

## THEMES FOR EDUCATIONAL PRACTICES ON HOME CARE FOR CHILDREN WITH LEUKEMIA USING A SEMI-IMPLANTABLE CENTRAL VENOUS CATHETER

TEMAS PARA PRÁTICAS EDUCATIVAS SOBRE CUIDADOS DOMICILIARES ÀS CRIANÇAS COM LEUCEMIA EM USO DE CATETER VENOSO CENTRAL SEMI-IMPLANTÁVEL

TEMAS PARA PRÁCTICAS EDUCATIVAS SOBRE CUIDADOS DOMICILIARIOS PARA NIÑOS CON LEUCEMIA Y CATÉTER VENOSO CENTRAL SEMI-IMPLANTABLE

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**Funding:** No funding.

**Submitted on:** 2020/05/09

**Approved on:** 2020/10/08

### Responsible Editors:

-  Bruna Figueiredo Manzo
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## ABSTRACT

**Objective:** to identify themes for educational practices on home care for children with leukemia using a semi-implanted catheter from the perspective of family caregivers. **Method:** a descriptive study with a qualitative approach carried out with 11 relatives of children with leukemia using a semi-implanted venous catheter. The data were obtained through semi-structured interviews, processed in the IRAMUTEQ software, and analyzed using the Descending Hierarchical Classification (DHC). **Results:** seven DHC classes were obtained in which the following themes were identified: hand hygiene and catheter dressing, care to keep the catheter dressing at home; catheter fixation; care of the catheter in the bath; and feelings related to complications with the catheter. **Conclusion:** when identifying these themes, the nurse has the possibility to intervene in improving home care for these children, based on the real needs of these family members, contributing to provide them with more security in their living experience.

**Keywords:** Pediatric Nursing; Health Education; Catheters, Indwelling; Leukemia.

## RESUMO

**Objetivo:** identificar temas para práticas educativas sobre cuidados domiciliares às crianças com leucemia em uso de cateter semi-implantado na perspectiva de familiares cuidadores. **Método:** estudo descritivo com abordagem qualitativa realizado com 11 familiares de crianças com leucemia em uso de cateter venoso semi-implantado. Os dados foram obtidos por meio de entrevista semiestruturada, processados no software IRAMUTEQ e analisados por meio da Classificação Hierárquica Descendente (CHD). **Resultados:** foram obtidas sete classes da CHD nas quais foram identificados os seguintes temas: higienização das mãos e curativo do cateter, cuidados para manter o curativo do cateter em casa; fixação do cateter; cuidados com o cateter no banho; e sentimentos relacionados a complicações com o cateter. **Conclusão:** ao identificar esses temas, o enfermeiro tem a possibilidade de intervir na melhora da assistência domiciliar a essas crianças, pautado nas reais necessidades desses familiares, contribuindo para fornecer-lhes mais segurança na sua vivência.

**Palavras-chave:** Enfermagem Pediátrica; Educação em Saúde; Cateteres de Demora; Leucemia.

## RESUMEN

**Objetivo:** identificar temas para prácticas educativas sobre cuidados domiciliares para niños con leucemia con catéter venoso central semi-implantable desde la perspectiva de los cuidadores familiares. **Método:** estudio descriptivo de enfoque cualitativo realizado con 11 familiares de niños con leucemia y catéter venoso central semi-implantable. Los datos se recogieron a través de entrevistas

### How to cite this article:

Corrêa VB, Silva LF, Góes FGB, Nunes MDR, Pacheco STA, Silveira ALD. Themes for educational practices on home care for children with leukemia using a semi-implantable central venous catheter. REME - Rev Min Enferm. 2020[cited \_\_\_\_\_];24:e-1347. Available from: \_\_\_\_\_

DOI: 10.5935/1415.2762.20200084

*semiestructuradas, procesadas en el software IRAMUTEQ y analizadas según el método de la clasificación jerárquica descendiente (CJD). Resultados: se obtuvieron siete clases de CJD en las que se identificaron los siguientes temas: higiene de las manos y vendaje del catéter, cuidados para mantener el vendaje del catéter en casa; fijación del catéter; cuidados con el catéter durante el baño; y sentimientos relacionados a las complicaciones con el catéter. Conclusión: al identificar los temas el enfermero tiene la posibilidad de intervenir en los servicios de atención domiciliar de estos niños en función de las necesidades reales de los familiares, contribuyendo a brindarles mayor seguridad en su vivencia.*

*Palabras clave: Enfermería Pediátrica; Educación en Salud; Catéteres de Permanencia; Leucemia.*

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## INTRODUCTION

Child and youth cancer has a high incidence and is the second leading cause of death in Brazilian children and adolescents. It is estimated that the number of new cases of this disease in Brazil for this population group, for each year of the 2020-2022 triennium, will be 8,460, with the predominant types being leukemias (28%), tumors of the central nervous system (26%) and lymphomas (8%).<sup>1</sup>

Therefore, the most common cancer in people under the age of 15 is leukemia, whose treatment has advanced significantly in recent years, with a current probability of survival of 80 to 90%, in the face of improvements in supportive care, treatment stratification based on risk relapse, identification of the biological characteristics of leukemic cells and optimization of treatment regimes, including cranial irradiation to prevent relapses involving the central nervous system.<sup>2</sup>

Currently, the treatment of cancer patients, including leukemia, regardless of their type, is commonly based on the administration of intravenous chemotherapy.<sup>3</sup> However, this route is also accessed for the administration of blood products, antibiotics, parenteral nutrition, analgesics and collection of blood sample during the entire stage of cancer treatment, which increases the risk of complications, such as endothelial irritability or tissue necrosis.<sup>4</sup>

Due to complications, the administration of intravenous therapy in Pediatrics is a challenging care for the Nursing team, as the pediatric population has peculiar characteristics, such as more capillary fragility, small venous network and difficult to see.<sup>5</sup> Such a reality can trigger repeated venous punctures that provoke in the child, among other consequences, memories that generate anticipatory anxiety, as well as higher levels of response to pain.<sup>6</sup> Thus, among the possible venous devices, the semi-implantable central venous catheter (SI-CVC) is often indicated in different scenarios, as it dispenses with percutaneous puncture, in addition to allowing the safe infusion of chemotherapeutic agents, blood products and antibiotics, in addition to collection frequent blood flow, being considered, therefore, a stable venous catheter.<sup>7</sup>

However, these catheters are not exempt from risks and complications, which requires special care in their insertion and management,<sup>7</sup> including maintenance by the patient and family, mainly because the SI-CVC is partially externalized in the skin, which can increase the risk of infections and accident. Therefore, family members of children with leukemia are faced with challenging health situations, as they need to learn to deal with a new reality of home care that involves maintaining the catheter and observing possible complications related to the use of this venous device.

In this context of care, it is necessary for nurses to be a facilitating agent in family health literacy regarding the teaching of new skills in the discharge process of children with leukemia.<sup>8</sup> This professional should guide families using educational practices tools that help to resolve doubts regarding treatment, since the instrumentalization of the family member to provide effective and safe home care can contribute to the minimization of complications and preventable readmissions.<sup>9</sup>

However, for the construction of effective educational practices based on the concrete reality of families, it is necessary to know how family members care for children with technological devices at home,<sup>10</sup> in this specific case, SI-CVC, in order to recognize their real doubts and information needs. Given the above, this research aimed to identify themes for educational practices on home care for children with leukemia using a semi-implanted catheter from the perspective of family caregivers.

## METHOD

Descriptive study with a qualitative approach, developed in an onco-hematology service, in which the participants were family members of children with leukemia using SI-CVC who met the following inclusion criteria: family members over 18, with previous care experience with the SI-CVC at home for at least 15 days after its placement, as this is the estimated time for the removal of stitches and definitive fixation of the catheter in the subcutaneous tissue. Family members of children with leukemia using SI-CVC in palliative care in the final stage of life were excluded, as care is focused exclusively on symptom management during this phase.

Data collection took place in the months of August and September 2019 through semi-structured interviews, using a script with closed and open questions. Closed questions were related to the characterization of participants and open questions to meet the research objectives. Thus, the following questions were asked: tell me how you take care of the child using the semi-implantable catheter on a daily basis; what do you think is important to know to care for the child using the catheter at home? What care do you consider important to be placed in educational practices for home child care using a semi-implantable venous catheter?

In capturing the participants, the approach was made personally by the main researcher, through her identification as

responsible for the study and data collection, and they were invited to participate voluntarily in the research based on clarifying the objectives, data collection procedure and ethical aspects. Agreeing to integrate the study, the Free and Informed Consent Term was provided for signature, where such clarifications were reported in writing.

At the time of data collection, 16 children with leukemia using SI-CVC were registered at the service. Twelve family members were approached, however, one refused to participate without mentioning the reason. The sampling of participants occurred by observing the theoretical saturation of the data, that is, when no new information or new topics were registered, the saturation point was identified.<sup>11</sup>

The interviews were carried out in a place reserved at the institution by the main researcher and recorded with the aid of a voice recorder for the complete record of the speeches and their storage for later analysis.

The textual content resulting from the interviews was submitted to lexicographic analysis, with the aid of the software *Interface de R pour Analyzes Multidimensionnelles de Textes et de Questionnaires (IRAMUTEQ)*. The use of software for data processing enabled the coding, organization, and separation of information, which allowed the quick location of the entire text segment used in qualitative writing.<sup>12</sup>

In this research, to extract the contents to meet the proposed objectives, the method of descending hierarchical classification (DHC) was used, since this interface allows, based on the original corpus, the recovery of the text segments and the correlation

between each one, which allows grouping of statistically significant words (classes).

The ethical precepts that involve research with human beings were followed according to Resolution Nr. 466, of December 12, 2012. Data collection occurred after approval by the Research Ethics Committee of *Universidade Federal Fluminense* and the Ethics Committee of institution where the research was carried out, Opinion Report Nr. 3,335,506 and 3,469,941, respectively. To preserve the identity of the participants, an alphanumeric code was used, with F1 being the first family member interviewed, F2 being the second family member interviewed, and so on.

## RESULTS

Eleven family members of children with leukemia using SI-CVC participated in the research, the majority of whom are mothers and only one father, in the average age of 30 years; six family members have completed high school, incomplete high school, two complete elementary school and two incomplete elementary school. Regarding housing conditions, most live in masonry houses, with basic sanitation and running water and live with approximately three to four family members, which indicated good living conditions for the participants.

When importing the text corpus configured for the program, in 23 seconds the following results were obtained: 11 texts, 113 text segments, 4,038 word occurrences, seven classes and an 80.53% retention of text segments in the Descending Hierarchical Classification (Figure 1).

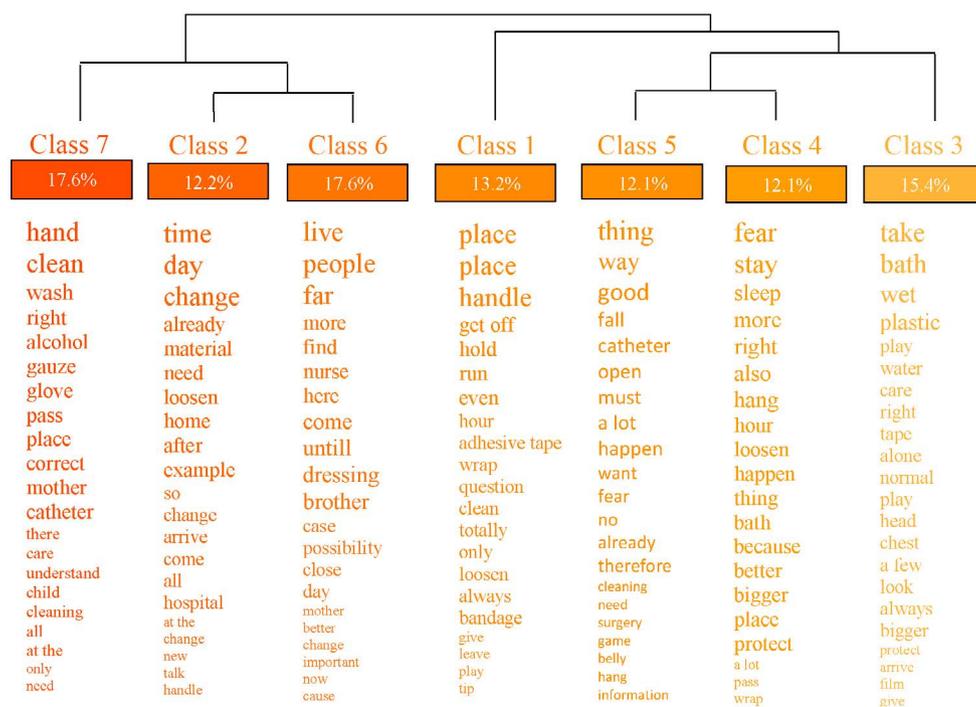


Figure 1 - DHC dendrogram of the family's textual corpus generated by IRAMUTEQ, Rio de Janeiro, RJ, Brazil, 2019

The percentage organization of the segments by classes, observed in the dendrogram, allowed to evidence the decreasing distribution by agglutination of text segments between the classes. Thus, it is observed that the classes with the largest number of text segments analyzed were classes 7 and 6, corresponding to 17.6% both; class 3 with 15.4%, class 1 with 13.2% and classes 2, 4 and 5 with 12.1% each.

The program divided the textual corpus into two subcorpus. The first, composed of class 7, with a second subdivision covering classes 2 and 6. The second, composed of class 1, with a second subdivision comprising class 3 and with a new subdivision encompassing classes 5 and 4. It is noteworthy that, in this research, the words that presented  $\chi^2$  equaled greater than 3.84 were used as selection criteria, as it determined the associative strength between them, and with  $p < 0.0001^{13}$  the other words were disregarded in the interpretation of the data.

After an exhaustive reading of the text segments, it was possible to extract five themes based on the association between the classes offered by the software, namely: hand hygiene and catheter dressing (class 7); care to keep the catheter dressing at home (class 2 and 6); catheter fixation (class 1); care for the catheter during bathing (class 3); and feelings related to complications with the catheter (class 4 and 5) (Table 1).

Table 1 - Corpus of the text. Rio de Janeiro, RJ, Brazil, 2019

Themes	Associative words	Themes to be addressed in educational practices
Class 7 - Hand hygiene and catheter dressing	Hand Clean Wash Right	- Importance of hand hygiene - how to dress the catheter at home
Classes 2 and 6 - Care to keep the catheter dressing at home	Live People Time Day Change	- Conduct if the dressing needs to be changed at home
Classe 1 - Catheter fixation	Place Catheter Handle	- What to do if there is a rupture or accidental externalization of the catheter
Classes 3 - Care of the catheter during the bath	Remove Bath	- Care not to wet the catheter
Classes 4 and 5 - Feelings related to complications with the catheter	Fear Stay Sleep Thing Way	- What to do, in case of complications with the catheter, at home

Source: research data, 2019.

## HAND HYGIENE AND CATHETER CLEANING

This theme emerged in the interviewees' statements and the most frequent words in class 7 were: **hand, clean, wash, right**. These terms refer to the importance that family members attach to

the protection of the child against SI-CVC-related infections in the home environment, based on hand hygiene and proper catheter dressing when necessary. Thus, these two topics are themes that families considered important to be addressed in educational practices.

*[...] washing your hands, rubbing alcohol on your hands before handling the child and the catheter, people need to know this care so as not to lose the catheter (F1).*

*[...] I think mainly the issue of hand hygiene, because sometimes we are a little careless, and how to remove and change the dressing (F10).*

## CARE TO KEEP THE CATHETER DRESSING AT HOME

The families reported that they try to keep the SI-CVC dressing intact at home and were committed to being in the hospital on the days of maintaining the catheter, even outside the schedule, if necessary. The words that obtained the highest frequency of association in classes 2 and 6 were: **time, day, change, live and people**.

*[...] my greatest care is to keep the dressing, I try not to move it and when I need it, I come here, but sometimes she does the dressing and two or three days later she is already taking the dressing out (F4).*

*[...] there was a day that I could not handle, she came to the hospital and changed everything correctly, but it was so hot that when she got home she took everything out and then I had to go back to the Aquarium [an outpatient clinic] and change it again (F7).*

Despite all the reported commitment, the fact that many families live far from the hospital and the concern that the dressing will loosen, and it will not be possible to travel to the hospital immediately was described. In this way, they express that they would like to know what to do if the dressing is loosen at home.

*[...] I think there needs to have more information in the case of the dressing unstick, things like this, the care of people to know at least how to change the dressing if something happens and we cannot come (F7).*

*[...] it is also important to know what to do if you loosen the dressing, so that you can know what to do, because, for example, if it loosen up on a Saturday, what am I going to do? Change at home or wait for the next dressing change? (F8).*

## CATHETER FIXATION

The most frequent words in class 1 were: **place, catheter, and handle**. The text segments and the words that characterized this theme express how family members try to keep the catheter firmly fixed on the child's skin until the next dressing is performed at the hospital.

*[...] I place the adhesive tape around it, then, even if it is going off and I have one stuck on top and no longer handle it (F3).*

Although family members are careful to keep the catheter firmly attached to the skin, questions related to what to do if the catheter comes loose or ruptures were frequent.

*[...] in an emergency, is there anything I can do? At this moment, like the catheter is pulled, do I come running or do I handle it?(F3).*

## CARE FOR THE CATHETER DURING THE BATH

The words that obtained the most frequent association in class 3 were **remove, bath, wet** and reflect the concern to protect the catheter at the time of the child's bath, preventing it from getting wet.

*[...] for her to bathe, we put a plastic wrap on it, secure it with tape and we are very careful of that do not to get wet (F4).*

*[...] to bathe we pass plastic film on the chest and bathe from the waist down and then wash the arm (F9).*

In addition to taking care during the bath, family members also reported apprehension when children want to play with water, due to the increased risk of wetting it at that time.

*[...] when she wants to play with the dolls in the water, I take care not to get wet, so she does not get infected by bacteria (F5).*

## FEELINGS RELATED TO CATHETER COMPLICATIONS

In this theme, two classes were grouped for expressing similar subjects, being the words **fear, stay and sleep** referring to class 4 and **thing and way** referring to class 5. The families expressed their fears and anxieties regarding possible complications and accidents with the SI-CVC when the child is at home, according to the statements below:

*[...] I am afraid because she keeps getting up and down on the bed and then I am afraid the catheter be pulled, and something can happen (F6).*

*[...] I keep looking at the position she sleeps for I am afraid she will move and loosen the catheter and harm herself (F5).*

## DISCUSSION

The research findings showed family members' concern about hand hygiene, a fundamental action for the prevention of infections, which is relevant, as bloodstream infections related to central catheters are associated with important unfavorable health outcomes, and in Brazil they are responsible for a 40% mortality rate among patients with bloodstream infection.<sup>14</sup> Additionally, there is evidence of a relationship between the patient's age and catheter-related infection, that is, children, especially those under 10 years old, have higher rates of fever/bacteremia and infection.<sup>15</sup>

Bloodstream infections are serious events and cause prolonged hospital stay, increased costs and a high risk of morbidity and mortality. It is known that the risk of infection is significantly linked to the patient's main diagnosis, and children with leukemia have higher rates of this type of infection, when compared to children with other hematological diseases.<sup>16</sup> Thus, hand hygiene is a primary care, highly recommended for preventing catheter-related bloodstream infection<sup>14</sup> and has emerged as a concern of the participants about the home care of the child using SI-CVC.

Therefore, the nurse, in educational practices, must address the importance of hand hygiene, family members and children, emphasizing that this must be done with water and liquid soap when they are visibly dirty, otherwise, it is allowed to use alcohol preparation for the hands.<sup>14,17</sup>

Also highlighted by family members, maintaining the catheter dressing is important, as the integrity of the cover minimizes the possibility of infection and promotes protection of the puncture site, through the interface between the catheter surface and the skin, in addition to fixing the device in place, preventing its movement and also damage to the blood vessel.<sup>14</sup> Therefore, this topic is also a demand for information that needs to be considered in educational practices among families.

Changing the SI-CVC dressing in the home environment emerged in the participants' statements. This is a sterile procedure performed in the hospital environment by health professionals. At the research setting institution, it is done privately by nurses. On the other hand, in the home environment, the dressing can be loosened, making it possible for the family to do it, and for that it must be properly oriented and prepared, according to institutional protocols.

In a previous research, family members of children with permanent catheters underwent an educational intervention before

hospital discharge, in which data before and after the intervention were compared. It was noted that before the intervention there was more vulnerability to infection of the ostium and bloodstream.<sup>18</sup> Thus, it is essential to adopt educational practices in the preparation of hospital discharge for family members for this home care.<sup>19</sup>

In this way, making sure that family members are able to handle the dressing at home is essential to promote safety in care. The adoption of practices in this sense is based on the feeling of insecurity that families report performing technical procedures at home, as these are care performed primarily by nurses.<sup>20</sup> In this sense, the nurse's social role as an educator in the hospital discharge process is reinforced, especially with regard to teaching procedural care, seeking to reach the family's competence and autonomy for technical care in the home environment.<sup>21</sup>

As for the protection of SI-CVC in the bath, the family members mentioned the child's chest wrapping with transparent plastic film fixed with adhesive tape before the bath. This is an important care to be guided by the nurse, since it is recommended to cover the catheter with impermeable material, regardless of the type of dressing used on the child, such as, for example, transparent plastic film, to reduce the probability of organisms entering the catheter and, thus, to prevent the risk of infection.<sup>14,17,22</sup> Therefore, this topic also needs to compose the set of guidelines in the preparation of families.

Despite the recommendation not to wet the catheter, families seek to provide safer conditions for children so that games that contain water are not removed from their daily lives. Seeking strategies for children to play in adaptive conditions promotes ways of coping with the difficulties they experience.<sup>23</sup> Although adaptation strategies are adopted to promote the child's well-being in their daily play, some care should not be adaptable, such as example, playing in a swimming pool, bathtub or beach, as the submergence of the catheter in water is not indicated,<sup>14,17,22</sup> and this was also a theme identified in the analysis.

In addition to bathing, family members showed great concern to keep the SI-CVC always firmly attached to the skin, thus avoiding traction. The accidental rupture and removal and the consequent loss of the catheter imply losses for the child and his family, such as unnecessary invasive procedures, increased risk of infection and more discomfort. In addition, when prolonging the hospitalization period, hospital costs with bed, exams and procedures for monitoring the migrated part or its removal are increased.<sup>24</sup> Particular care should be taken with catheters with implantation time of less than 15 days, when there is a high risk of accidental removal and externalization of the cuff.<sup>15</sup>

In view of this analysis, the nurse has a fundamental role in carrying out educational practices, which are important instruments in the transition from hospital care to home care, especially in addressing the handling and specific care of devices.<sup>25</sup> For this, the themes emerging from the testimonies of family members

can be the starting point for the construction of contextualized educational practices that meet the real needs of children using SI-CVC and their families.

## CONCLUSION

By listening to family members of children with leukemia using a semi-implantable central venous catheter (SI-CVC), it was possible to identify topics for educational practices on home care for children with leukemia using a semi-implanted catheter for this audience.

Family members highlighted topics related to care regarding hand hygiene, maintenance, and fixation of the dressing, as well as mentioning care performed in the child's bath and games involving water, with the aim of not wetting the catheter site. In addition, they addressed the fear they feel with the possibility of some complication and accident with a catheter at home.

When identifying these themes, the nurse has the possibility to intervene in improving home care for these children, based on the real needs of these family members, contributing to provide them with more security in their experience. Thus, this research contributes to the incorporation of knowledge in the area of child and adolescent health, especially those with SI-CVC to improve their quality of life through health education among family members responsible for home care.

As a limitation of this study, the fact that the results reflect the daily reality of only a portion of family members is pointed out, which may not represent the totality of people who experience this universe. In this sense, it is recommended to carry out further studies to identify the demands for guidance needs of family members of children with other chronic diseases in addition to leukemia using SI-CVC, increasing its scope in order to contribute to the care practice of Pediatric Nursing.

## ACKNOWLEDGEMENT

Professional Master's Program in Nursing Assistance at *Escola de Enfermagem Aurora de Afonso da Costa* (EEAAC/UFF).

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