge in the same perspective as another that states that, when the booklet presents content appropriate to the demands of the target audience, combined with the understandable text, written in a way that is attractive to the reader, clear, objective and with a logical sequence, it will contribute to the child's learning and the way in which they deal with the procedures during hospitalization[2].

Drawings are able to provoke emotions and interest in reading, facilitating learning. Images (photos, drawings, graphs, tables, among others) are of fundamental importance, as long as they are didactically placed in the text. Thus, they should focus the reader's attention, in order to invite them to read, in addition to assisting in the understanding of the text read, complementing content, and contributing to the lightness and motivation to read[13].

Another study, aimed at the production of folders for the elderly, demonstrated that the use of figures and illustrations with large letters facilitated reading for the elderly, in addition to stimulating knowledge and motivating them[14].

Thus, the image and textual resources are of paramount importance to understand the subjects glimpsed in the educational materials and to fix the readers' attention. Regarding the relevant themes to compose the educational materials, care with food and catheters emerged, as well as difficulties in understanding medical prescriptions.

Regarding food, family members expressed concern about what to offer the child after the discovery of leukemia, especially after the start of treatment. However, they were unaware that even foods considered healthy such as fruits could carry microorganisms, causing harm to the child's health.

In this sense, food preparation requires special care in children undergoing cancer treatment, in order to avoid infections resulting from neutropenia (decrease in neutrophils)[15].

Although much of the scientific literature recommends a restrictive diet, including cooked or roasted fruits and vegetables[16,17], this diet has been challenged because it does not present a difference in the prevention of infections when compared to the general well-sanitized diet. In addition, it has a significant loss of nutrients and vitamins due to the high temperature to which food is subjected[18-20]. Thus, we started to recommend the consumption of these foods only well sanitized according to the new consensus of oncological nutrition[21].

They are modified usual care that requires guidance from family members so that they can provide care for their children when at home. Therefore, dialogue between health professionals (nutritionists, doctors, and nursing staff) and family members is essential to find out what are the difficulties of food care with their children during chemotherapy treatment.

In addition, educators (nurses) and students (caregivers) should see themselves as subjects in the care of children with leukemia. That is, both must assume the task of cooperation, exchange knowledge, reflect on the inserted reality and transform it, aiming at the child's quality of life. When they reach the knowledge of reality, through reflection and common action, they become "permanent remakers"[3].

The participants also pointed out the care related to the use of the catheter as important aspects to be included in the educational materials. Catheter handling is a sterile procedure that must be performed by trained healthcare professionals (doctors and nurses) to avoid infection. In the institution where data collection was carried out, only nurses maintain the catheters in the outpatient clinic and/or hospitalization.

Care with the central venous catheter are: selection of the catheter, verification of the best insertion site, use of technique to avoid the risk of complications depending on the type of duration of therapy that will be administered, skin antisepsis and hand hygiene, disinfection of the skin with appropriate antiseptic before insertion of the catheter and dressing changes, manipulation of the catheter with sterile technique, notification of signs and symptoms of infection, and education of the patient and their caregiver[17].

The dressing has the function of protecting the puncture site, minimizing the possibility of infection and fixing the device in place to prevent movement and damage to the blood vessel. Thus, during health education activities, caregivers should be instructed by nurses to change the catheter dressing every 48 hours when sterile gauze is used and every seven days if sterile clear coverage is used. The involvement of catheters covers and connections with plastic or other impermeable material during bathing should also be emphasized, and that any type of cover should be changed immediately if it is dirty, lose or wet[22].

Furthermore, in this research, the importance of explanations about the prescription of medications that the child should take at home was also pointed out. However, there is a medication process before the medication reaches the child. This process begins in production, continues with prescription and dispensation, and finally, administration. Administration comprises the entire process of checking, diluting, preparing, and administering to the patient. Nursing is the professional area responsible for the administration of medicines, therefore, it is essential to act in the prevention of errors of this nature[23]. Medication errors may be in prescriptions and are considered preventable events. It is important that patients and family members ask the physician for information on the dilution of medications, side effects and adverse reactions, time of use, interactions with other medications and laboratory tests, and check that they understand the professional's handwriting if it is written by hand, this will help in prevention, contributing to the safe use of medications[24].

A study conducted at the medical clinic also found that half of the prescriptions analyzed did not contain sufficient information, presenting illegible and incomplete data, thus compromising the administration of medicines and, consequently, the principles of patient safety. In this research, the main errors were in the registration of the pharmaceutical presentation (90.04%), in the dose (90.77%), in the route of administration (96.31%), in the dilution (83.39%) and in the interval between doses (95.57%)[25]. In this regard, it is worth mentioning that if the family member does not understand a single instruction of a single drug, this would already be enough to bring serious health problems to their child.

In addition, another family member also mentioned that, although in medical prescriptions, the dosages of the drugs are in milligrams, which made it difficult to understand the dose to be administered, making it return to the hospital for another doctor to transcribe the prescription. In this regard, the literature shows that the main errors that occur are linked to the route and dose of drug administration, medication preparation, schedules, among others[26].

Thus, it is necessary for health professionals, especially doctors and nurses, to dialogue with family members and ask if the information contained in the prescriptions is clear, avoiding errors in the administration of medicines at home, so that children are not vulnerable due to the administration of high doses and/or underdoses of medicines.

In addition, the methodology used in this study allowed health professionals to recognize that the doubts and difficulties of family members are as important as theirs and that they are not the same. For example, a professional easily understood the prescriptions and acted appropriately because it allowed family members to dialogue and be seen as equal in relation to professionals and not in an inferior position, that is, as recipients of knowledge. However, if the method were performed in another oncology unit, it is possible that other doubts would arise. Thus, among the limitations of the study, only one oncology unit in Brazil stands out.

Thus, the results of this study contribute to the construction of educational materials more appropriate to the target audience and help to understand how health teams working with oncology can help families and children with leukemia in the health education process in the hospital environment, preparing these families for the discharge of the child.

CONCLUSION

The present study allowed us to identify the perceptions of family members of children with leukemia about the proposal to build educational materials for home care and to know the relevant themes to compose the educational materials pointed out by them.

The main results indicate that family members were in favor of the proposal to create educational material for the home care of children with leukemia, claiming that it can provide security in the provision of care to the child and serve as an important instrument to help the early recognition of warning signs in the child's health status, and the need to seek hospital care or not.

In addition, they pointed out relevant topics to compose the educational materials such as feeding care, catheter care and difficulties in understanding medical prescriptions. Other points mentioned were the need for the material to contain illustrations and texts to stimulate reading and to present a simple language to facilitate the understanding of family members.

Finally, it is noteworthy that considering the perception of family members in the construction of educational material can contribute assertively in the choice of content and in the way of addressing them, since this construction would be based on experience, making the strategy more effective in this continuous process of health education of family members of children with leukemias or other special health needs.

CONTRIBUTIONS

All authors contributed substantially in the design and/or planning of the study; in the analysis and/or interpretation of the data; in the writing and/or critical review; and approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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