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First transition from hospital care to home care for children with cancer: guidelines of the multi-professional team

Primeira transição do cuidado hospitalar para domiciliar da criança com câncer: orientações da equipe multiprofissional

Primera transición de la atención hospitalaria a la atención domiciliaria de niños con cáncer: directrices del equipo multiprofesional

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Abstract

Objective: To describe the guidelines for the first transition from hospital care to home care of children with cancer from the multi-professional team's perspective. **Method**: A qualitative exploratory-descriptive study conducted in a University Hospital in southern Brazil by nine professionals from the multi-professional team of a pediatric oncology inpatient unit between July and September 2018. Semi-structured interviews were carried out and submitted to thematic content analysis. **Results:** Three theme categories were identified, namely: multi-professional planning for hospital discharge of children with cancer and their family; the multi-professional team facing the discharge process; guidelines for the first hospital discharge for families of children with newly diagnosed cancer. **Conclusion/practical implications**: multi-professional planning and systematization for the guidelines of the first hospital discharge are essential to deliberate the needs of the patient and their families, with the nurse having a central role. Improvements are needed in this process.

Keywords: Transitional care; Child; Multi-professional team; Cancer; Patient safety.

Resumo

Objetivo: Descrever as orientações para a primeira transição do cuidado hospitalar para o domiciliar da criança com câncer sob a ótica da equipe multiprofissional. **Método:** Estudo de abordagem qualitativa do tipo exploratório-descritivo realizado em um Hospital Universitário do Sul do Brasil, com nove profissionais da equipe multiprofissional de uma unidade de internação de oncologia pediátrica entre julho e setembro de 2018. Foram realizadas entrevistas semiestruturadas submetidas a análise de conteúdo temática. **Resultados**: Foram identificadas três categorias temáticas: planejamento multiprofissional para a alta hospitalar da criança com câncer e sua família; a equipe multiprofissional frente ao processo de alta hospitalar; orientações para a primeira alta hospitalar a famílias de crianças com câncer recém diagnosticado. **Conclusão/implicações para prática:** o planejamento e sistematização multiprofissional para as orientações da primeira alta hospitalar são fundamentais para contemplar as necessidades do paciente e suas famílias, tendo o enfermeiro papel central. Mostram-se necessárias melhorias nesse processo.

Palavras-chave: Cuidado de transição; Criança; Equipe Multiprofissional; Câncer; Segurança do paciente.

Resumen

Objetivo: Describir las principales pautas para la primera transición de la atención hospitalaria al contexto domiciliario de niños con cáncer bajo la óptica del equipo multidisciplinario. **Método:** Estudio cualitativo de tipo exploratorio-descriptivo realizado en un hospital universitario en el sur de Brasil, con nueve profesionales del equipo multiprofesional de una unidad de hospitalización de oncología pediátrica entre julio y septiembre de 2018. Se realizaron entrevistas semiestructuradas que han sido sometidas a análisis de contenido temático. **Resultados**: Se identificaron tres categorías temáticas: planificación multiprofesional para el alta hospitalaria de niños con cáncer y sus familias; el equipo multidisciplinario frente al proceso de alta hospitalaria; pautas para el primer alta hospitalaria para familias de niños con cáncer recién diagnosticado. **Conclusión/implicaciones para la práctica**: la planificación y sistematización multiprofesional en relación a las pautas del primer alta hospitalaria son esenciales para contemplar las necesidades del paciente y sus familias, teniendo la enfermera un papel central. Es necesario implementar mejoras en este proceso.

Palabras clave: Cuidado de transición; Niño; Equipo multiprofesional; Cáncer; Seguridad del paciente.

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INTRODUCTION

Cancer diagnosis has an important impact on the life of children and their family. Cancer treatment is long and complex, requires specific care by a multi-professional team, and significant changes in the daily life of the families involved. Given the varieties of the protocols being currently used for cancer treatment, the care center deviated from an exclusively hospital composition. Part of the treatment is carried out on an outpatient basis, which facilitates maintaining the child in co-living with the family.[1,2] The first hospital discharge tends to be challenging for the family members because they often feel unprepared to take care of the child at home by themselves.[3]

Returning home requires care transition, which consists of moving the patient from one place of care to another, such as from the hospital to the home. This trajectory brings vulnerability to the safety of patients and their families, due to possible inconstancy of care due to lack or loss of essential information.[4] The multi-professional health team has a fundamental role to equip the family for this transition from the hospital care environment to the home context. In addition to the clinical aspects, the professionals must consider the needs and experiences of the patient and their family.[3]

Although many favorable results have been attributed to the education of patients and their families, among which are the increase in treatment adherence, reduced number of hospitalizations, improvement of self-management and shorter hospital stay periods,[5] in the national literature consulted, evidence-based practices of an effective approach to the education of newly diagnosed patients and their families were not identified. No studies were found in the Brazilian context focusing on the performance of the multi-professional team in this context. Health professionals use their own experience to define methods, time and content of patient and family educational activities.[6]

The Children's Oncology Group (COG) Nursing Discipline, recognizing the importance of family education, identified as a priority in the research studies to be carried out those related to the understanding of the effective provision of education to patients and families in COG institutions.[7]

Inadequate guidance of the patient and their family can negatively influence treatment outcomes. Understanding the principles and strategies for effective learning for family members in the context of a recent cancer diagnosis in the child is essential to provide well-being and safety to the patient and the family itself.[5]

Therefore, the main question of the study was the following: What are the guidelines for the first transition from hospital care to home care of children with cancer from the perspective of the multi-professional team? To answer this question, the general objective was to describe the guidelines for the first transition from hospital care to home care of children with cancer, from the perspective of the multi-professional team. The specific goals were as follows: to know the strategies that the multi-professional team uses in planning and the guidelines for hospital discharge of the newborn diagnosed with cancer and their family, and to identify the guidelines of the multi-professional team related to patient safety in the home environment.

METHOD

This is a qualitative study of the exploratory-descriptive type, carried out as a Residency Completion Work (*Trabalho de Conclusão da Residência*, TCR). It was developed in a pediatric oncology hospitalization unit of a reference hospital in southern Brazil, between July and September 2018.

The inpatient unit has exclusive 24 beds for oncohematological patients from 0 to 18 years of age. Patient care is offered by a multi-professional team composed of 37 nursing technicians, 14 nurses, eight physicians, a nutritionist, a psychologist, a social worker, a pharmacist and a physical educator. Currently, the unit has the support of a dentist who provides care to patients on a research and volunteer basis. They also provide assistance to professional patients of the Multi-professional Integrated Residency in Health (*Residência Integrada Multiprofissional em Saúde*, RIMS) with emphasis on oncohematology composed of a nurse, a nutritionist, a pharmacist, a social worker and a psychologist.

The invitation to participate in the study was personally carried out by the researcher herself and later on formalized by e-mail. All the invited professionals agreed to participate.

Nine professionals from the multi-professional team were included in the study: two nurses, two physicians, a pharmacist, a nutritionist, a psychologist, a social worker and a dentist, selected by intentional sampling, because they are the professionals responsible for the guidelines to the relatives of hospitalized children with cancer.[8]

The inclusion criterion defined was the following: professionals from the multi-professional team working in the care of children in cancer treatment for at least one year. Those professionals away from work or on vacation during the data collection period were excluded from the study.

For collecting the information, the semi-structured interview was adopted as a strategy, conducted by the researcher herself. Five guiding questions were elaborated that addressed questions about how the guidelines were performed, which professionals were essential for this educational process, whether there is any planning for the development of the guidelines, what orientations have implications for patient safety, and whether any instrument is used to conduct the educational process and the guidelines with the child and the family. A meeting was scheduled with each professional, in a reserved room, lasting approximately thirty minutes, and recorded in audio with the use of a digital recorder. The interviews were later transcribed in their entirety, and the participant's name was replaced with the letter "P" followed by a number according to the order in which the interviews were conducted. The statements were adjusted from the spelling point of view to facilitate reader's understanding, but without altering the meaning given by the interviewee. Interruption of data collection was based on the criterion of information saturation.

For the analysis of the information, content analysis of the thematic type proposed by Minayo[9] was used. The discussion of the results was based on the national and international literature relevant to the theme.

The participating professionals obtained feedback from the results of the study through its public presentation and later on by means of a printed version made available in the unit.

The ethical aspects were respected and followed according to Resolution 466/12 of the National Health Council.[10] The study was approved by the Research Ethics Committee (*Comitê de Ética em Pesquisa*, CEP) of the Clinical Hospital of Porto Alegre, via *Plataforma Brasil*, CAAE No. 82979618.1.0000.5327. All the participants signed the Free and Informed Consent Form (FICF) approved by the CEP.

RESULTS

Nine professionals from the Pediatric Oncology multi-professional team aged from 30 to 55 years old participated in this study. Their working time in Pediatric Oncology ranged from one to 22 years; and their time since graduation, from four to 32 years.

The analysis of the information revealed three thematic categories, namely: multi-professional planning for hospital discharge of children with cancer and their families; the multi-professional team in the face of the hospital discharge process; guidelines for the first hospital discharge to families of children with newly diagnosed cancer.

Multi-professional planning for hospital discharge of children with cancer and their families

It was identified that there is no structured multi-professional planning for the realization of the guidelines and the transition from hospital care to home care, but rather a segmented process and independent organization of each professional. The joint and anticipated planning was scored as casual, when the family difficulties were identified in understanding the care needed at home.

Despite identifying the importance of multi-professional planning for discharge, some interviewees reported having difficulties in performing this process, such as when hospital discharge is anticipated or not foreseen. Feelings of frustration were mentioned by the professionals when there are flaws in the process of providing guidelines for discharge.

> *[…] in my opinion it doesn't happen, multi-professionally no, each one goes seeing the needs of that patient and goes planning according to their profession [...] (P1).*
>
> *There's no formal planning [...] in some situations yes, we end up doing some planning [...] the more severe patient, or the patient with greater vulnerability, whether of understanding, whether social, financial, finally, we end up organizing a little better for these cases [...] (P6).*
>
> *[...] sometimes, by the rush to discharge, the professional gets frustrated because they can't properly guide this family [...] (P3)*

The multi-professional team in the face of the hospital discharge process

Regarding the time for providing the guidelines, some professionals reported waiting for discharge confirmation, which sometimes occurs only on the same day, to start this process. However, when difficulties on the part of the family were identified, such as insecurity to provide care at home, low income, and/or lack of instruction to read and write (illiterate relatives), among other situations, the participants referred seeking to anticipate the guidelines, in order to enable better use, implementing care transition. On the other hand, there are professionals who signaled starting the guidelines during hospitalization.

> *[...] we'll follow up soon after the diagnosis [...] based on the demands [...] with this we already have a preview of the resources they'll need for discharge. So we work throughout the hospitalization process, at the time of discharge we make a closure of this [...]. (P1)*
>
> *[...] we always expect high certainty and this is sometimes on time [...] for example, cases where the families are illiterate [...] we try to start the discharge process a little before so that the families have a little more security at the time of discharge. (P2)*

With regard to the difficulties for the orientations, the professionals highlighted that the first hospital discharge is a time when family members are usually very insecure because they need to incorporate several information in a short period of time, emphasizing the importance of educational actions occurring throughout the hospitalization period. The participants pointed out that they believe that the fundamental guidelines are provided to the family members; however, there is difficulty in verifying assimilation of the information.

> *[...] what we realize is that in the first hospitalization there is some family disorganization, the mother or the caregiver has to take care of the things here in the hospitalization, the things that stayed at home [...] and we see that they are having security with the team during this first hospitalization [...]. (P9)*
>
> *[...] the major difficulty today is not so much providing guidance, but to ensure that it was perceived [...] I think sometimes we lack mechanisms for us to ensure that the family has the ability to implement [...] to understand what you are saying [...]. (P7)*

When it comes to the responsibility for the guidelines, the participants were unanimous in considering all the professionals who were members of the multi-professional team as elementary elements for this process. However, they indicated the nurse as a reference regarding the education of the family and the patient. However, the importance and need to carry out the planning process of hospital discharge in a shared manner was emphasized.

> *[...] I don't see the pharmacist far from it, I don't see the social worker away from that either, but I think it ends up, on the front line, being Nursing in general, in relation to this, care and education. (P6)*
>
> *[...] I think it's fundamental that everyone always works together, this multi-professionality, inter-disciplinarity is essential, I see all areas as fundamental. (P8)*

Guidelines for the first hospital discharge to families of children with newly diagnosed cancer

The guidelines related to the identification and recognition of signs of oncological urgency, such as fever, vomiting, diarrhea and bleeding, were highlighted, emphasizing that such signs mean that there is a need for referral to the hospital for immediate management.

> *[…] guidance in case of urgency, what to do if the patient has bleeding at home, what to do if they have fever at home [...] make the family understand what situations are considered urgencies for us and that this means hospital referral. (P7)*

The participants also highlighted that it is extremely important that the families know the different stages of cancer treatment and that, through the guidelines offered, they develop an understanding about the importance of maintaining the highlighted care actions. The guidelines made by the multi-professional team to the families need to be added to the daily life of each child. Thus, it is important that the families trust the team, and that this is their reference for clarifying doubts that may arise both during hospitalization and during the time that the child remains in their home. To this end, it is essential that ways to keep in touch with the professionals are made available.

> *[...] guidelines of the everyday life for this patient [...] ranging from the aspect of nutrition, food, life in society, if they can go to school, if they can have an animal, of the house [...] a patient, to get out of here the family has to be able to know what the warning signs are, when to refer to the multi-professional team [...] and how to do that [...]. (P7)*
>
> *[…] I always say that the child who is immunodepressed, who is lowering the defenses a lot, because of such condition, they get easily infected so that's why we do all these care actions here, they need to follow these same care actions that we have here, and they need to do this at home. (P5)*

Regarding the specific guidelines of each professional, considering the pediatric patient in cancer treatment as a child with special health needs, the ones that stood out were those related to the use of health technologies, such as the use of a long-term central venous catheter. Feeding by enteral route, polymedication were also emphasized, in addition to the use of high-risk medications, such as chemotherapy, which is corroborated by the following statements.

> *[...] the yellow sheet that we call it, all the prescriptions are placed in a table with schedules and way of administration of these medications [...] so we always advise care on the issue of schedules, the way of administration and also every medication that needs to perform a pharmaceutical derivation [...]. (P2)*
>
> *[...] I try to guide the care with the portocath [...] the care with the nasoenteric tube for when the patient goes with a tube [...]. (P3)*

The participants also brought as aspects treated in their guidelines to the families, the prevention and management of symptoms caused by the disease itself or by the chemotherapy treatment, as well as the different ways of obtaining the necessary drugs for continuity of home treatment, in addition to access to the health network in the territory of these families.

> *[…] where to get this medication, if this medication is available in the center, if this medication is available in the state, if it will have to be purchased, then the access we also advise [...]. (P2)*
>
> *[…] I greatly reinforce the importance of oral hygiene to reduce other sequelae of the antineoplastic treatment [...] when they can't do the hygiene with a brush because they are with lesions in the mouth, for being sick, being sick I teach to do hygiene with gauze [...]. (P8)*

The instruments and strategies used by the professionals for the guidelines were adapting the language used according to the level of understanding of each family member, and using printed educational materials, such as institutional folders, for example. The use of drug tables and the repetition of information were also mentioned, both by the professional and by the family member, to ensure assimilation.

> *[…] I try to speak their language well so, have to explain in the understanding of the mother, we can't explain with difficult words either. (P3)*
>
> *[...] we have specific folders [...] according to the clinical situation of that patient, we guide and deliver more the written material. (P6)*
>
> *[...] we always ask the family to reproduce what we explained at that moment, it's important that the information receiver repeats it [...]. (P2)*

When the family members identify difficulties in understanding and reproducing information, other strategies are created for these caregivers to understand more easily. They seek to use didactic, demonstrative and playful teaching materials to support learning and understanding of the guidelines. In other words, several materials available in the unit are used to help teaching and favor the understanding of information by the families, such as syringes with color markings or dolls, that is, creative ways to explain care.

> *[…] when we realize that it's not happening with that family member, we try to ask if there's someone who can come to help, or when the patient is more adolescent [...] also involve them in that care [...]. (P6)*
>
> *[...] we've already used dolls with catheter puncture and with the use of the tube, we've already installed in a doll and showed how it worked, for the child and for the family a more playful thing [...]. (P5)*
>
> *[...] there have already been cases that we made a small box with color for them, with a drawing of pills there, how many and a little clock with time [...]. (P2)*

Regarding the safety of the pediatric cancer patients at their homes, care related to the correct storage of medications and the handling and disposal of chemotherapy drugs was highlighted. In addition, the necessary care with the possible complications that the patient is subjected to, such as fever, diarrhea and bleeding, was encouraged. These situations in which the patient will have to be immediately referred to the hospital where they undergo treatment or, when not possible, to health services close to the family territory.

> *[...] all the patients with oral chemotherapy we then advise care for those who will administer these medications [...] bring to the hospital and dispose of in the appropriate location. (P2)*
>
> *[...] being able to minimally identify the care network in that territory because if something happens, especially patients who live in the inland sometimes there's no time to arrive [...]. (P1)*

Other aspects also emphasized were those related to dietary restrictions, school life and the limitation of visits. Furthermore, the necessary care with body hygiene, the environment in which the patient lives and the foods to be consumed were emphasized.

> *Without the slightest doubt, the issue of personal hygiene and what we call food hygiene [...] we've been working much more on this issue today, focusing on food hygiene and the caregiver, the food handler, than on the food itself. (P6)*

In addition, the need to adapt the guidelines to the socioeconomic reality of the family was highlighted, so that they are as close as possible to the ideal. Another question presented was the indispensability of feedback, of knowing whether the guidelines offered to the caregiver was properly understood.

> *[…] you have international parameters that guide you, the house has to have a floor, it can't have exposed foundations, it can't have several things like smoke, soot [...] and then you come to a social reality that is not quite that [...] as much as the guidelines that are best for the patient are known, the social reality of the patient does not allow [...]. (P6)*
>
> *[...] you don't have feedback on how much that was understood by the family, I think that insecurity is not in the absence of information, it's in the absence of implementation of what was oriented, correctly [...]. (P7)*

DISCUSSION

When children are diagnosed with cancer, a process begins in which they and their families experience different emotional reactions. It is necessary for the family to adapt to the new requirements in their daily routine, which imposes changes in family organization and dynamics, changes in behaviors and acquisition of new knowledge related to the disease and its treatment for the safe care of the child, especially at home.[11,12] The need to educate and enable them to make this transition during the first hospitalization is a challenge for the health professionals.[3]

The professionals are incumbent upon identifying the needs and vulnerabilities generated by the process of change in the family's daily life. They are also responsible for providing knowledge, enabling the family members to continue care safely, previously performed in the hospital environment, now at their homes.[6,11]

The development and implementation of a discharge plan is essential for the safe transition of the patient to home care. The multi-professional team needs to prepare this plan in order to enhance family participation in the treatment of the child. Structured hospital discharge plans allow qualifying care from the first hospitalization to the maintenance of home care, which minimizes the occurrence of unscheduled hospitalizations and allows home care to be developed in a conscious manner, ensuring patient safety.[13-14]

Performing a prior planning for the first hospital discharge allows for the guidelines to be made systematically throughout the hospitalization, avoiding excess information in a short period of time, which may impair the assimilation of information.[14-15] It also contributes to avoid situations of stress and feelings of insecurity towards discharge by the family, it also values teamwork and family participation in treatment, as well as it contributes to continuity of care at home.

Gaps were identified in the systematization of the discharge process, which interfere with the quality of the guidelines. The lack of multi-professional planning of transitional care for discharge, which would allow for a prior organization of the educational activities to be carried out since the beginning of hospitalization, makes it difficult for the family to acquire information, which reduces the perception of doubts, and it does not even allow the team to assess how much these guidelines was understood by the family members.

Failure to provide or to implement the guidelines provided tends to cause feelings of frustration in the professionals involved. This feeling was also identified when approached with the family members, in addition to the feeling of inability to provide care to the child, either due to the professionals failing in the guidelines or because of the limited understanding of the information provided related to the impact of the diagnosis.[3]

Through this study, it was recognized that, despite the importance of all the professionals that make up the multi-professional team in the guidelines for discharge and family training, the nurse stands out as a reference professional in this process, which was corroborated by the literature.[3,5,13]

As educators, nurses have the responsibility to prepare the family for active participation in the child care process. To such an end, they need to have adequate knowledge, resources, time and support. However, in the care practice, sometimes, due to the demands of activities and functions that they assume (care management, the nursing team, and direct assistance to the children and their family), it can be difficult for them to develop the educational dimension to its fullest. The presence of a nurse to work exclusively in health education in the multi-professional team contributes to strengthening the bond between the members of the care team, child, family and with the services that make up the health network of the territory to which the family belongs, favoring the safe return to home.[13,16]

In order to increase the satisfaction of the family and of the health professionals in relation to transitional care, the program called *"Road to Home"* was developed by means of a study. The results of such research demonstrated improvements in the educational processes, but also revealed that the professionals continued to complain about the lack of time to carry out a satisfactory job. Based on that, it was proposed to insert a team nurse to address mainly the teaching of family members, which resulted in more quality in the information provided.[15]

The quality of care provided by the family members to the child at home is directly linked to the education received during hospitalization. In this sense, identifying the primary information that is essential for the instruction of the caregivers, even during the child's first hospitalization after diagnosis, is essential for a standardized education, which allows ensuring the delivery of information in a consistent manner to the family members.[6,17] That is, clarifying with the family what information they need to receive in order to provide safe care in the home environment can contribute to effective education.[5]

In this study, elementary guidelines to be provided to the families during the first post-diagnosis hospitalization were highlighted, especially those related to emergency signs, medications and environmental and dietary precautions.

Recognizing the common signs and symptoms of clinical worsening during cancer treatment was highlighted by most of the professionals in this study as one of the indispensable guidelines, as well as in other research studies in the same field, in view of the importance of the immediate referral of the child to the hospital or reference health care service in their territory. Fever being the most common sign, since it is the main indicator of the presence of infectious processes, which are potentially fatal if not treated early.[3,15,18]

The instructions related to the necessary care with the hygiene of the environment, the body and food were mentioned by the professionals as an important way to reduce the risks for infections. However, it is known that hand hygiene is the most effective and economical way to prevent infections,[19] which is an action taken by the professionals; however, despite its relevance, this action was not signaled as a focus on the guidelines.

The information on drug treatment, including chemotherapy, was also indicated by the professionals participating in this study as a fundamental instruction to be given to the family members. Errors in drug administration, especially in dosage, is one of the most common problems after discharge and can directly interfere with treatment success. These problems can be minimized by the health professionals, with the implementation of demonstrative interventions regarding the administration of medications, as well as the provision of standardized printed instructions.[3,15,18] In this study, it was possible to identify strategies used by some professionals to qualify the guidelines regarding drug administration, such as using syringes marked with different colors according to the drug and the prescribed dose, as well as the delivery of tables with the organization of the medical prescription in a language that is accessible to the family members.

For an effective educational practice, it is not enough to identify the essential information, it is also necessary to qualify the methods used for this. The needs and particularities of each patient and their family must be taken into account, with regard to the capacity and time necessary to understand the information, as well as the social, economic and literacy conditions of the family, adapting the recommendations to their realities.[3,6,20]

In this study, instruments and methods, used to carry out the guidelines, playful and demonstrative practices, the use of printed materials, and the repetition of information by the professional and especially by the caregiver, and also the availability of telephone contact were identified in case of doubts. Such instruments and methods corroborate with the recommendations indicated to increase the quality of care and the safety of children undergoing cancer treatment for hospital discharge.[4,21]

By means of this study, the participating professionals showed concern about the lack of tools to ensure that all the necessary guidelines are provided, as well as mechanisms to identify the level of understanding of the family members about the guidelines provided before the first hospital discharge. The multi-professional team is responsible for validating the family's understanding of the guidelines provided.[3] To this end, it is important to encourage the family to confirm with their professionals their understanding of the guidelines received, encouraging the family to self-question, for example, about the administration of medications, the warning signs that indicate the child's clinical worsening, and about care measures for the prevention of infections.[21]

Some alternatives are being developed to qualify the educational practices to guide families of children with cancer, with a view to safe home care. An example is the development of a standardized checklist, which facilitates the work of the team, especially nurses, in the education of the families. Such an instrument is adaptable to the needs and the economic and psychosocial reality of each family. This instrument is part of a program called *"Road to Home"*, previously mentioned, which is an interactive method of education between the professionals and the family members, consisting of a board that simulates a board game, an education station containing written and practical materials, a printed manual and a kit with items necessary to safely care for the child at home.[15,22]

Such alternatives, despite having evidenced important improvements in the quality of the educational practice in the institutions participating in the studies, require financial investment and an increase in the number of professionals, measures that do not fit in the current reality of Brazilian public health institutions.

FINAL CONSIDERATIONS – IMPLICATIONS FOR THE PRACTICE

Care transition from the hospital to the home at the first discharge of the child with cancer is a complex process, both for the health professionals and, especially, for the family. All the professionals involved in assisting these children and their families are responsible for turning this transition process into a learning period, enabling them to carry out continuity of safe care at home.

Although this responsibility lies on the multi-professional team, the nurses' important role in this process is evident, as they are the professionals who work continuously with the patient, being the facilitators in the identification of difficulties faced by the family. The role of nurse educator in strengthening the family of the child with cancer for home care is reinforced, this being a priority in care and which needs continuity, reinforcement and daily appreciation in face of the demands of the work process.

It was evident that the content of the guidelines provided by the different professionals corresponds to what is necessary for safe home care, corroborating with what was found in the literature; however, the planning process and guidelines for discharge must be considered a priority, enabling that the education of these families occurs since admission and does not end in that first period.

The identification of the psychosocial needs of each child and their families stood out as an essential aspect in the process of planning and executing discharge guidelines. In view of this, it is suggested that, before the educational process begins, consultations are carried out to welcome them in order to provide qualified listening, identify the care demands of each family, and better define approach methods.

In addition to identifying the content for family education, it is also essential to recognize effective methods for such end. Maintaining uniform communication among the professionals regarding the care guidelines, considering the needs of each family, using demonstrative tools and printed material to facilitate the family's understanding, and ensuring that all the necessary content has been exposed and understood for safe home care are some of these methods.

Therefore, it is recommended to systematize the guidelines for the care transition to home care and educational actions through the construction of a structured script to standardize the process and share responsibilities between the multi-professional team under the leadership of the nurse. This initiative corroborates the necessary improvements in this care process and would add value to multi-professional work with direct implications for children and families.

As limitations of this study, the fact that data collection was performed in a single research location can be highlighted, which restricts the number of participants in each professional area, limiting the generalization of the data, as well as the non-inclusion of nursing technicians as participants in the study, since they remain very close to the child and the family for a longer period of time during hospitalization, which favors the identification of family needs in the care actions.

The scarcity of other studies in the national literature consulted with the same theme highlights the relevance of this study and points out to the need for further research studies with the same study object. It is also suggested to carry out further studies with the participation of family members of children already undergoing treatment, which could enrich the identification of elementary information from the difficulties they faced after the first hospital discharge.

AUTHOR'S CONTRIBUTIONS

Study design. Sara Raquel Kuntz. Wiliam Wegner.

Data collection or production. Sara Raquel Kuntz. Wiliam Wegner.

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REFERENCES

1. Cruz EF, Silva LF, Goes FGB, Aguiar RCB, Moraes JRMM. Orientações de enfermagem junto à criança em tratamento quimioterápico antineoplásico. Rev. Eletr. Enf. Goiânia. 2014 abr/jun;16(2):378-85. http://dx.doi.org/10.5216/ree.v16i2.27009.
2. Aburn G, Gott M. Education given to parents of children newly diagnosed with acute lymphoblastic leukemia: the parent's perspective. Peditr. Nurs. 2014 set;40(5):243-56. PMID: 25929116.
3. Silva-Rodrigues FM, Bernardo CSG, Alvarenga WA, Janzen DC, Nascimento LC. Transição de cuidados para o domicílio na perspectiva de pais de filhos com leucemia. Rev Gaúcha Enferm. 2019;40:e20180238. http://dx.doi.org/10.1590/1983-1447.2019.20180238. PMid:31188974.
4. World Health Organization. Transitions of care: technical series on safer primary care [Internet]. Geneva: WHO; 2016 [citado 2019 nov 19]. Disponível em: https://apps.who.int › bitstream › 9789241511599-eng
5. Landier W, Ahern J, Barakat LP, Bhatia S, Bingen KM, Bondurant PG et al. Patient/Family Education for Newly Diagnosed Pediatric Oncology Patients: consensus recommendations from a Children's Oncology Group Expert Panel. J Pediatr Oncol Nurs. 2016;33(6):422-31. http://dx.doi.org/10.1177/1043454216655983. PMid:27385664.
6. Rodgers CC, Laing CM, Herring RA, Tena N, Leonardelli A, Hockenberry M et al. Understanding Effective Delivery of Patient and Family Education in Pediatric Oncology: a systematic review from the Children's Oncology Group. J Pediatr Oncol Nurs. 2016;33(6):432-46. http://dx.doi.org/10.1177/1043454216659449. PMid:27450361.
7. Landier W, Leonard M, Ruccione KS. Children's Oncology Group's 2013 Blueprint for Research: nursing discipline. Pediatr Blood Cancer. 2013;60(6):1031-6. http://dx.doi.org/10.1002/pbc.24415. PMid:23255369.
8. Polit DF, Beck CT. Fundamentos de pesquisa em enfermagem: avaliação de evidências para a prática da enfermagem. 7ª ed. Porto Alegre: Artmed; 2011.
9. Minayo MC. (Org.). Pesquisa social, teoria, método e criatividade. 29ª ed. Petrópolis (RJ): Vozes; 2010.
10. Resolução n. 466, de 12 de dezembro de 2012 (BR). Diretrizes e normas regulamentadoras de pesquisa em seres humanos. Diário Oficial da União, Brasília (DF), 2012.
11. Nair M, Paul LT, Latha PT, Parukkutty K. Parents' knowledge and attitude regarding their child's cancer and effectiveness of initial disease counseling in pediatric oncology patients. Indian J Palliat Care. 2017;23(4):393-8. http://dx.doi.org/10.4103/IJPC.IJPC_83_17. PMid:29123344.
12. Nemati S, Rassouli M, Ilkhani M, Baghestani AR. Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. Scand J Caring Sci. 2018;32(1):309-16. PMid:28869659.
13. Delatorre PG, Sá SPC, Valente GSC, Silvino ZR. Planning for hospital discharge as a strategy for nursing care: integrative review. J Nurs UFPE on line. 2013:7(esp):7151-9. http://dx.doi.org/10.5205/reuol.4767-42136-1-ED.0712esp201324.
14. Zatoni DCP, Lacerda MR, Hermann AP, Gomes IM, Nascimento JD, Rodrigues JAP. Suggestions for the improvement of guidance at the hospital discharge of children in post hematopoietic stem cell transplantation. Cogitare Enfermagem. 2017;22(4):e50265. http://dx.doi.org/10.5380/ce.v22i4.50265.
15. Wilson Smith MG, Sachse K, Perry MT. Road to Home Program: a performance improvement initiative to increase family and nurse satisfaction with the discharge education process for newly diagnosed pediatric oncology patients. J Pediatr Oncol Nurs. 2018;35(5):368-74. http://dx.doi.org/10.1177/1043454218767872. PMid:29633659.
16. Silva KL, Sena RR, Castro WS. A desospitalização em um hospital público geral de Minas Gerais: desafios e possibilidades. Rev Gaúcha Enferm. 2018;38(4):e67762. http://dx.doi.org/10.1590/1983-1447.2017.04.67762. PMid:29933425.
17. Withycombe JS, Andam-Mejia R, Dwyer A, Slaven A, Windt K, Landier W. A Comprehensive Survey of Institutional Patient/Family Educational Practices for Newly Diagnosed Pediatric Oncology Patients. J Pediatr Oncol Nurs. 2016;33(6):414-21. http://dx.doi.org/10.1177/1043454216652857. PMid:27283721.
18. Monnerat CP, Silva LF, Souza DK, Aguiar RCB, Curcino EG, Pacheco STA. Health education strategy with family members of children in continuous medication. J Nurs UFPE on line. 2016;10(11):3814-22. https://doi.org/10.5205/reuol.9881-87554-1-EDSM1011201601.
19. Lima MFS, Minetto RC. Conhecimento de pacientes onco-hematológicos em tratamento quimioterápico sobre os cuidados para prevenção de infecções [Internet]. Com. Ciênc Saúde (Porto Alegre). 2014; [citado 2019 nov 19];25(1):35-44. Disponível em: https://bvsms.saude.gov.br/bvs/periodicos/conhecimento_pacientes_onco.pdf
20. Klassmann J, Kochia KRA, Furukawa TS, Higarashi IH, Marcon SS. Experiência de mães de crianças com leucemia: sentimentos acerca do cuidado domiciliar. Rev Esc Enferm USP. 2008;42(2):321-30. http://dx.doi.org/10.1590/S0080-62342008000200016. PMid:18642745.
21. The Paediatric Society of New Zealand and Starship Foundation. Checklist before leaving hospital [Internet]. Paraparaumu, NZ: The Paediatric Society of New Zealand; 2018 [citado 2019 nov 19]. Disponível em: https://www.kidshealth.org.nz/checklist-leaving-hospital?language=zh-hans
22. Rodgers C, Bertini V, Conway MA, Crosty A, Filice A, Herring RA et al. A Standardized Education Checklist for Parents of children newly diagnosed with cancer: a report from the Children's Oncology Group. J Pediatr Oncol Nurs. 2018 jul;35(4):235-46. http://dx.doi.org/10.1177/1043454218764889. PMid:29589818.