

Transitional care to home in the perspective of parents of children with leukemia



Transição de cuidados para o domicílio na perspectiva de pais de filhos com leucemia
Transición de cuidados para el hogar en la perspectiva de padres de hijos con leucemia

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ABSTRACT

Objective: To describe the experiences of parents of children and adolescents with leukemia in regards to the transition from hospital care to home.

Method: A qualitative, descriptive study conducted with nine mothers and two fathers, in a pediatric public hospital. The data were collected through semi-structured interviews, from May 2017 to January 2017, organized in the software Atlas.ti 7^o and submitted to inductive content analysis. The Change Theory was used as theoretical framework.

Results: The central category was "Returning home: the birth of a new reality", which originated three subcategories: apprehension with the new reality of care; immediate impact of changes; and implementation of the guidance plan.

Conclusion: The transition to the home setting made parents adapt to a new and complex reality of care. Improvements in the planning and systematization of the first hospital discharge are necessary.

Keywords: Pediatric nursing. Oncology nursing. Patient discharge. Child care. Caregivers.

RESUMO

Objetivo: Descrever as experiências de pais de crianças e adolescentes com leucemia quanto à transição de cuidados do hospital para o domicílio.

Método: Estudo qualitativo, descritivo, realizado com nove mães e dois pais, em um hospital público pediátrico de São Paulo-SP. Os dados foram coletados por meio de entrevistas semiestruturadas, de maio de 2016 a janeiro de 2017, organizados no software Atlas.ti 7^o e submetidos à análise de conteúdo indutiva. Adotou-se a Teoria das Mudanças como referencial teórico.

Resultados: A categoria central foi "A volta para casa: apropriando-se de uma nova realidade", composta de três subcategorias: apreensão com a nova realidade de cuidados; impacto imediato das mudanças; e implementação do plano de orientações.

Conclusão: A transição para o domicílio fez com que os pais tivessem que se adaptar à nova e complexa realidade de cuidados. Melhorias no planejamento e sistematização da primeira alta mostram-se necessárias.

Palavras-chave: Enfermagem pediátrica. Enfermagem oncológica. Alta do paciente. Cuidado da criança. Cuidadores.

RESUMEN

Objetivo: Describir las experiencias de padres de niños y adolescentes con leucemia en cuanto a la transición de cuidados del hospital para el hogar.

Método: Estudio cualitativo, descriptivo, realizado con nueve madres y dos padres, en un hospital público pediátrica en São Paulo-SP. La recolecta de datos fue llevada a cabo mediante entrevistas semiestruturadas, de mayo de 2016 a enero de 2017, organizados en el software Atlas.ti 7^o y sometidos al análisis de contenido inductivo. La Teoría de los Cambios fue utilizada como referencial teórico.

Resultados: La categoría central fue "La volta a casa: el nacimiento de una nova realidade", que derivó tres subcategorías: aprensión con la nova realidad de cuidados; impacto inmediato de las mudanzas; e implementación del plano de orientación.

Conclusión: La transición hacia el domicilio ha hecho que los padres se adapten a una nueva y compleja realidad de cuidados. Las mejoras en la planificación y sistematización de la primera alta se muestran necesarias.

Palabras claves: Enfermería pediátrica. Enfermería oncológica. Alta del paciente. Cuidado del niño. Cuidadores.

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■ INTRODUCTION

Acute lymphoblastic leukemia (ALL) is the most common type of cancer in children and one of the most common types of cancer in adolescents⁽¹⁾. A combination of therapies have increased the survival rate of pediatric patients with ALL, although the cancer and its treatment has serious implications for patients and their families⁽²⁾. The main treatment is chemotherapy⁽³⁾, during which patients can return home between cycles depending on their general condition, diagnosis, and protocol⁽³⁻⁵⁾.

Returning home requires a transition to ensure continuity when the patient moves between locations and levels of care⁽⁶⁾. Although returning home has a positive effect on the biological recovery of children, as well as their well-being and quality of life⁽⁵⁾, it raises care-related questions and concerns of the parents and workers who prepare them for this transition^(4,7). All the information about the disease, procedures, tests, and therapy must be transmitted clearly for the parents to continue care at home and cope with the changes imposed on them after a cancer diagnosis⁽⁷⁾. The need to answer questions about the diagnosis and treatment plan and empower the parents to manage care during the child's initial admission, which is usually short, is a challenge for health care professionals⁽⁷⁻⁸⁾.

There are no recent national studies that focus on the subject in question, especially in the initial stage of treatment, and research in the context of Brazil does not use the theoretical framework to discuss the transition process. We only identified one national study⁽⁹⁾ on this subject.

The families cope with complex transformations during this process and the nurses are responsible for recognizing these changes and creating an adequate context to help and support the families⁽⁸⁾. Knowing how and to which extent these families change to receive the child with cancer at home and provide the care previously offered at the hospital helps identify the vulnerabilities and needs of specific care. Any particularities can be considered to train the parents in relation to home care and help them cope with the changes. Based on these observations, the aim of this paper is to describe the experiences of the parents of children and adolescents with ALL when they transition from hospital care to home care. To guide the study, we established the following question: What are the experiences of the parents of children and adolescents with ALL regarding the transition from hospital care to home care after the first discharge?

■ METHODOLOGY

This is a qualitative, descriptive study based on the concepts of the Theory of Change to understand and discuss the experience of parents with children diagnosed with ALL undergoing induction therapy who are transitioning from hospital care to home care⁽⁸⁾. This theory focuses on how families remain stable or change when their family structure is altered or when it is influenced by external events⁽⁸⁾.

The study was conducted in the oncology-hematology sector of a pediatric specialty hospital in the city of São Paulo, SP, Brazil. The participants were the parents of children and adolescents diagnosed with ALL in the induction period of oncological treatment, who had already provided home care to their child or children after the first discharge from hospital at the beginning of therapy. We excluded the parents who had not returned home after their child was diagnosed or whose adolescent girl or boy/child had initiated therapy in another service and had been transferred to the institution where the study was conducted.

The method used to select the participants was convenience sampling, and none of the participants refused to take part in the study. We consulted the outpatient schedule and inpatient census to identify potential participants. Then, the parents were approached and invited to join the study.

The data were collected from May 2016 to January 2017 due to the strict participant inclusion criteria, such as the choice of a specific cancer diagnosis (ALL) and patients in a specific period of therapy (induction), and because the data were collected at a single unit. Semi-structured interviews were conducted and recorded at the pediatric oncology-hematology nursing ward and outpatient sector. In the outpatient sector, the interviews were conducted in available consultation rooms, while at the inpatient sector, they were conducted in meeting rooms, to ensure privacy. The guiding questions asked during the interview include the following: "Tell me about the first time [name of child or adolescent] was admitted after you discovered the disease and what was the return home like after discharge?"; "How were you prepared and supported at the hospital to take care of your child at home?"; Depending on the interaction, other questions were created to elaborate on the subject. The participants were interviewed only once, for 35 minutes, by a trained research assistant supervised by a researcher who had experience in interviews of this nature. Data collection was interrupted when the empirical data was sufficient to achieve the objective of this study and when it provided insight into the phenomenon of interest⁽¹⁰⁾.

To analyze the data, we used the assumptions of inductive content analysis⁽¹¹⁾. In the initial phase, called preparation, the evidence is transcribed and the units of meaning are identified, represented by words and expressions of interest for the study. The following stage, called organization, includes the analytical process of encoding. The first two phases were processed using the intuitive software Atlas.ti 7[®], which helps to organize and manage data in qualitative research by means of coding. Two researchers with experience in analyzing qualitative data conducted an independent analysis and subsequently compared and discussed the codes with the other authors. Finally, in the results reporting stage, the analysis was synthesized and presented in a central category with subcategories. The COREQ (Consolidated Reporting Criteria for Qualitative Research)⁽¹²⁾ was observed for the qualitative research report to increase accuracy.

Since this study involved the participation of human beings, we obtained approval of the research ethics committee, protocol 1.419.308/2016, according to the ethical provisions of Resolution 466/12 of the National Health Council. The participants were notified of the objective of the study and data collection procedures in the informed consent statement. Those who agreed to participate, signed the statement, thus consenting to the research and the recorded interviews.

■ RESULTS AND DISCUSSION

We interviewed two fathers and nine mothers with ages ranging from 29 to 48 (Md = 37). These parents had seven children (of the mothers M2, M5, M6, M7, M8, M9, and father P1) and four adolescents (of mothers M1, M3, M4, and father P2) aged between 2 and 17 years. The children and adolescents were undergoing induction therapy according to the European protocol ALL-BFM (Berlin-Frankfurt-Münster), the standard used in the sector where data were collected. The time of therapy varied from 21 to 75 days. The participants' education level ranged from primary school not completed to completed secondary school. Most of the participants (n = 6) came from other Brazilian states.

In the inductive process of data analysis, we created a central category titled "Returning home: taking ownership of a new reality" and the following three subcategories: 1. Apprehending the new care scenario; 2. Immediate impact of changes; and 3. Implementing the guidance plan. Figure 1 illustrates the subcategories that represent the parents' experiences as they transition to home care after the first discharge from hospital of the child with ALL. Home care is characterized as a new reality pervaded by complex changes that interferes with family functioning as the members adjust to manage the care.

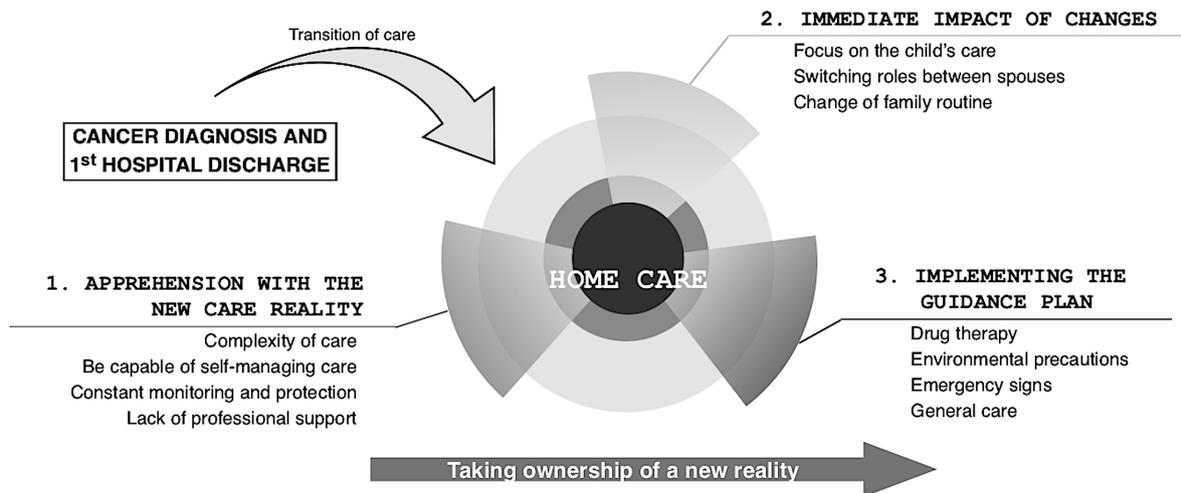


Figure 1 - Central category and subcategories representing the experience of parents transitioning to the home care of pediatric patients with ALL, after the first hospital discharge

Returning home: taking ownership of a new reality

Apprehending the new care scenario

The discharge from hospital marked the start of a process in which the parents must take responsibility for and

learn how to take care of their child in cancer treatment. The first return home was compared to the challenge of receiving a newborn baby at home for the first time.

[...] The feeling is like someone coming out of the maternity ward with a small baby for the first time, and then everything is your responsibility, it all depends on you. That was

the sensation, like leaving the maternity ward, because then it's you who has to take care of the child [...] (M2)

[...] It was like bringing a baby home. First-timer, coughed, vomited, we already start to worry. It's as if she were a baby and you are a new mother and you do not know how to deal with the baby. (M9)

According to the Theory of Changes, families are always going through changes triggered by important life events, such the birth of a child or serious disease⁽⁸⁾. As shown in the statements above, bringing a child diagnosed with cancer back home triggered recollections of taking their first child home, which entailed huge transformations and demanded responsibility, protection, and the development of skills to provide care.

The parents felt fear and insecurity during the initial care process of the sick child after the first hospital discharge and justified this fear by the fragile state of the child, the complexity of care required and not executed, and the need to feel capable of self-managing care and remaining vigilant.

You think that here (hospital) you are safe. So, at first, I was scared, a little apprehensive, I was afraid of having to go back at any time, of something happening and not realizing it. [...] (M10)

That really scared me... [pause]. I felt that he was too weak, fragile, he was like broken glass, and it was if they (multi-disciplinary team) were fixing this glass. Then, I had to take him home and I did not if he would feel bad, if he would eat, how he would react away from the doctors. [...] (M4)

Fear, because, whether we like it or not, is a complicated disease, but the care [pause] ... I have to pay attention to a lot of things [...] (M8)

The statements revealed that the parents feared they would be incapable of taking care of their children without the protection of the hospital or they would be unable to identify some significant clinical complications. According to a study, the first weeks at home are the most challenging because returning home with a sick child involves a series of new tasks related to the disease and the therapy that can significantly alter the family's routine⁽⁵⁾. Their feelings are directly connected to fear of the unknown, in this case represented by a pathology characterized by frequent complications throughout treatment⁽⁴⁻⁵⁾.

In this study, the discharge from hospital meant that the professional support and the care the parents perceived as

shared and safe would be interrupted. The feeling of being alone during the transition to home care increased among the parents who felt more confident in the hospital because of the comprehensive and qualified care offered to their children.

[...] I was really afraid, because when he was hospitalized, you would open the door and there was a nurse there to help with anything you needed. Now, at home, I was always petrified that he would cut himself, that there would be bleeding. [...] (M2)

[...] I even thought that here at the hospital, we feel safer, more confident, because all you have to do is call the nurse, but not at home [pause] ... Then, at first, I could not sleep because I was always checking on (the child) to know if she had a fever [...] (M6)

The habitual and nursing care the parents have to provide at home is a challenge for the families. Other studies corroborate these results and show that the parents are fearful and apprehensive when they take their children home and feel anxious about not knowing how to protect them from disease-related dangers, especially fever and the risk of infection^(7,13). In addition, they feel overwhelmed by the adaptations involved in returning home and the considerable amount of information they must apply, which is not always appropriately understood at the hospital, especially because of their fragile emotional state after they receive the diagnosis^(4,7).

These factors also make the hospital discharge complex for the health team because it must ensure the transition from hospital to home runs smoothly and help the parents develop the capacity for self-management to guarantee patient safety. Patient safety involves strategies to reduce risks and unnecessary harm associated with health care, identifying risk situations, and preventing and reducing incidents⁽¹⁴⁾. Therefore, in the care transition process, the hospital staff should provide quality information adapted to the patients and their families, schedule follow-up consultations, assess needs for discharge, and, above all, monitor care after discharge through phone calls or home visits⁽⁵⁻⁶⁾. According to the Theory of Change, efforts to promote and facilitate changes in the family system should also consider the perception of the parents on their new reality of care and any restrictions and resources available for the transition⁽⁸⁾.

In this study, the parents were not supervised after discharge and they did not have the support of an effective social network with primary, secondary or tertiary

care workers immediately after leaving the hospital. Such fragmented care after discharge increases the risk of unnecessary harm associated with home care. Involving the patients, their families, and other health workers improves the overall well-being of the children and their family members after discharge, either by phone⁽¹⁵⁾ or by referring the families to health care services, especially the family health strategy ("ESF"), and ensures the continuity of care and patient safety.

With regard to the social support network, family members, neighbors, and friends can offer valuable support to these parents. A study⁽⁵⁾ on providing care to children with cancer at home found that the family members, and even other parents in similar situations, were considered the source of emotional and instrumental support and of information in light of the series of changes and adaptive responses imposed on the families during the hospital-home transition.

Despite reports of concern, fear, and insecurity in relation to returning home, four mothers stated they were relieved to leave the hospital because it would be better for the child. This attributed a dichotomous representation to the hospital-home transition.

[...] It was a huge relief, it was great, but he (child) was very distressed. In fact, he is still, and he also cries a lot whenever they touch him [...] (M5)

[...] After a long hospital stay, you are dying to get back home, so I guess I was not afraid [...] (M7)

Despite the antagonistic feelings about returning home, literature reinforces that parents tend to feel safer in the hospital environment^(4,13,16), possibly due to the presence and easy access to health workers who are constantly monitoring the physical, emotional, and medical needs of their children⁽¹³⁾. Most of these families (n = 8) lived far from their child's treatment center - an important factor given the time and distance to reach the service in case of an emergency.

The mothers who stated they were relieved to return home had younger children (two years old), which is when it is harder for children to understand therapy and collaborate with care - imperative in this context given the frequent painful or painless procedures. Children in this age group are more sensitive to any changes to their routine and may develop eating and sleep disorders, hyperactivity, and irritability⁽¹⁷⁾. In such cases, returning home can be emotionally beneficial for these patients and may minimize the effects of hospitalization⁽⁶⁾. The Theory of Changes highlights that changes may differ for each family member because they occur at different times and affect people in

a particular manner⁽⁸⁾. This explains why the return home represents stability to some families and helps them gain control over the situation, considering hospitalization can make them feel they have lost their role as parents⁽¹⁶⁾.

Immediate impact of changes

The changes triggered from the moment of diagnosis were intensified in the first return home. This moment was marked by the need to adapt and consolidate changes that greatly interfered with family functioning. Of the series of changes mentioned by the parents, the most significant was shifting the family's focus to the pediatric cancer patient, as shown in the following statements:

[...] you have to keep your eyes open, you cannot take your eyes off him (child), I live for him. I check to see if he has a fever, I check his feces, urine, his small body during bath time, so, you have to observe everything. [...] (M7)

[...] Our life turns upside down, because they become the center of our lives". (M8)

The role of the caregiver is notoriously intermittent. The role of parent and caregiver is challenging since it may require postponing future plans and giving up a social life to focus exclusively on the sick child^(6,16). Another study confirms this result by stating that the parents go through a period of mourning with the loss of their family routine after the child's diagnosis, and they are forced to incorporate a series of new tasks⁽⁴⁾.

In addition to the shift in focus, the interviewees mentioned the reversal of roles as another expressive factor that affects their family lives.

My routine (of the father) also changed, because now I am here (hospital), and I had some business to do, since I sell cell phone accessories to complement our income (P2)

My husband was unemployed and I worked, so my husband took care of him (child) at home. He took him to the hospital (for the chemotherapy sessions), while I worked outside home. (M5)

According to the Theory of Change, the reaction to change occurs among the family members and, although it does not occur in a similar manner, it may be related to the way they behave in relation to each other⁽⁸⁾. As in other studies published in the literature^(16,18), these results show the shift in the parental role, when the care primarily provided by

the mother is performed by the father, who then becomes the person responsible for care-related tasks, such as taking the child to chemotherapy, preparing food, administering medication, and attending to other needs of the sick child. A study shows that the mother also takes on other roles, such as becoming the provider of the household⁽¹⁸⁾. These shifts demonstrate how a cancer diagnosis can change the lives of families, prompt the establishment of new roles, and alter the bond and cohesion among its members^(8,18).

The respondents mentioned instrumental changes in family functioning, such as home cleaning, to minimize the risk of infection and symptoms of nausea in the child.

[...] now it is with alcohol, his bed, the floor, the furniture, everything is with alcohol, no products with perfume because we cannot use them, and the bathroom has to be disinfected with alcohol, it got really [pause], now it is really very strict. [...] (M1)

[...] my cleaning changed, before I liked products with a nice smell, but now I cannot use them, I mostly use chlorine and bleach to clean the house, and when I clean, he cannot be in there. I was also given a liter of alcohol gel, so I use it to clean around his entire bed, I change the sheets every day too. [...] (M4)

Similarly, another study indicated increased concerns with cleaning the house during the children's cancer treatment⁽⁵⁾. The participants of this study had to clean the smallest objects in their homes, such as doorknobs, baseboards and window sills, with a disinfectant.

Another instrumental change of family functioning involved feeding the child, as shown in the statements below:

[...] the diet also changes because he does not eat food with salt or sugar, so the routine of the entire household changes, because everyone ends up eating "bland" food, for now. [...] (M6)

The food was not controlled, but now it has to be well balanced, meal times, now everyone eats together. So, it is I, my husband, and my four-year-old daughter and, then, we ended up having to change our habits, not just hers, but of the family also. [...] (M9)

The child's diet was restricted in several ways since many foods were banned from the menu. In addition, the entire family was forced to adapt to such changes for the benefit of the child. Other studies⁽⁴⁻⁵⁾ also reported significant changes in the eating pattern of families of children

with cancer and stressed the importance of specific guidelines, given the restrictions during treatment.

Implementing the guidance plan

The participants mentioned the guidelines they received verbally at discharge and stated they were mostly related to medication, environmental precautions, prophylactic measures, diet, and general care. Nurses were the main source of information for these parents, and they described the health workers as reliable and accessible sources in case of doubts during hospitalization.

They (professionals) showed us how to take care of him (child), for example, in relation to the environment, that could not be humid, that, depending on the environment, he should use a mask because of the low immunity, these were the recommendations [...] We are advised not to administer any other medication at home. (P3)

[...] Whenever I have any doubt, they (nurses) provide good guidelines, all things related to care, medication, the effects of medication. [...] (M8)

Educating the family that will take care of the child after discharge is critical to successfully develop and implement a plan to assess the family's literacy in health care and confirm their understanding of each component they will be responsible for at home⁽¹³⁾. Other studies also stress the role of nurses in the provision of guidelines at discharge, for emotional support, and for training the family to continue with care when transitioning from hospital care to home care^(6,13). These roles highlight the responsibility of nurses as the facilitators of change⁽⁸⁾.

Drug therapy was the most frequently mentioned factor in home care and it was considered the most complex for the parents.

[...] I've always been very forgetful with meds and I have even forgotten to administer the medication a few times. That is my biggest fear because, in the hospital, all the medication is administered at the right time and, at home, because of the busy schedule, you do one thing, you do another, and when you realize, the time to medicate has passed, that worries me a little. (M6)

[...] She [nurse] advised me about the prescription, the form of medication, diet, the care I should take with him, the issue of leaving home; they recommend those things. [...] (M10)

Other studies also mention information on drug therapy at home^(6,18) and stress that this topic is one of the main concerns of the families. One of the most frequent problems after discharge is errors when following the instructions of medication - which can be minimized when the health worker demonstrates the correct dosage, supervises the dosages, and teaches the parents using standard printed instructions⁽¹⁹⁾. These strategies can determine the success of treatment since committed adherence to therapy significantly increases the chances of relapse⁽¹⁹⁾.

Of all the information and guidance provided at discharge, the parents stressed those that were specifically related to bringing the child or adolescent back to the hospital in emergencies, which are common in pediatric cancer treatment. According to the parents, the verbal information provided by the health workers helped them identify the signs and symptoms of the clinical worsening of their child and allowed them to adequately manage these situations by administering medication, taking the child to the hospital, or monitoring the child's health status.

[...] I was told that if he (child) has a fever, I should give him Dipyrrone or Paracetamol, wait a while to see if went down. If he has a fever again, bleeding, some patches on his skin, I have to rush to the hospital. (M4)

[...] So, depending on what is, for example, if it is a fever, they advised me to take her to the hospital immediately; diarrhea or something that I notice will not stop, then I have to take her [pause]. Bleeding, stuff like that, that you cannot solve at home. (M6)

[...] If he has a fever of 37.8°C, you have to bring him. But, if at first you do not know, do not bring him. Then if he has diarrhea, things that are not common in the treatment, you have to bring him here (referral hospital), because if you stay home and he gets diarrhea 4 or 5 times, he will be dehydrated already. (M11)

The statements revealed that the parents monitored the potentially serious clinical changes and needed to make decisions related to treatment options, which implies they are capable of recognizing and managing the cancer emergencies of their children. Fever was mentioned in all the statements because it was considered the primary sign of infectious processes that can be fatal if not treated early. The parents must acquire the skills and knowledge of home care - which are critical in the context of children's cancer - in order to recognize the early signs of an emergency^(6,16). However, a systematic review showed that more than 70%

of parents were unable to recognize important signs and symptoms that are compatible with the diagnosis of their children⁽¹⁹⁾. A study with the parents of children with cancer revealed the urgent need to provide parents with information on the signs and symptoms of the disease, risk of infection, diet, changes to the sleep cycle, tiredness, and pain⁽⁶⁾.

Although the participants stated they had received guidelines constantly in all the hospital visits, some mothers reported faults in the information provided by the medical staff. According to some interviewees, differences in the information provided by the workers and guidelines that were not compatible with the health care literacy level of the parents negatively affected their education.

At first I had many doubts, each doctor said something, so I try not to talk with many doctors, because each one has a different view. Some of them tell me it is not that hard, that the treatment is intense, painful, but not so difficult, while others really frighten you, so I thought it better not to talk with all of them. (M7)

One of the mothers said that, despite having received instructions, she would have liked *more detailed guidelines without the 'language of doctors' (sic)*. (M9) According to another participant, some health workers provided clear guidelines and others used *more technical language*. (M10) Both parents referred to the medical jargon, which is difficult to assimilate when they are learning about home care at the hospital.

Clear and effective communication with health workers is essential at the beginning of treatment because it minimizes the fears related to home care and because it helps the parents understand their child's sickness process⁽⁴⁾. Taking care of a child or adolescent in cancer treatment is complex and the feeling of being incapable expressed by the parents can be exacerbated by faulty guidelines or by the limited capacity to understand the guidelines after the shock of the diagnosis⁽⁶⁾. Consequently, an adequate hospital discharge must observe patient safety and quality care - including effective communication, teamwork at the hospital and in primary care, and the involvement of patients and families to minimize errors and faults⁽²⁰⁾.

The guidelines must be provided by the team during the hospital stay in a clear, continuous, and gradual manner so the parents can learn and perform safe and competent care at home⁽⁵⁾. Moreover, the multidisciplinary team should establish a positive relationship with the families and provide converging guidelines⁽⁴⁻⁶⁾. The type and manner in which this information is provided can affect the assimilation and implementation of instructions during discharge^(6,15). Issues

related to communication with the health workers have also been found in another study⁽¹⁹⁾. The workers did not provide individualized guidelines and the information they did provide was divergent, which created insecurities and made the parents reluctant to ask questions or seek members of the team that transmitted more credibility⁽⁴⁻⁵⁾. In addition to the lack of understanding, important information that is transmitted verbally can be forgotten, so it is critical to also provide information in writing for parents to care for their children at home⁽⁵⁻⁶⁾.

However, the parents of this study did not report receiving information in writing and they were not offered the option to call a health worker in case of doubts. The recommendation to increase the quality of care and patient safety is that the children should leave the hospital with all the instructions for discharge in writing in a language their parents can understand, with clear guidelines regarding concerns or problems, who to call in these cases, and when the patients should seek emergency assistance⁽¹⁵⁾. These recommendations reinforce the need for better planning and the systematization of cancer patients in the hospital of this study. Nurses should seek ways to tailor interventions to the changing context of families, investigate family problems, monitor compliance with specific goals in home care and, above all, modify the vision or the family's beliefs regarding the disease⁽⁸⁾.

■ FINAL CONSIDERATIONS

The transition from hospital care to home care in the first discharge of children and adolescents with ALL in the induction period of treatment was marked by changes that imposed a new reality of care on the parents. The transformations were permeated by feelings of fear and insecurity due to the complexity of the treatment and the need for parents to acquire the ability to self-manage care. We also observed changes related to family functioning. The nurses essentially prepared the parents for discharge but the parent statements revealed a lack of follow-up immediately after leaving the hospital, differences in the information provided by the workers, guidelines that disregarded the parents' level of health literacy or that had not been transmitted in writing. These factors may cause the fragmentation and inadequate performance of home care and increase the insecurity of parents.

The Theory of Change shed valuable insight into the changes and the affects of these changes on the family. Nurses can facilitate this process of change by sharing their knowledge regarding the management of childhood cancer through education and training, thus ensuring safe

care. To increase the success of discharge and the quality of home care, a series of interventions that focus on pediatric patients and their families must be implemented at the hospital during hospitalization.

Maintaining constant communication among team members in relation to care guidelines, supporting the families after discharge, considering the health literacy of parents in the teaching of new skills, and observing and supervising parents during their training for home care can significantly facilitate the transition of care. It is also important to register guidelines, allow time for questions from parents, and validate their understanding of the disease and treatment in order to reduce adverse events after hospitalization and readmissions.

The results of this study highlight the need for further research that addresses the training and the role of parents in home care after discharge. Therefore, studies that investigate improvement to the planning and implementation of discharge processes and increase the health literacy of parents for safe home care will certainly contribute to a smoother transition between the scenarios in which the treatment of pediatric cancer patients occurs.

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