

# Information needs on self-care for children with leukemia for the creation of a mobile application

Necessidades informacionais sobre autocuidado de crianças com leucemia para criação de aplicativo móvel Necesidades de información sobre el autocuidado de niños con leucemia para crear una aplicación móvil

Vanessa Ramos Martins<sup>1</sup><sup>®</sup>; Fernanda Garcia Bezerra Góes<sup>11</sup><sup>®</sup>; Aline Cerqueira Santos Santana da Silva<sup>11</sup><sup>®</sup>; Eliza Cristina Macedo<sup>1</sup><sup>®</sup>; Laura Johanson da Silva<sup>1</sup><sup>®</sup>; Liliane Faria da Silva<sup>11</sup><sup>®</sup>

Universidade Federal do Estado do Rio de Janeiro. Rio de Janeiro, RJ, Brazil; "Universidade Federal Fluminense, Rio das Ostras, RJ, Brazil

#### ABSTRACT

**Objective:** to identify the information needs of children with leukemia regarding self-care for the creation of mobile applications. **Method:** qualitative research, carried out between November 2023 and January 2024 in a support home in Rio de Janeiro, Brazil, through semi-structured interviews conducted with ten children diagnosed with leukemia. Data was processed using IRAMUTEQ® software and interpreted using thematic analysis. Research protocol approved by the research ethics committee. **Results:** a total of five themes were identified as a result of the interpretative grouping of the seven classes of text segments related to information needs for self-care: treatment repercussions, diagnosis, chemotherapy, body care and the home environment, as well as desirable media in mobile applications, especially videos and games. **Conclusion:** the information needs described can facilitate the sharing of guidance in an attractive, playful and accessible way, generating possible positive contributions to the self-care process of these children.

Descriptors: Nursing; Child; Neoplasms; Educational Technology; Mobile Applications.

#### RESUMO

**Objetivo:** identificar as necessidades informacionais sobre autocuidado de crianças com leucemia para a criação de aplicativos móveis. **Método:** pesquisa qualitativa, realizada entre novembro de 2023 e janeiro de 2024 em uma casa de apoio no Rio de Janeiro, Brasil, mediante entrevistas semiestruturadas com dez crianças com leucemia. Dados processados no *software* IRAMUTEQ<sup>®</sup> e interpretados por análise temática. Protocolo de pesquisa aprovado pelo comitê de ética em pesquisa. **Resultados:** identificaram-se cinco temas resultantes do agrupamento interpretativo das sete classes de segmentos de texto relacionadas às necessidades informacionais para o autocuidado: repercussões do tratamento, diagnóstico, quimioterapia, cuidados com o corpo e ambiente domiciliar, além das mídias desejáveis em aplicativos móveis, com destaque para vídeos e jogos. **Conclusão:** as necessidades informacionais descritas podem facilitar o compartilhamento de orientações de forma atrativa, lúdica e acessível, gerando possíveis contribuições positivas no processo de autocuidado dessas crianças. **Descritores:** Enfermagem; Criança; Neoplasias; Tecnologia Educacional; Aplicativos Móveis.

#### RESUMEN

**Objetivo**: identificar las necesidades de información sobre el autocuidado de niños con leucemia para crear aplicaciones móviles. **Método**: investigación cualitativa, realizada entre noviembre de 2023 y enero de 2024 en una casa de apoyo en Río de Janeiro, Brasil, mediante entrevistas semiestructuradas a diez niños con leucemia. Los datos fueron procesados en el *software* IRAMUTEQ<sup>®</sup> e interpretados mediante análisis temático. El protocolo de investigación fue aprobado por el comité de ética en investigación. **Resultados:** se identificaron cinco temas resultantes de la agrupación interpretativa de las siete clases de segmentos de texto relacionados con las necesidades de información para el autocuidado: repercusiones del tratamiento, diagnóstico, quimioterapia, cuidado del cuerpo y del ambiente domiciliario, además de medios que se espera que estén presentes en las aplicaciones móviles, principalmente videos y juegos. **Conclusión:** las necesidades de información descritas pueden facilitar el intercambio de orientación de forma atractiva, lúdica y accesible, y generar posibles contribuciones positivas al proceso de autocuidado de estos niños.

Descriptores: Enfermería; Niño; Neoplasias; Tecnología Educacional; Aplicaciones Móviles.

## INTRODUCTION

Over the years, cancer has become one of the leading causes of death by disease in children worldwide, ranking second among all causes of mortality in this population. According to the latest data from the World Health Organization's International Agency for Research on Cancer (WHO), approximately 280,000 people aged between zero and 19 are diagnosed with cancer every year worldwide. In Latin America, it is estimated that this figure reaches at least 29,000 children a year<sup>1</sup>.

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Corresponding author: Vanessa Ramos Martins. Email: vanessa0205@msn.com Editor in Chief: Helena Gallasch; Scientific Editor: Juliana Amaral Prata



The National Cancer Institute (INCA) estimates that approximately 8,000 new cases of childhood cancer will be diagnosed in Brazil by 2025. Early detection and appropriate treatment result in a cure rate of around 80% and a mortality rate of 8% for children and adolescents in the country<sup>2</sup>.

Leukemia is the most common childhood cancer, with around 11,000 cases diagnosed every year in Brazil, according to the latest information available<sup>3</sup>. According to the Brazilian Society of Pediatrics, acute lymphoid leukemia is the most common type of leukemia, accounting for around 80% of cases today. This type of leukemia is up to four times more common than acute myeloid leukemia, which accounts for 15% to 20% of cases. Chronic myeloid leukemia is rare in children, with an incidence of around 2%<sup>4</sup>.

Leukemia affects the hematopoietic system, impacting the bone marrow's production of white blood cells, which are responsible for fighting infections. While acute myeloid leukemia and chronic myeloid leukemia affect the myeloid cells, acute lymphocytic leukemia and chronic lymphocytic leukemia affect the cells of the lymphatic system. These four types constitute the most recurrent groups of leukemia in children<sup>5</sup>.

The impact of leukemia diagnosis and treatment on the child's life and daily life can be measured by the need for multiple pieces of information that are essential for maintaining family care and the child's own self-care in the home environment. Significant changes in the family routine occur when a child with leukemia is at home, including the need for special feeding, daily medication administration and the use of adaptive technologies such as catheters<sup>6</sup>. These changes essentially involve adaptive adjustments in self-care that are crucial to preventing complications and ensuring survival, especially outside the clinical environment. Therefore, involving children in managing their own self-care makes them feel important in the therapeutic process, and improves adherence to treatment and quality of life<sup>7</sup>.

Considering that self-care involves the ability of the child and their family to adopt practices aimed at promoting or maintaining health, or even managing a condition of illness, it is essential to pay special attention to children whose childhood development occurs in the context of chronic conditions, such as cancer. However, despite the importance of self-care for the health-disease process and for promoting health over time, children are not always involved, and information is often passed on by health professionals directly to guardians and caregivers, excluding the child from decision-making. However, the literature highlights the importance of involving children in the whole process, with family support, adapting to individual needs related to individual development<sup>8</sup>.

The nursing team must share safe and reliable information so that children with leukemia can make assertive self-care decisions. Empowerment for self-care in cancer treatment develops throughout the therapeutic process, so it is crucial to guide and prepare children and their families from the outset. Ongoing support can significantly improve treatment outcomes<sup>8</sup>.

Health education is therefore a strategy used by nurses to enhance care through educational activities aimed at stimulating self-care through the patient's own daily experiences and attitudes<sup>9</sup>. In this context, the creation and implementation of educational technologies are efficient and effective ways of sharing guidance, supporting children with leukemia and their families with safe information about the best care at different treatment stages<sup>6</sup>.

Educational technologies facilitate contact between health professionals, family members and/or patients when they use language appropriate to the target population, as well as accessible illustrations and design/layout, and are adapted to the local culture. They increase motivation for learning and provide a gateway to relevant and reliable information<sup>10</sup>.

Research carried out in Brazil revealed that there are 464 million digital devices in use, with smartphones dominating not only in sales, but also in banking, shopping and social media<sup>11</sup>. The growing use of electronic devices and the internet is increasing in our country, especially among children and young people<sup>12</sup>. However, data from the Brazilian Institute of Geography and Statistics highlights disparities that reflect socio-economic inequalities between Brazilian regions. In 2022, there was a greater lack of access to the internet and mobile telephony in the North and Northeast regions, especially in rural areas, where cell phone ownership was 90.8%, compared to 97.4% in urban areas<sup>13</sup>.

A study carried out among children and adolescents found that 35% of those interviewed searched for information related to health and well-being on the internet, covering topics such as diet, disease treatment, physical exercise and medication, demonstrating the relevance of the internet as a source of support for dealing with health issues<sup>12</sup>.

Therefore, while on the one hand there is an important discussion about the negative impacts of cyberdependence on childhood and the repercussions of excessive use of screens on human development, on the other, it is understood that the intelligent and appropriate use of information and communication technologies can represent significant advances, functioning as a learning resource for contemporary childhood, increasingly inserted in the digital scenario<sup>14</sup>.





Considering the beneficial potential of technologies in childhood, especially in the context of the growing use of smartphones, the creation of educational technology aimed at children must consider their individual needs and ensure their participation from the outset<sup>6</sup>. In areas with greater access to cell phones and the internet, mobile apps stand out as a suitable tool for children, offering accessibility, interactivity and personalization, which makes the learning process more engaging and effective. By giving a voice to children with leukemia, it is possible to identify emerging themes from their daily lives, ensuring their active participation in the process of creating educational technology<sup>15</sup>.

Involving the end user in all phases of building technological resources can reduce challenges and increase the therapeutic impact of these tools, to ensure their effectiveness, efficiency, satisfaction and usability. In addition, interventions through mobile digital solutions, taking into account users' perspectives, can make them more inclusive and accessible, contributing to improved health outcomes<sup>16</sup>.

Despite the topic's relevance, there is a scarcity of studies in scientific literature on the information needs of children with leukemia for the design of mobile applications focused on self-care. This gap highlights the importance of adopting a more inclusive, participatory and targeted approach that actively involves the end user in the development process of technologies, including mobile applications aimed at children with leukemia. It should be emphasized that research in which the target audience is involved in generating data and solving problems makes use of identifying the everyday know-how of those involved in order to promote social change<sup>15</sup>.

Considering this research gap, the guiding question of this study is: "What are the informational needs on self-care of children with leukemia for the creation of mobile applications?"

From the perspective of Dorothea Orem, the theoretical reference for this study, self-care is understood as the practices performed to maintain life, oriented towards an end goal, involving decision-making and actions that result in engagement in treatment. These practices can be affected by various factors, such as daily life habits, environmental, cultural and socio-economic factors<sup>18</sup>. Orem's theory contributes to understanding the importance of children with leukemia actively participating in the planning and execution of their self-care practices, reinforcing the importance of a personalized, patient-centered approach, including the creation of educational technologies such as mobile applications. In this study, self-care is reinforced by the role of children in identifying their own information needs.

The aim was to identify the self-care information needs of children with leukemia in order to create mobile applications.

# METHOD

This is a qualitative, exploratory-descriptive study, following the guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ), with data collection carried out between November 2023 and January 2024.

The setting consisted of a support home located in Rio de Janeiro/Brazil, for children, adolescents and their families who live outside the state capital during cancer treatment. This is a non-profit organization, established in Brazil in 1994, with offices all over the world. The infrastructure includes living areas, recreation, food and daily care. This setting was selected because of its capacity to accommodate several children and because it provides an environment outside the hospital context, making it easier to identify their information needs.

The sample was selected for convenience and the participants were chosen based on the guest list managed by the social worker, taking into account the following inclusion criteria: being aged between six and twelve incomplete years; having been diagnosed with leukemia; having started treatment; and being aware of their diagnosis. This age group was chosen considering the transition of care responsibilities, where children begin to develop skills to get involved and share new tasks, demonstrating competencies and responsibilities, as well as beginning the phase of independence in self-care<sup>20</sup>. Children who were absent from the research site for examinations or procedures, as well as those unable to verbalize their needs, were excluded.

Data collection was carried out by prior appointment in collaboration with the institution's social worker, a professional who plays a key role in organizing the patients, controlling the guest list, which details information such as entry dates, length of stay, room allocations, responsible companions and other relevant data such as the children's age and diagnosis. The first contacts with the children and their guardians were brokered by the social





worker in the afternoons, as in the mornings they are sent to the base hospital for tests, therapies and/or consultations, returning to the support home afterwards.

After agreeing to take part, the child and their guardian were taken to a private meeting room, thus guaranteeing the necessary privacy. During the interview, only the researcher, the child and their guardian were present. The researcher, the first author, identified herself as a nurse and a master's student, supervised by the doctoral professor, the second author, with expertise in research of this nature. After presenting her credentials, she explained the aims of the research and formally invited family members and children to take part in the study. It should be noted that the family members acted as mediators for the children's participation in the study, in terms of consent and monitoring, and the children were the participants interviewed.

The data was obtained through semi-structured interviews, guided by a script constructed by the authors. The pilot test with the first two children was included in the sample, and no changes were necessary. The interviews were carried out until the theoretical saturation of the data, with ten children, at which point no more relevant information emerged from the participants' answers. In this way, the qualitative validity standards of completeness, representativeness, homogeneity and relevance of the data were met<sup>21</sup>.

It took five visits to the scenario, one a week, to allow new families to be admitted, avoiding a repetition of participants interviewed. It was not possible to give the study results back to the participants, since the application, which will meet the information needs identified, is still being developed and validated by experts. Subsequently, the app will be evaluated by the target audience itself.

None of the children refused to take part or dropped out during the process. During the interviews, some of the children were initially shy, but were encouraged by their guardians to communicate with the researcher. It should be noted that the children developed a dialog with the researcher in order to identify their information needs, in an autonomous and participatory way.

In addition to the interviews, the children themselves answered a brief sociodemographic questionnaire, containing the variables age, gender, leukemia diagnosis, time since diagnosis and school situation. The interviews, conducted only by the first author, explored aspects related to the self-care of children with leukemia and their preferences for a mobile app, using the following questions: 1) What would you like to know about your care? 2) Would you find an app interesting to learn about the care you need to take about your health? 3) What would you like this app to look like? 4) What would you like this app to have?

The interviews, which lasted a mean of 21 minutes, were recorded using the Records® application on a smartphone belonging to the researcher for later transcription and analysis. The transcriptions were made entirely in Microsoft Word® and the data was then processed using the software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (IRAMUTEQ®), which offers a range of multidimensional analysis techniques, facilitating the interpretation of the material with methodological rigor<sup>22,23</sup>.

The corpus to be analyzed was built from the interview transcripts, each of which was a text, separated by command lines. The data was then run through the analysis techniques available in the software, generating text segments which are the main units of analysis.

This study used the word cloud, which visualizes the most frequent terms in the text, highlighting the most relevant ones in a central and larger way. The analysis of classic textual statistics was used to identify the number of words, average frequency of words and hapax (words with a single occurrence).

Similarity analysis was also used to identify recurring patterns and content groupings, revealing connections between different words and text segments. Finally, descending hierarchical classification (DHC) made it possible to organize the text segments into semantic classes, providing a deeper understanding of the structure and meanings present in the data. In this analysis, words with a  $\chi^2$  greater than or equal to 3.84 (p<0.05) in each of the classes were used as a selection criterion, as this determines a strong association between the words in the classes, especially those with p<0.0001, which reveals a high association<sup>22,23</sup>. In the analyses, the lemmatization process was used to reduce the words to their roots. In addition, adverbs were eliminated from the active forms, which made the analytical process more objective, allowing a clearer focus on the keywords relevant to the study.

After processing the data, the results were interpreted using thematic analysis<sup>24</sup>. By carefully reading the text segments, inferences and interpretations of the data were made, identifying the core meanings of the responses, which enabled an in-depth understanding of the study object.



All ethical aspects were taken into account, and the research protocol was approved by the research ethics committee of the proposing institution. Participants who agreed to take part voluntarily signed an informed consent form, while their guardians signed an informed consent form. The anonymity of the participants was preserved using alphanumeric codes, and strict security measures were implemented to protect the information, including storing the data on password-protected servers and restricting access to authorized research staff only.

## RESULTS

The study included ten children, five girls (50.0%) and five boys (50.0%). The mean age was 8.4 years, ranging from six to 12 incomplete years, which corresponds to the intended extremes. Most of the children were diagnosed with leukemia in the same year as the interviews (60.0%), while two children were diagnosed in the previous year (20.0%) and another two three years ago (20.0%). All the children interviewed were away from school due to treatment.

After processing in the IRAMUTEQ<sup>®</sup> software, the textual corpus was made up of 10 texts from the children's interviews, totaling 1,195 terms, of which 307 were distinct forms. Of these, 168 (14.06%) occurred only once (hápax), with a mean of 119.5 occurrences per text.

The word cloud included words that appeared at least five times in the text corpus. The most recurrent terms included video (n=15), care (n=14), stay (n=14), know (n=13), find out (n=11), year (n=11), only (n=9), like (n=9), talk (n=9) and school (n=9). These terms were highlighted as central and largest in the cloud, providing a clear view of the predominant keywords in the interviews with the children. The letter "f" refers to the occurrence frequency of each term in the textual corpus, i.e. how many times the word was mentioned in the interviews (Figure 1).



Figure 1: Word cloud and similarity analysis of the text corpus. Rio de Janeiro, RJ, Brazil, 2024.



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In the interpretative process, the most recurrent word "video" showed that children with leukemia pointed to videos as one of the most attractive ways of learning about self-care. The term "care", together with "stay", was the second most recurrent, highlighting the importance of guidance on the care needed during leukemia treatment. For the children interviewed, videos on mobile applications about care are important as they can add visual and audio information in a dynamic and attractive way.

The similarity analysis also included words that appeared at least five times in the textual corpus, making it possible to identify their interconnections and helping to understand the structure of the lexical content. The analysis revealed that the textual corpus is distributed in seven distinct halos, which are connected by the thickest central line through the most recurrent words, which emphasizes the strong correlation between these words. From the most relevant terms, branches were formed with other words that also connected with the words within the halos. It should be noted that the word cloud and the similarity tree are generated at different times during textual processing in the IRAMUTEQ® software. However, in this study, they were combined into a single figure by the authors, to make it easier to understand the study object.

The strong connection between the terms "child", "stay", "treatment", "find", "like", "cell phone", "play", "video", "catheter", "care", "know" and "talk" reflects the main objective of the interviews with the children. This indicates that they are interested in using mobile applications to watch videos and play games, and that they find it interesting to obtain information and talk about treatment and specific care, such as the use of catheters, through the media mentioned.

The first halo, in red, shows words that are interconnected with a sense of the need for knowledge. It includes "child" and "mother", who is presented as the main caregiver during the treatment process. Other terms, such as "learn", "eat" and "game", are close to the thicker branch, indicating the importance of learning food-related knowledge for one's own health. The word "game" stood out as a particularly attractive way to meet the information needs of this target audience, including guidance on food, as well as hygiene and medication.

In the yellow halo, the connection between the words "stay", "need", "chemotherapy" and "food" also indicated informational needs for self-care, such as guidance on the types of chemotherapy and the appropriate foods that children can eat during treatment. In addition, the terms "fever", "alone", "fall", "give, "reaction" and "mucositis" are interconnected in branches within the same halo.

The pink halo is connected by the terms "being" and "treatment", with ramifications for "nausea" and "treatment". Thus, in the interpretative process, it was found that children consider it important to know the possible symptoms and reactions to treatment, such as fever, nausea and mucositis. The central halo, in blue, indicated a process that all the children interviewed had to go through, involving the terms "feel", "discover", "leukemia", "stop", "school", "8\_years", "year" and "home". The diagnosis of leukemia meant that they had to leave social life behind, especially school, forcing them to devote more time to treatment.

The intersection between the previous halo and the light green halo highlighted an activity that the children often do due to the time away from school and other activities during treatment: using their cell phones. The terms identified indicate that children use cell phones to play games, as demonstrated by the strong link between "like", "cell phone" and "play," and it is also one of the desirable ways for them to learn about their self-care, based on their informational needs. These terms are also associated with "good" and "purple," one of the colors mentioned to help build educational technology.

The purple halo indicates the words "video" and "catheter," with branch distributions for the terms "show" and "pass," indicating the need for information about devices, which can be semi- or fully implanted during chemotherapy, with the help of educational videos. Colors such as "pink" and "blue", also considered to be preferred by children, were flagged for incorporation into apps.

The last halo, represented by watery green, groups together terms that are strongly interconnected, enabling a more comprehensive understanding of the information needs of the children interviewed in this study, reinforcing issues related to food, chemotherapy and their consequences. Thus, the terms "knowledge", "care", "talk", "body", "food", "immunity" and "form" emerged as essential elements, highlighting the main areas of self-care that require special attention.

Using the Reinert method, the CHD dendrogram was generated with seven textual classes, achieving a score of 84.21% (Figure 2).





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Figure 2: Text corpus dendrogram. Rio de Janeiro, RJ, Brazil, 2024.

The class with the highest percentage was class 2 (gray), with 18.8% of the text segments, followed by class 3 (fluorescent green) with 15.6% and class 7 (pink), also with 15.6%. Other classes include class 4 (green), class 1 (red), class 5 (light blue) and class 6 (dark blue), each representing 12.5% of the text segments.

The software first divided the corpus into two sub-corpuses. The first was split twice, with class 7 in one and classes 4 and 3 in the other. The second subcorpus gave rise to two groupings: one made up of classes 1 and 5, and the other of classes 2 and 6. The relationship between the classes in the dendrogram is read from top to bottom, where the divisions correspond to segments of text with similar mean vocabulary frequency, but different between the classes.

This grouping of classes proved to be a b3-alanced distribution of responses, revealing more details about the information needs of the children interviewed. Figure 3 shows the results of interpretative grouping.

In the analytical process, conducted carefully by the authors, five themes were identified as a result of the interpretative grouping of the seven text segment classes organized into two blocks by IRAMUTEQ: Block 1: Leukemia treatment repercussions (class 3); Media for educational technology (classes 4 and 7). Block 2: Leukemia diagnosis (class 2); Chemotherapy care (class 5) and Care of the body and environment at home (classes 1 and 6).



Block 1			
Themes and classes	Associated words	Information needs on self-care	Topics to be covered in the app
Repercussions of leukemia treatment	To be, to stay	Information on process expectations for treatment	<ul> <li>What is expected during the treatment period</li> </ul>
(class 3)			- Emotions about expectations for treatment
			<ul> <li>The hospital environment for procedures and treatment</li> </ul>
Media for educational technology (classes 4 and 7)	Game, child, people, pass, only	Media that facilitate learning	<ul> <li>Use of media such as games and videos in educational technology</li> </ul>
Block 2			
Themes and classes	Associated words	Information needs on self-care	Topics to be covered in the app
Leukemia diagnosis (class 2)	Treatment, 8 years, year, stop, school, discover, feel, start	Identifying signs and symptoms in your own body	<ul> <li>Signs and symptoms that indicate the need to see a health professional</li> <li>Changes needed to support treatment</li> </ul>
Chemotherapy precautions (class 5)	Purple, taste, chemotherapy	Chemotherapy reaction and how to proceed with post- chemotherapy self-care	<ul> <li>Types of chemotherapy</li> <li>Post-chemotherapy symptoms</li> <li>Self-care during chemotherapy</li> </ul>
Body and environmental care at home (class 1 and 6)	Catheter, home, care, body, eat, feel, thing, know	Body hygiene Eating habits Maintenance of the semi-	<ul> <li>Self-care: body hygiene, nutrition</li> <li>(food), hydration</li> <li>The need to use a semi- or fully</li> <li>implanted catheter and its care</li> </ul>

Figure 3: Identified themes to be used in building the mobile app. Rio de Janeiro, RJ, Brazil, 2024.

### Leukemia treatment repercussions

From class 3 onwards, the child's perspective revealed the need to share detailed information and expectations before treatment. Aspects such as trips to the hospital, skin reactions, hemodynamic instability, general symptoms of malaise and treatment details only being discovered when they actually occurred were mentioned. The words with the strongest associations in this class were: be and stay.

*I itched all over and my skin turned red. My blood pressure, heart rate and saturation dropped, and the chemotherapy had to be stopped because I had a reaction. (C4)* 

[...] feeling unwell, tired. In hospital I felt weak in my legs. (C5)

The children therefore expressed a desire for clear and detailed information about what lies ahead, in short, the repercussions of leukemia treatment on their lives. They stressed the need for prior knowledge in order to be better prepared and not be surprised by possible procedures such as catheter placement, side effects and adverse reactions to treatment, emphasizing the importance of including this information in mobile applications.

No, I didn't know. It's better to talk about what you might feel with the treatment. (C9)

Catheter... I only found out I had to have it put in after I was in hospital. (C8)

They show videos telling the story, showing what they have to do, what they've been through and what they're going to go through soon. (C5)

[...] the child knows what immunity is, red blood cells, platelets, potassium too. (C1)

### Media for educational technology

According to classes 4 and 7, the words with the most significant occurrences were: game, child, people, pass and only. Thus, the children expressed a preference for information content in video format due to its entertainment capacity and ease of understanding. They highlighted their liking for mobile games and videos, emphasizing that these forms of media are more dynamic and attractive.

I like playing games on my cell phone. I like watching videos. It's better on video. (C2)



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I think in video form is better because there are people who don't have the patience to read and in video it would be the easiest way to pass on the information. The care you have to take, because you have to be very careful. (C5)

I like using my cell phone, playing games and watching cartoons. (C7)

*I like playing games on my cell phone. Something to get the children excited. A video to show the children so they don't get so discouraged. (C8)* 

With educational support, the media identified by the children interviewed, such as games and videos, reflect resources to improve the learning experience in the use of applications to be developed containing, for example, guidance on hygiene, food and medication.

A video would be the easiest way to convey the information. I think a question-and-answer game. It should be linked to the problem. And even the answer could help, because you might get it wrong, and the right one appears. (C5) The game is something that makes us learn everything. Hygiene, food, medication. (C6)

### Leukemia diagnosis

Class 2 analysis revealed the words: treatment, start, feel, find out, school and stop. These words pointed to the children's individual experiences with the disease and referred to the initial leukemia signs and symptoms for each of them and, above all, the need to withdraw from school activities.

I found out when I was 12. I only went to school until the day I got sick. (C5) I found out when I was six. I stopped going to school, went on vacation and got tested and it showed. (C9) I want my little school back. I like going to school and now I don't. (C10) Now I'm not going so I can have treatment. (C4)

In particular, the frequent mention of the word "school" pointed to a very important issue: the need to be away from school activities due to the leukemia diagnosis. The stories resonated with feelings of anguish and worry, as they recalled the signs and symptoms that triggered the medical investigation and disease confirmation.

I found out I had leukemia when I was seven. I had to stop going to school. I got a bit sick." (C2)

[...] how it started too, what happened when I found out I was ill. A little purple spot on my body. (C7)

Despite having been diagnosed and having already started treatment, many reported that they had no prior knowledge of the disease's signs and symptoms and stressed that they considered it important for apps to include information about this in order to alert family members to seek professional help. One child specifically mentions sore throat, fever and weight loss as indicators that can signal the need for leukemia treatment, and which could be included in educational technology.

[...] how to find out if you need treatment. Sore throat and fever. Pain in the throat and fever, if you feel you're losing weight. Because then the child can get sick, alerting the father and mother too. (C8)

### **Chemotherapy precautions**

In class 5, from the child's perspective, there was a need to obtain information about the different types of chemotherapy and the possible treatment side effects. Aspects such as neuropathy, adverse reactions, hemodynamic instability and general symptoms such as fever, malaise and tiredness were mentioned. The words with the strongest associations were: purple, taste, chemotherapy.

I don't know if the doctors tell the mothers this, but there was chemotherapy I had that we only found out afterwards that it caused neuropathy. (C1)

[...] the chemotherapy I had, the names. Everyone has a different reaction. (C5)

The children interviewed reinforced the importance and need for concise information about the signs and symptoms they may experience during leukemia treatment, as well as the types of chemotherapy.

Can you talk about the chemotherapy symptoms and what can happen? (C2) What you have to do when you have chemotherapy. The type of chemotherapy. (C10)

### Body and environmental care at home

In classes 1 and 6 analyses, the words that appeared most frequently were: catheter, home, care, body, eat, feel, thing and know. Thus, the children highlighted the importance of learning about self-care at home. They emphasized





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the need to learn about caring for the body, especially in relation to food and hygiene, as well as preparing the home environment.

They also mentioned the need to avoid certain foods, such as dairy products with live lactobacilli, pepperoni, ham, bologna, pork and sausage, as well as raw foods, due to the potential health risks during chemotherapy. These findings include fundamental elements such as adequate food and water intake, which are essential for well-being and maintaining life.

[...] food, Chamyto® is not suitable because it has live lactobacilli, with low immunity it's not allowed. (C1)

[...] some care with food. You know what you can and can't eat. I know I can't eat pepperoni. They said I could eat everything. (C3)

[...]bBe careful with food. You can't eat ham, bologna, pork, sausages. (C7)

[...] you have to drink a lot of water; you can't eat raw food. You could say that you have to drink water to get rid of all the chemicals in your body. (C4)

[...] food you can eat, take care of your body. (C8)

[...] mucositis too, what you can eat with mucositis. (C1)

The importance of consuming an adequate amount of water to help eliminate chemical substances from the body during chemotherapy treatment was emphasized. These observations highlight the importance of dietary guidelines in applications in order to minimize complications during the recovery process. Attention to personal hygiene, medication administration, mask use, treatment time and preparation of the home environment (especially in the context of transplantation) were also mentioned as important points, highlighting the relevance of useful information in apps for the self-care of this public.

[...] hygiene, food, medication. The treatment time. The house, because when you have a transplant, the house needs to have a suitable pan, there must be no mold, no dust, no humidity. The pot has to be aluminum." (C6)

[...] there's the care after you leave here and go home. (C10)

[...] the care you have to take, because you have to be very careful. Because immunity goes down, everything goes down and you have to wear a mask, so you don't catch any bacteria. (C5)

Still from the perspective of bodily self-care, the children also pointed out the importance of learning in the apps about catheter care (semi-implanted or fully implanted) during leukemia treatment. They highlighted the need to avoid getting the catheter wet and to perform the appropriate dressings to ensure its integrity and functionality. In addition, they mentioned the late discovery of the need to have the catheter inserted, stressing the importance of receiving advance information about this need and understanding that it does not cause pain.

How to look after the arm catheter and the semi-implanted catheter (C1)

[...] with a catheter you can't get it wet, it doesn't hurt, you keep the dressing on. My catheter has two curled ends. (C4)

[...] and inside there will be a video about having to put in a catheter, that it's important to take care of this catheter. (C7)

# DISCUSSION

Based on the results, it was possible to identify the information needs related to self-care of children with leukemia to support the development of mobile applications. This data provided insights into the content and resources desired by the children, highlighting their interest and need for active participation in their health-disease process. A study at a pediatric oncology outpatient clinic in Japan highlighted the importance of children understanding their illness, pointing out that a lack of information leads to anxiety when dealing with the diagnosis<sup>25</sup>.

Participants in the study showed that they used smartphones, in line with data from the 2023 survey on internet use by children and adolescents in Brazil (ICT Kids Online Brazil), which indicated that 82% of children and adolescents watched videos, programs, films or series. In addition, 82% used the internet to carry out school research and 59% played online games<sup>12</sup>, which reinforces the findings and the relevance of the current study.

The use of mobile applications can increase the ability to support patients with chronic diseases, strengthening their skills in identifying signs and symptoms, control, intervention and co-participation in their care, as emphasized in the study carried out in Iran<sup>26</sup>. This confirms the importance of studies aimed at developing mobile health applications for children with leukemia, based on their specific needs.





It is essential, however, to consider the importance of broadening children's access to digital technologies, so that everyone can benefit from the opportunities they and the internet offer. To do this, it is essential to address the inequalities that limit this use and adopt the perspective of meaningful connectivity<sup>12</sup>. In addition, it is recommended that health professionals do not restrict guidance on self-care to this type of resource, neglecting individual and collective actions carried out in person.

The findings indicate that children are interested in multimedia and entertainment, especially videos and games. In the digital age, the use of digital content, such as audiovisual resources, facilitates the understanding of knowledge, learning and promotes quality of life, coping with the disease and autonomy in self-care, as mentioned in the study on the development and validation of an educational video aimed at hypertensive children carried out in São Paulo, Brazil<sup>27</sup>.

Educational videos can facilitate the sharing of information on self-care practices and contribute to the early identification of the condition. In addition, educational interventions based on videos can improve interaction with children and their families, promoting a more effective understanding of health guidelines. Videos, with their audiovisual dynamics, make knowledge sharing more accessible and engaging, especially for children with leukemia<sup>28</sup>.

Educational interventions based on videos are effective tools for facilitating learning and can be directed at various areas, such as medication adherence and identifying signs and symptoms in chronic diseases, as demonstrated in a study carried out in the United States of America<sup>29</sup>. Research also highlights the usefulness of videos in reducing the need for anesthetic interventions in children undergoing radiotherapy, with proven effectiveness in almost all cases<sup>30</sup>. Videos are therefore attractive, communicative educational tools that enable active participation in the teaching-learning process<sup>31</sup>.

Another relevant aspect is children's interest in games. This type of media can offer a facilitated form of learning, seeking to achieve various objectives, including changes in behavior for the sake of quality of life and health maintenance<sup>32</sup>. A study carried out in Lithuania highlights the concept of "Serious Games", designed not only for entertainment, but also with a focus on education, training and/or health promotion. These games are increasingly being developed based on scientific evidence, aiming to provide motivation and engagement in healthy habits<sup>33</sup>. This benefit was evidenced by a study carried out in Poland, which highlighted the positive impact on the biopsychological well-being of children undergoing cancer treatment through physical activities provided by interactive video games<sup>34</sup>.

In the past, children were often protected from knowing about their diagnosis and the reality surrounding it, both by their families and by the healthcare team, in order to preserve them from unfavorable prognoses and invasive procedures, due to uncertainties about the children's ability to understand<sup>35</sup>. However, the interviews revealed a growing and significant demand for direct communication with children. They have identified the first signs that led to an unfavorable diagnosis and value transparency and involvement in managing their own health condition.

By realizing the importance of taking care of themselves during and after treatment, children can benefit significantly from mobile applications that present information in an accessible and motivating way. Thus, nursing plays a crucial role in offering support in health education, using technological tools developed based on children's specific self-care needs. By integrating videos and games into the apps, nurses can provide personalized and engaging guidance, facilitating both the understanding and practice of self-care by children with leukemia<sup>36</sup>.

Involving children in the management of their own health leads to better effectiveness and adherence to treatment at home. From this perspective, data from a study conducted in Sweden during the transition period from hospital to home shows that children feel comfortable maintaining their daily routines while receiving care at home<sup>37</sup>. However, involvement in life-sustaining strategies raises questions and challenges, as the interview results show. Information on bodily hygiene, nutrition, chemotherapy and maintenance of the semi-implanted catheter was identified as crucial to these children's quality of life and were topics they wanted to see in mobile apps.

This study's results therefore highlight the importance of providing children with guidance on leukemia treatment, including what to expect during the process, especially in relation to chemotherapy, its types and potential side effects. The findings are in line with a study carried out in Brazil, which revealed children's perceptions regarding the use of chemotherapy, where nausea and vomiting were identified as the most recurrent symptoms, directly impacting their daily routines and activities<sup>38</sup>.





Hygiene practices are equally crucial and are directly associated with quality of life. These routines include skin care, including the use of cleaning products, moisturizing and protection, as well as maintaining oral hygiene to prevent infections during chemotherapy treatment and possible systemic complications related to lesions in the mouth. These findings, identified in the interviews, are in line with a study carried out in the Amazonas state in Brazil<sup>39</sup>.

In line with the results presented, a study conducted in Rio de Janeiro, Brazil, identified important aspects related to feeding children with leukemia, such as the need to consider different moments and specific challenges, such as feeding the child during periods of neutropenia, nausea and vomiting, dysgeusia, mucositis, constipation and diarrhea. In addition, the study highlights the importance of hygiene and proper food preparation to ensure the safety and health of these children<sup>40</sup>.

Concerns related to the semi-implanted catheter arise from the moment patients are confronted with the need for its insertion, extending to returning home with the device. These concerns, highlighted by the children, cover various aspects, such as hygiene care, maintenance of the bandage, the possibility of needing to change it, proper catheter fixation and the fear of accidental exteriorization. In addition, there are concerns about care during bathing to avoid getting the catheter wet, doubts about carrying out daily activities and what limitations are necessary. These themes, which can be included in apps, were also identified in a study carried out in an oncohematology service<sup>41</sup>.

Mobile apps should provide clear and accessible guidance, as well as interactive features, to make learning more engaging, in order to empower children to play a more active role in their own health care, thus promoting a better quality of life during leukemia treatment. The informational needs identified in this research are crucial to the development of mobile applications aimed at these children. These themes reflect the individual needs and responsibility that these children have in managing their own health and quality of life. Therefore, apps should be designed in such a way as to address these issues comprehensively, offering information and practical resources to help children cope with the specific challenges associated with leukemia treatment.

## **Study limitations**

A study limitation is that the results reflect the reality exclusively of children with leukemia undergoing treatment, who are in a support home in a large urban center. This limited sample may not adequately represent the diversity of experiences and challenges faced by other children with this diagnosis in different treatment contexts, such as hospitals or homes, and in situations of greater social and digital vulnerability, where access to mobile devices and the internet may be restricted. Thus, new studies with an expanded scope, including a variety of treatment and home contexts and different patient groups, are needed to provide a more comprehensive and representative understanding of the information needs of children with leukemia.

# CONCLUSION

It can be concluded that the self-care information needs of children with leukemia mapped in this study with a view to creating mobile applications were related to diagnosis and the repercussions of treatment, as well as care for the body and the home environment in the face of chemotherapy, in addition to the types of media desirable in mobile applications, with an emphasis on videos and games.

These resources should address the various information needs identified in a playful way, including guidance on diagnosis, signs and symptoms of leukemia, types of chemotherapy with their side effects and adverse reactions, maintenance of the semi-implanted catheter, as well as care for body hygiene, nutrition, hydration and the environment.

Making this information available in mobile applications through videos and games can facilitate the sharing of guidelines in an attractive and dynamic way, generating possible positive contributions to the self-care process of these children.

The voices of the participating children highlighted the need for self-care information, indicating that they need to be considered as active agents in self-care, with the support of their family caregivers, in order to face the changes and challenges imposed by leukemia and its treatment.

This study contributes significantly to the advancement of research in the child health area, especially for children with leukemia, seeking to improve their quality of life. Its contribution lies in the demarcation of important information needs that need to be addressed in an accessible and entertaining way, aimed directly at children, and





which could serve as a basis for educational actions or technologies. In addition, it enables the development of mobile applications based on the principles of medium-intensity participatory action research, in which the target audience is involved from the conception of the technology, incorporating themes that emerge from everyday experiences.

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## Author's contributions

Conceptualization, V.R.M. and F.G.B.G.; methodology, V.R.M., F.G.B.G., A.C.S.S.S., E.C.M., L.J.S. and L.F.S.; software, V.R.M. and F.G.B.G.; validation, V.R.M. and F.G.B.G.; formal analysis, V.R.M. and F.G.B.G.; investigation, V.R.M. and F.G.B.G.; resources, V.R.M. and F.G.B.G.; data curation, V.R.M. and F.G.B.G.; manuscript writing, V.R.M., F.G.B.G., A.C.S.S.S., E.C.M., L.J.S. and L.F.S.; writing – review and editing, V.R.M., F.G.B.G., A.C.S.S.S., E.C.M., L.J.S. and L.F.S.; writing – review and editing, V.R.M., F.G.B.G., A.C.S.S.S., E.C.M., L.J.S. and L.F.S.; writing – review and editing, V.R.M., F.G.B.G., A.C.S.S.S., E.C.M., L.J.S. and L.F.S.; writing – review and editing, V.R.M., F.G.B.G., A.C.S.S.S., E.C.M., L.J.S. and L.F.S.; writing – review and editing, V.R.M., F.G.B.G., A.C.S.S.S., E.C.M., L.J.S. and L.F.S.; writing – review and editing, V.R.M. and F.G.B.G.; supervision, F.G.B.G.; project administration, F.G.B.G. All authors read and agreed with the published version of the manuscript.