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Learning needs of relatives of children and teenagers under oral antineoplastic chemotherapy treatment

Necessidades de aprendizagem de familiares de crianças e adolescentes em tratamento com quimioterápicos antineoplásicos orais

Necesidades de aprendizaje de los familiares de niños y adolescentes en tratamiento con quimioterapia antineoplástica oral

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ABSTRACT

Objective: to describe the learning needs of family members of children and adolescents with cancer regarding treatment with oral antineoplastic chemotherapies. **Method:** a descriptive qualitative research developed in a federal hospital in Rio de Janeiro, Brazil. Data were collected in the months from July to September 2020 from semi-structured interviews with twenty-three family members of children and adolescents with cancer undergoing oral antineoplastic chemotherapy. Data was processed in the software *Interface de R pour Analyses Multidimensionnelles de Textes et de Questionnaires* by the Descending Hierarchical Classification. **Results:** among the themes that demand learning by the family members are oral administration, storage and handling of oral antineoplastic drugs, as well as adverse effects and emergencies that require hospital care. **Conclusion and implications for practice**: in oral antineoplastic treatment, the learning needs of family members of children and adolescents need to be problematized in dialogic educational practices in order to favor the safety, adherence, and efficacy of the treatment.

Keywords: Oral Administration; Adolescent; Antineoplastic Agents; Children; Family.

RESUMO

Objetivo: descrever as necessidades de aprendizagem de familiares de crianças e adolescentes com câncer quanto ao tratamento com quimioterápicos antineoplásicos orais. **Método:** pesquisa qualitativa descritiva desenvolvida em um hospital federal do Rio de Janeiro, Brasil. Os dados foram coletados nos meses de julho a setembro de 2020 a partir de entrevistas semiestruturadas com vinte e três familiares de crianças e adolescentes com câncer em quimioterapia antineoplásica oral. Os dados foram processados no *software Interface de R pour Analyses Multidimensionnelles de Textes et de Questionnaires* pela Classificação Hierárquica Descendente. **Resultados:** dentre os temas que demandam aprendizagem pelos familiares estão administração oral, armazenamento e manipulação dos quimioterápicos orais, além dos efeitos adversos e emergências que demandam atendimento hospitalar. **Conclusão e implicações para a prática:** no tratamento com quimioterápicos orais, as necessidades de aprendizagem dos familiares de crianças e adolescentes precisam ser problematizadas em práticas educativas dialógicas para, assim, favorecer a segurança, a adesão e a eficácia do tratamento.

Palavras-chave: Administração Oral; Adolescente; Antineoplásicos; Criança; Família.

RESUMEN

Objetivo: describir las necesidades de aprendizaje de familiares de niños y adolescentes con cáncer en cuanto al tratamiento con quimioterápicos antineoplásicos orales. **Método:** investigación cualitativa descriptiva desarrollada en un hospital federal de Río de Janeiro, Brasil. Los datos fueron recogidos en los meses de julio a septiembre de 2020 a partir de entrevistas semiestructuradas con veintitrés familiares de niños y adolescentes con cáncer en quimioterapia antineoplásica oral. Los datos fueron procesados en el *software Interface de R pour Analyses Multidimensionnelles de Textes et de Questionnaires* por la Clasificación Jerárquica Descendente. **Resultados:** entre los temas que demandan aprendizaje por los familiares están administración oral, almacenamiento y manipulación de los quimioterápicos orales, además de los efectos adversos y emergencias que demandan atención hospitalaria. **Conclusión e implicaciones para la práctica:** en el tratamiento con quimioterápicos orales, las necesidades de aprendizaje de los familiares de niños y adolescentes necesitan ser problematizadas en prácticas educativas dialógicas para, así, favorecer la seguridad, la adhesión y la eficacia del tratamiento.

Palabras clave: Administración oral; Adolescente; Antineoplásicos; Niños; Familia.

INTRODUCTION

The incidence of childhood and adolescent cancer has increased in recent years in Brazil and worldwide[1] and this study addresses the chemotherapeutic drugs that, in the treatment of children and adolescents with cancer, contribute in a relevant way to survival rates, since pediatric tumors have a high proliferative index and are mostly chemosensitive.[1,2]

For many years, the pharmacological treatment of cancer used exclusively intravenous antineoplastic therapy and health services were structured based on this treatment model. However, in recent decades, an exponential increase has been observed in the development and use of oral antineoplastic drugs with less aggressive toxic effects that are not only well tolerated, but also easy to manage.[3]

Studies have pointed out the advantages and disadvantages of this therapy. The advantages of oral administration refer to the fact that it is simpler, more economical, less toxic, and non-invasive, eliminating the need for the use of a venous catheter that causes pain, fear, and stress in children and adolescents. In addition, it can be administered in the home environment, by the family, which implies more time with family members and less time in hospitals, thus promoting a better quality of life for this public.[3,4]

On the other hand, the disadvantages are the variations in the absorption of the therapeutic dose, the risk of accidents with overdose, the need for efficient self-care, and the difficulty in managing side effects. These risks can increase the chances of non-adherence to oral therapy and generate harmful effects. Thus, this type of treatment can become a huge problem if family members are not properly oriented and prepared to carry it out.[3,4]

Understanding how to properly store, prepare, handle, administer, and dispose of oral antineoplastic drugs is necessary to reduce the risk of exposure and ensure that children and adolescents receive the appropriate therapeutic dose. A systematic literature review evaluated the management of patients and caregivers about oral antineoplastic drugs, identifying the need to develop education strategies that address the administration in this scenario, because many fail to perform essential safety tasks, such as hand washing before and after administration, waste disposal, and doubts about handling.[5]

Another study conducted with 64 caregivers of pediatric patients with acute lymphoblastic leukemia highlighted that the inadequate management of antineoplastic agents poses a risk of exposure to hazardous substances for the people involved, including through household surfaces and the environment. He added that errors in the management of these drugs arose mainly due to caregivers' lack of knowledge about the handling of oral antineoplastic drugs.[6]

Therefore, the families of children and adolescents who use oral antineoplastic drugs should receive special monitoring and guidance from a multidisciplinary team. The adequate preparation becomes fundamental in this process, guiding the correct use of drugs, monitoring adverse reactions and interactions, in order to reduce the risk of errors and treatment discontinuity. In this context, guidance by nurses becomes crucial, because it favors the effective participation of the family in care.[7]

It is the role of the nurse, during the nursing consultation, to talk to the family member about the recommendations in the patient's follow-up, including guidelines on antineoplastic drugs and other medications associated with the treatment and tips on possible adverse reactions.[8] Therefore, the nurses' role as educators is emphasized, since the final purpose is to contribute to the success of the treatment and the reintegration of the children and adolescents to their life routine, in order to stimulate them and their families to leave the role of passive subjects and start to relate to the team, revealing their learning needs, doubts, anxieties and feelings during the treatment.[9,10]

Thus, this study is based on Paulo Freire's theoretical conceptions of problematizing education[11] that deals with the practice of freedom that breaks with the verticality of the banking practice, and proposes, through dialogicity, a transversal relationship between the subjects. From this point of view, dialogue and critical reflection of reality are sought for the development of any educational action. Thus, more than the acquisition of knowledge coming from a translation of knowledge, the goal is that knowledge be built, experienced and harmonized in a collective and participatory way.[12]

Therefore, before implementing health educational practices, especially when dealing with children and adolescents dependent on home care, it is necessary to listen to the family members, get to know their learning needs, doubts and fears in order to think of strategies that aim at the best for the family, the child and the adolescent.[13] However, scientific evidence on the real learning needs of family members regarding the treatment with oral chemotherapies among children and adolescents that can support the construction of educational practices by health professionals working in this area, including nurses, is still scarce. Thus, the objective of this research was to describe the learning needs of family members of children and adolescents with cancer regarding treatment with oral antineoplastic chemotherapy drugs.

METHOD

Descriptive research with a qualitative approach,[14] in which the criteria defined by the Consolidated Criteria for Reporting Qualitative Research (COREQ) were adopted.[15] The research was conducted at a federal hospital located in the municipality of Rio de Janeiro. This is an auxiliary body of the Ministry of Health in the development and coordination of integrated actions for cancer prevention and control in Brazil.[1]

The hospital has two chemotherapy centers: one for adult patients and the other, the study setting, for children and adolescents, with an average of 23 children/adolescents per day. This sector is open from 7am to 7pm, every day of the week, including holidays. For this service, it has two nurses on duty and a day nurse. The nurse in this sector is responsible for administering chemotherapy to patients admitted to the pediatrics and children's hematology department and to the Children's Intensive Care Center (CICU), which cares for patients up to 19 years of age.

Twenty-three family members of children/adolescents undergoing treatment with oral antineoplastic chemotherapy participated in the research. The inclusion criteria were: being a caregiver of the child/adolescent; having previous experience of more than one month administering oral chemotherapy, both in the outpatient setting and at home, and being over 18 years of age. Family members of children and adolescents who were hospitalized during the data collection period were excluded.

The recruitment of the participants was carried out, personally, by the master's student nurse, first author. During the period of data collection, 45 children/adolescents in treatment with oral antineoplastic agents were registered in the service. Twenty-four family members were approached; however, one refused to participate, saying he did not feel comfortable having his words recorded. The delimitation of the number of participants occurred during the fieldwork through the theoretical saturation of data identified in the organization of statements.[16]

Data was collected between July and September 2020, through semi-structured interviews, using a script with closed and open questions. The closed-ended questions corresponded to the characterization of the participants, and the open-ended ones to the fulfillment of the research objective. Thus, the following questions were asked: "How do you care for the child/adolescent being treated with oral antineoplastic agents? What is the care that you have with oral antineoplastic drugs? What are your questions?".

The interviews were conducted by the first author in the study setting, had an average duration of twenty minutes and were held in the Nursing office of the children's chemotherapy unit, which is a reserved place. They were recorded with the aid of a voice recorder to fully register the participants' speeches and, later, transcribed in full.

The data was processed using the software *Interface de R pour Analyses Multidimensionnelles de Textes et de Questionneires* (IRAMUTEQ), which is a computerized method for processing texts (corpus), which scrutinizes the structure and organization of the enunciates, expressing the associations between the lexical worlds. The use of this software enabled the coding, organization and separation of information, promoting greater methodological rigor.[17] Thus, the analysis of the textual data took place in three stages: 1) preparation and coding of the textual corpus with the description of the material from the interviews; 2) processing of the textual data in the software and 3) interpretation of the data obtained by the researchers.[18]

In the processing stage, we used one of the five available analysis methods, the Descending Hierarchical Classification (DHC) method, since this interface provides, according to the original corpus, the retrieval of text segments and the correlation between each one through the grouping of statistically significant words into classes.[19,20]

To do this, the software performs a well-known statistical test in quantitative studies, Pearson's chi-square, where the larger it is, the more likely is the hypothesis of dependence between the active word and the class.[18] Thus, words that have $\chi 2$ equal or greater than 3.84 ($p<0.05$) present an association in the class, with emphasis on those with $p<0.0001$, with a very strong association.[18] Next, the step of interpreting the classes, the text segments and the words associated with them occurred in light of the theoretical framework of the study[11] and other scientific evidence on the subject.

The research was approved by the Research Ethics Committee of the proposing institution (CAAE: 30134320.2.0000.5243; Opinion number 4.012.929) and of the co-participating institution where the research was conducted (CAAE: 30134320.2.3001.5274; Opinion number 4.074.187, in June 2020) and the data was produced by signing the Free and Informed Consent Term (FICT).

The participants had their identities preserved and were identified by codes referring to the interview number, F1 being the first family member interviewed, F2 the second family member interviewed, and so on, successively, in order to maintain anonymity. It is worth mentioning that the researcher undertook the commitment to care for the integrity of the research participants during data collection with the family members and followed all the necessary precautions against the risk of transmission of the new Coronavirus according to the general guidelines for the conduction of research protocols in the setting of SARS-CoV-2 (COVID-19).[21]

RESULTS

Twenty-three family members (100%) of children and adolescents using oral antineoplastic chemotherapies participated, among them, sixteen mothers (69.6%), four fathers (17.5%), two brothers (8.6%) and one grandmother (4.3%). Most family members were in their 40s (52.2%), had completed high school (52.17%), and 87% of the families had other children. As for the characteristics of the children/adolescents, the most prevalent age was ten years old (39.4%) and, regarding diagnosis, twelve were under treatment for oncohematologic diseases, the most prevalent type being leukemia, while eleven were under treatment for solid tumors, among which 54% were central nervous system tumors. The most commonly used oral antineoplastic drugs were Mercaptopurine (47%) and Metotrexate (26%), indicated for the treatment of hematological diseases such as leukemias, lymphomas and histiocytosis. Temozolamide (13%) was also prominent, being used for the treatment of central nervous system tumors.

The DHC retained 256 text segments, from the 23 processed texts, classifying them into five stable classes, with a utilization rate of 84.77%, according to the dendrogram (Figure 1), which shows the relations between these classes and the percentage of each one in relation to the total of the of the analyzed corpus.

The five classes were stable, that is, composed of text segments with similar vocabulary, thus constituting distinct lexical worlds according to lexical parameters in common and vocabulary distinct from the other classes. The reading of the relationship between the classes performed in the dendrogram is done from top to bottom. Thus, the first sub-corpus undergoes two divisions, into classes 3 and 2. Through the dendrogram, it

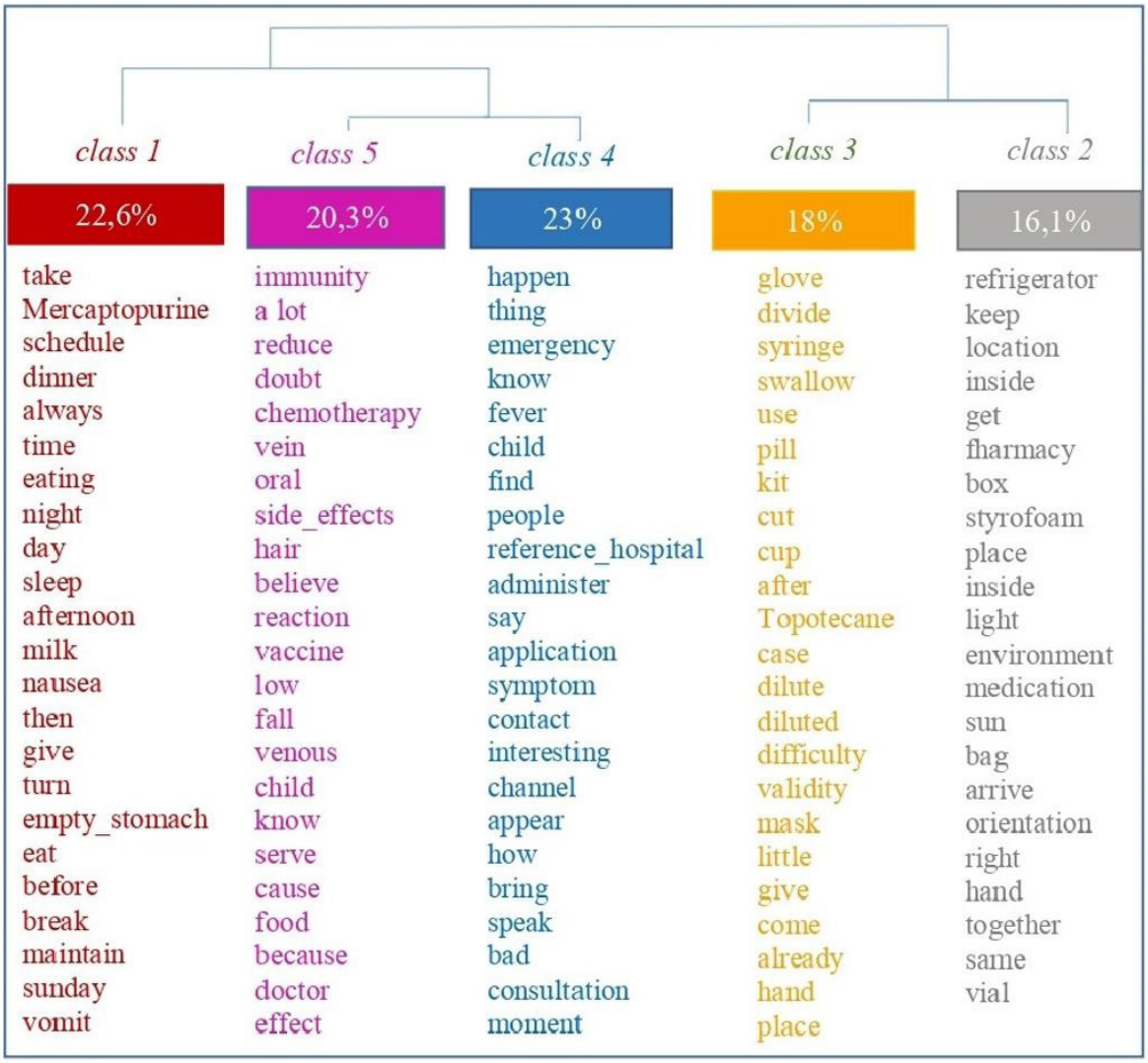

Figure 1. DHC dendrogram of the text segments related to the learning needs of family members of children and adolescents with cancer regarding treatment with oral antineoplastic antineoplastic drugs. Niterói, RJ, Brazil, 2020.
Source: provided by IRAMUTEQ software.

was possible to contemplate the words that reached a higher percentage as to average frequency among themselves and different among them.[17]

After the exhaustive reading of the text segments of each class, it was possible to achieve the research objectives, naming the five classes offered by the software according to the themes emerging from the interpretation of the findings. The classes will be presented below based on the main words associated in each class, however, relating them to the text segments from which they emerged, giving context to what was said by the interviewees in light of the theoretical framework of the study.

Class 1 - Administration of oral antineoplastic drugs

In this class, family members described how the administration of oral antineoplastic agents is done, thus revealing distinct learning needs on this topic. Thus, the main words associated were: take; mercaptopurine; schedule; dinner; always; time; feeding. The following descriptions highlight some aspects that are considered primordial in the performance of care by these family members, such as following the recommended times and the need to modify the child's/adolescent's eating routine.

> *I take care by keeping to the schedule of taking the antineoplastic agents. I always try to keep the right schedule of the medicine, and with food, I only give what you can eat. (F5)*

> *We changed the diet: during the day, he has a balanced diet, fruits and juices. So, he has lunch and then we give him his medicine; it is once a day, always at 12 o'clock sharp (F19)*

Other family members reported some learning needs related to the chemotherapy schedule such as not knowing if the antineoplastic agents can be administered with food and whether to handle the tablet with the hand or not. There is also in the reports a divergence in the way the antineoplastic drug "mercaptopurine" is administered: family member 22 reported not offering milk, while family member 21 offers it with milk after a while after the administration of the drug.

> *I don't make any distinction if he had dinner or not, nobody passed me anything like that, so I stick to the 9 pm schedule. Usually, I take the pill in my hand and put it in his hand and he takes it. (F17)*
>
> *We always give Mercaptopurine at night because I couldn't give it with milk, so we give it with the first or last spoonful of dinner. (F22)*
>
> *Mercaptopurine is from Monday to Monday without break, at 10 pm at night. First, he eats something and then takes the medicine; I wait a little and give him a glass of milk so that he doesn't have an empty stomach. (F21)*

In the experiences, it is highlighted that the families of children/adolescents in treatment for oncohematologic diseases have a differentiated protocol scheme, with more than one oral antineoplastic agents (30.4%), and that they are prescribed in different ways throughout the week, which can be a confusing factor at the time of administration, which demands the need for reinforcement in the orientations by the professionals.

> *Every day there is a pill: the Mercaptopurine she takes every day and the MTX (methotrexate) she takes six pills once a week, which is on Sunday, and, so, we have to keep watching. (F12)*
>
> *She takes the Mercaptopurine at 6 in the afternoon, one and a half pills, from Monday to Saturday and on Sunday she takes two pills. The MTX (methotrexate) she takes 11 pills only on Saturday. I have forgotten a few times to give her antineoplastic agents. (F23)*

Family member F16 reported that her main doubt is about the amount of pills, because the child takes a certain amount of pills during the week and, at the weekend, it is a different amount of the same antineoplastic agents.

> *The doubt I have is about the amount of pill because there is a right dosage, whether she will take it whole or half. (F16)*

Family members F20 and F22 reported how they proceeded in case of vomiting before or after the administration of antineoplastic agents, even showing that the decision not to offer new medication was based on their own observation and not on professional guidance.

> *There were days when he took the antineoplastic agents and vomited afterwards; we wouldn't give him another one, because he was constantly vomiting. So, there would be no point in giving another, it would be a waste of medicine. (F20)*
>
> *We did not give the antineoplastic agents a few times, yes, it was not because we forgot, it was on the days he woke up vomiting, we did not give him Mercaptopurine. This was not a medical orientation, we followed this way. (F22)*

Class 2 - Storage of oral antineoplastic agents

In this class, the words most associated with the learning needs of family members were: leave; refrigerator; keep; place; inside. They refer to the way family members store medication at home, according to their own experiences. In this sense, some family members pointed out that these are stored in the same place, in a box, together with all the other drugs used by the child/adolescent, without any differentiated care being taken because they are antineoplastic drugs.

> *I keep the antineoplastic agents in its own bag along with all her other medicines. (F6)*
>
> *I keep the antineoplastic drugs in a closed box along with all her other medications. (F23)*

Family member F14 reported that, when storing antineoplastic agents, she separates the pills that are whole from those that are already cut. This reduces the contact with the cut ones, that is, with those that were handled by the family member at home.

> *I keep the medicines in two bottles: one for the whole pills and the other glass I keep for the cut pills; I keep them separate so I don't move the cut pills around too much. (F14)*

Regarding the temperature, one family member reported leaving the medication at room temperature, highlighting uncertainty about the conduct, because they reported not knowing if they had read the orientation correctly. Another family member reported keeping it in the refrigerator, although they said that they didn't know which part of the refrigerator they should leave it in.

> *I don't know if I read it right. But, I keep the medicine at room temperature, I don't leave it in the sun, in a dry place, I don't put it in the fridge. (F17)*
>
> *My doubt is very much the question of storage; I come home with the medicine in the Styrofoam and put it in the refrigerator, I don't know which part of the refrigerator I have to leave it in. (F8)*

The reports showed that family members store oral antineoplastic agents in different ways. Some are stored in refrigerators and others in other places, such as kitchen, bedroom,

bags and pouches. This non-uniformity is also presented as a need for learning in relation to storage, because the decisions are still based on perceptions, observations and experiences acquired in the execution of care and not on contextualized and problematizing educational practices.

Class 3 - Manipulation of oral antineoplastic drugs

The words that obtained the highest frequency of association in this class were: glove; divide; syringe; swallow; use; tablet. The text segments and words that characterized this theme translate how family members handle and manipulate oral antineoplastic drugs at home, as well as indicate their learning needs.

Some family members took the oral antineoplastic agents and went to the chemotherapy pharmacy service to have them handled and, thus, received a closed kit containing the syringes with the diluted antineoplastic agents, gloves, cups, and a bag to put the empty syringes for disposal at the hospital. In this sense, they followed the care that was oriented in the handling of the medication.

> *Along with the syringes, the pharmacy gave me a kit. They come with the glove, some cups for diluting and the syringes ready with the medicine. (F7)*
>
> *I only use the gloves that come in the kit to give the Topotecan to my daughter and I collect the syringes in the bag and throw them away at the hospital. I give the cyclophosphamide normally with my hand and throw it in the garbage at home. (F15)*

On the other hand, other family members reported that they do not send the antineoplastic drugs for dilution to the pharmacy, but manipulate (cut, divide, and dilute) the oral antineoplastic agents drugs at home. These findings reinforce the need to be oriented for greater safety in handling these drugs.

> *I have an acrylic case to cut the pill. I divide it in the middle and then cut it in the middle again, I don't use a glove to divide the pill. (F14)*
>
> *We divide the medicine, the dosage is only half a pill. So, we always cut it. And we always use the tablecloth, clean. (F22)*
>
> *I put a little water in a little glass and let the pill melt, and then I give it to him to swallow. Because he has difficulty swallowing all kinds of pills. (F18)*

In addition, family member F14 reported that he received no guidance regarding the handling and dilution of antineoplastic agents.

> As she is very small, she can't swallow the pill. I dissolve it in a little cup. Nobody told me how I should dilute the pill, so I bought a small bottle. (F14)

The speeches showed that when the family members are neither oriented in a contextualized way, nor directed to acquire the kit with the necessary materials for the adequate handling of oral antineoplastic agents at home, they perform the care in the same way they do with other non-chemotherapeutic drugs.

Class 4 – Need for guidance of family members

Family members reported the main subjects that they would like to be addressed in the orientations for home care. The words with the highest frequency of association were: happen; thing; emergency; know; fever. In the following interviews, the family members signaled that they would like to be oriented about adverse effects.

> *It would be nice to know about what can happen, what effect the medicine has on the child. (F23)*
>
> *I would like to know about the reaction, because if you know what the reaction is, you manage it well, if you don't know it can cause fever, dizziness, the child can become neutropenic and you don't know, and sometimes it is because of the oral antineoplastic agents, and this is very important: the orientation. (F9)*

In addition to side effects, family members would like information regarding the circumstances that require taking the child/adolescent to the emergency room of the referral hospital.

> *If the child might have some kind of reaction, something that might prepare those who are with the child to be able to come to the referral hospital. (F21)*

Some family members asked for guidance regarding the handling of antineoplastic agents: whether or not they can place their hands on them; how to share the drugs; the correct place for storage and disposal.

> *How to manipulate it? Because I take it myself with my hand, cut the medicine, give it to her and she takes it. I was never informed on how to divide the medicine. (F23)*
>
> *How should we handle the antineoplastic agents, not to put our hands on it, how do we keep it, and where should we dispose of the bottle of medicine. (F12)*

Class 5 - Concerns about treatment with oral antineoplastic drugs

In this class, family members reported their concerns about treatment with oral antineoplastic agents, these aspects being important learning needs to be addressed by professionals involved in the care of children and adolescents on oral antineoplastic agents. The words with the highest frequency of association were: immunity; a lot; abate; doubt; chemotherapy.

Family members showed concern about the adverse effects and the drop in immunity.

> *A big doubt I have is if the effect of chemotherapy ends up affecting other organs, because she already left the hospital with very low immunity. That is my doubt, is the chemotherapy good or bad? (F13)*
>
> *I would like to know what can cause it because they didn't explain to me much if it could cause some reaction, I tried to find out from someone here and someone there, I have doubts about the side effects. (F7)*

Family member F20 was concerned about under what circumstances to refer the child to the emergency room and what the correct procedure should be if the child has vomited after taking antineoplastic agents.

> *I have some doubts: in what situation is it important to bring, immediately, to the reference hospital? With fever, do you bring him to the hospital or not? If he took the antineoplastic agents and vomited, how long does it take to be absorbed? Should I give him another one? (F20)*

In the statements, it drew attention that two family members reported not knowing that the oral medication they administered at home was a antineoplastic drug. One family member even showed that, in an attempt to get more information to guide their care, they read the drug's package insert, but even so, they are not sure if they are doing the right care.

> *I didn't know that Mercaptopurine was an antineoplastic agents, I thought it was like Bactrim, for me, antineoplastic agents was just MTX. (F21)*
>
> *I have a doubt yes because, although I did not know that this drug was a chemotherapeutic, I read the package insert and saw that it was a very important drug. My doubt is if I am doing the right thing, if it is really important to take it before bedtime. (F17)*

DISCUSSION

The text corpus scored well in the hierarchical top-down analysis, with a percentage higher than 75%.[17] Thus, the textual material was considered useful to adequately perform this type of analysis.

The data from this research showed that family members provide care based on their own experiences, from a body of knowledge built during their lives, and that there are not always contextualized dialogues with the professionals who care for the child or adolescent. Thus, there are still recurring doubts about, for example, administration and handling that may, over time, affect the conduction of the treatment, storage, and disposal, among others, which reveals important learning needs to be problematized by professionals in the educational practices with family members. In this sense, according to the Freirian conception, it is necessary to establish, with these families, a problematizing educational process based on a true dialogue among all those involved, in which there is room to listen to the subject and the reality he/she experiences, thus breaking with the verticality of the banking practices.[11]

During treatment with oral antineoplastic drugs, many factors can hinder adherence to therapy and become a barrier to compliance with the recommendations of the multi-professional team, including the deficiency of understanding related to the treatment itself, complexity in the dosage regimen, administration of other drugs, interaction with another drug and with food, the cost of therapy, and adverse effects.[22] It is also noteworthy that, for the administration of each antineoplastic agents, their specificities should be considered regarding the management with food, observing and respecting the intervals, also paying attention to conduct related to vomiting after drug administration, considering the absorption time of the drug. It is reinforced that, in face of this range of learning needs, it is fundamental to establish dialogical meetings,[11] through attentive listening that facilitates the sharing of knowledge with each family, according to the oral antineoplastic prescribed, adding their experiences and previous knowledge to the dialogue.

In this directive, dialogicity must be the guiding principle of health educational practices with these families, so that it is possible to know and reflect on their concrete reality, thus enabling professionals and family members to find, together, viable solutions that facilitate care in everyday life. A strategy that can be recommended to the families of children and adolescents is the use of a calendar with the record of dates, times, and doses of medications, with a space for checking each intake. This calendar must be periodically evaluated by the multi-professional team to assess the treatment adherence of each family, considering their weaknesses and potentialities.[23]

In addition, the nursing actions should include guidance on the prescription of antineoplastic agents, removing doubts about the dose, time, duration of treatment, adverse effects, in addition to encouraging the family at the time of administration to talk to the child and adolescent, using strategies to make it a pleasant moment.[23,24]

In the interviews, family members reported different ways of storing oral antineoplastic drugs, which indicates that there is lack of knowledge, doubts and mistakes and, therefore, it is necessary to address this issue in the guidelines to be developed by health professionals, including nurses, in a participatory manner, in order to minimize the complications of an inadequate treatment.

It should be noted that storage conditions are important to ensure the effectiveness of the drug, because poor packaging can lead to degradation and, therefore, antineoplastic agents may not have the desired therapeutic effect. Antineoplastic agents, when stored in hot and humid places, such as kitchen, bathroom, or in environments with high luminosity, can suffer alterations in their composition, which can be chemical, physical or microbiological,

decreasing the therapeutic effectiveness or increasing the risk of toxic effects according to the type of degradation suffered by the drug.[25] Listening to the subjects to understand their reality and socialize their knowledge[11] is fundamental for the transformation of habits and the adoption of the necessary and safe care with oral antineoplastic drugs.

Some family members reported that they take the pills out of the original packaging, cut them up, and put them in glasses. This care is based on their own life experience, as an attempt to search for a solution, showing naive awareness about this care practice. About this, a study highlighted that keeping the medication in its original packaging is important, because it helps to avoid drug exchanges, when they are intact and identified, besides maintaining its stability.[25] Thus, guidance on the proper conditioning of oral antineoplastic agents should be given during treatment, considering that this learning need was evident in the statements. In this way, practices that may harm the therapy of children and adolescents are avoided, which will make it easier for family members to move from naive awareness to critical awareness.[11]

Regarding the handling of antineoplastic agents by family members in the home environment, evidence indicates that oral antineoplastic therapy needs to maintain the same safety precautions that are used for intravenous therapy in order to protect patients, caregivers and the environment.[26] Therefore, educational actions are needed for guidance on safe handling and proper administration of oral antineoplastic agents, avoiding the direct placement of hands on tablets or capsules. This manipulation should be done with gloves or reduce, to a minimum, the touch using a glass, the bottle cap itself, or kitchen paper, and wash your hands after the procedure. It is not recommended to break, open, crush, or chew the antineoplastic agents in order to avoid inhaling or touching the contents. It is also advisable to avoid direct contact with feces, urine, or other excreta, and flush twice after urinary or fecal elimination or other excretion during oral antineoplastic therapy and 48 hours after the end of treatment.[26,27]

Furthermore, regarding the disposal of antineoplastic agents, mentioned in the interviews, in view of the environmental risks that can be minimized, it is necessary to invest in educational practices[11] based on the context of people's lives and critical reflection so that knowledge is built. It is known that, regarding the proper disposal of waste resulting from the use of cytotoxic agents, it must be packed in standardized containers, closed and of rigid consistency, which prevents perforation or leakage, so that it can be neutralized or incinerated. This care is important for the safety of people and the environment, because the family member must know the correct destination of expired drugs, as well as the return of unused antineoplastic agents to the reference hospital for proper disposal. It is also necessary to warn that antineoplastic agents should not be disposed of through the sewage system, as this waste can contaminate the environment.[25]

The comments of family members about the issues that they would like to have guidance on and that generate concerns are also important learning needs to be addressed in educational practices. Among these issues, the adverse effects of medications, signs and symptoms indicating the need to return to the hospital, and storage and handling of medications were highlighted. Thus, gaps in educational practices about the treatment with oral antineoplastic agents were explicit.

In this directive, patients participating in a study identified the importance of having written information that they could consult at home and medication calendars to take notes like a diary. They also requested that these educational materials should address the following topics: information about adverse effects; how and when to take the antineoplastic agents; how the drug works; drug interactions; alarms; storage; handling; disposal, and education about antiemetic drugs.[23] Such results are similar to those of this research and reinforce the need for studies and actions in this context.

Health education about oncological drugs can be complex, because it requires the nurse to guide family members about the specific care with oral antineoplastic drugs, addressing important issues about hygiene and nutrition; handling of antineoplastic agents; correct dosage of drugs; risk factors that can lead to febrile neutropenia and infections; treatment-related adverse effects; when family members should refer children or adolescents to the emergency room, and guidance on the medications used to prevent and treat symptoms, such as antiemetics, antihistamines, corticosteroids, and analgesics, among which many are high-risk medications and also require close monitoring by the family member and health care team.[28,29] Therefore, faced with the complexity of this type of care, nurses need to perform educational practices that go beyond the mere narrative and that provide conditions for awareness and a critical attitude in order for the family members to voluntarily and autonomously make real changes in reality.

Based on the assumption that nurses play a fundamental role in the management of the therapeutic regimen of this clientele, it is recommended their effective participation in the health education process in the transition from the administration of oral antineoplastic agents to the home context and its subsequent monitoring, seeking to develop the capacity of self-management of family members, encouraging critical reflection on their situation and actions, to ensure the safety of the child or adolescent and reduce to a minimum unnecessary risks and harms associated with health care and treatment adherence and effectiveness.[30]

As a limitation of this study, it is possible to highlight that the results reflect, exclusively, the experience of an institution, which may not express the totality of people who experience this universe.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

The findings of the study allowed us to describe the learning needs of family members regarding home treatment for children and adolescents undergoing treatment with oral antineoplastic agents, in addition to revealing how the antineoplastic therapy is carried out by them. It is noted that, sometimes, much care is

performed in a mistaken manner, contradicting the recommendations in the scientific literature, which can cause risks to people and harm the environment where they live.

The learning needs reported by family members, which are key points for health education actions, were related to the proper form of administration, storage and handling of oral antineoplastic agents. They would also like to have guidance on side effects and signs and symptoms that indicate the need to take the child and adolescent to the hospital emergency room. Such themes need to be problematized in the development of dialogical educational practices by health professionals, including nurses.

Regarding the implications for practice, the importance of the nursing team in providing the family members with support to solve doubts and difficulties arising from the therapy should be emphasized, so that the antineoplastic agent treatment is carried out properly and the family feels able to care for the child and adolescent, thus ensuring that the use of the drug is administered safely and effectively.

This study enriches the existing knowledge on the subject, since it provides a theoretical deepening and promotes reflection on childhood cancer in a way that is able to encourage and sensitize health professionals about the importance of educational practices in the treatment with oral antineoplastic drugs.

AUTHOR'S CONTRIBUTIONS

Study design. Gabriele Alvernaz Silva Franco. Liliane Faria da Silva.

Data collection or production. Gabriele Alvernaz Silva Franco.

Data analysis. Gabriele Alvernaz Silva Franco. Liliane Faria da Silva. Flavio Luiz Seixas. Fernanda Garcia Bezerra Góes. Ana Carolina Alves Vollu. Eduardo Charpinel Lagoeiro.

Interpretation of results. Gabriele Alvernaz Silva Franco. Liliane Faria da Silva. Fernanda Garcia Bezerra Góes.

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