

Preparing the return home of the children with cancer

Summary

Children with oncologic disease, between treatments, if there are no complications, return home until the next treatment. Planning the discharge is essential to promote a continuity of cares at home. An adequate preparation for discharge leads to a better management of collateral effects and to a minor risk of rehospitalisation. The goals of this study were: to identify the preparation for discharge performed to the parents / caregivers of children / adolescents with cancer submitted to chemotherapy; to identify the strategies of preparation for discharge. A qualitative, exploratory, descriptive and transversal study was developed. After the return home, 11 parents of children with cancer submitted to chemotherapy treatment, participated in the study. Data was collected using a semi-structured interview and its treatment made using content analyses, based on Bardin. From the data analyses emerged the domain The Return Home that aggregates the category Preparation for Discharge and its subcategories: Oral Information, Written Information, Comprehensibility of the Information and Information Content. The return home is simultaneously a desired and feared moment. Parents and children return to their environment, but face difficulties in daily life activities, due to the fear that is provoked by the child's vulnerability. This way, the return home should be prepared early and adequate to the singular context of each family. Oral information should be reinforced by written information, given the difficulty to process it. The comprehensibility and the content of information are peremptory components in the preparation for discharge.

KEYWORDS: PARENTS; CHILD; NEOPLASMS; PATIENT DISCHARGE; NURSING.

Introduction

Oncologic disease is a chronic illness¹, that affects individuals in all age groups. The duration of the course of the disease and the unpredictability of its evolution lead to profound and permanent changes in the lives of children and families².

Attending to the existent statistic, tumours in pediatric ages are rare. According to the International Agency for Research, in 2018, all over the world, the estimated incidence of infantile cancer in ages below 15 years was 10.2 per 100.000 children³ and in Portugal the incidence was 16.6 per 100.000 children. The three main types of tumour with higher incidence were leukemia (5.0/100.000), central nervous system tumours (2.8/100.000) and Hodgking lymphomas (1.4/100.000)⁴. As mentioned by RORENO, in 2009 in the North of Portugal, the number of cases of cancer in children with less than 15 years was 77, corresponding to 0.53% of the total number of diagnosed tumours that year⁵.

Chemotherapy is the first treatment modality for the majority of children

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with oncologic disease, and can be combined with surgery and/or radiotherapy. Its goals are: to remove or decrease the size of the tumour, stop or delay its growth, prevent metastization, reduce the recurrence, as well as to relieve the symptoms⁶.

Although chemotherapy destroys the cancer cells and tries to decrease its effects in healthy cells⁷, it presents a wide variety of short, medium and long term side effects, depending on the type of cancer, the performed treatments and on the child's / family's own characteristics.

In the last two decades, there have been significant changes in the organization of Pediatric Oncology services, with shorter hospitalization periods being recommended, so that in the treatment intervals the children stay at home⁸. After the hospitalization period, they return home with a new life condition. So that this transition happens in a smooth way, nurses, who are in the first line of care, have the duty to prepare an adequate and timely return home, focusing on a family centered care.

The child submitted to chemotherapy needs specific home cares, so parents need to acquire knowledge

and practice the execution of procedures related to the treatment and manage eventualities that may occur^{8,9,10}. Thus, capacitating parents / caregivers for self-care and self-management at home, takes on particular difficulty, because of the unpredictability of the side effects dimension and emotional vulnerability of parents¹¹ who have to deal with a life threatening illness.

To succeed in the hospital discharge planning, it is crucial the parents preparation, by the nursing team, during hospitalization¹². However, the involvement of a multidisciplinary team, is needed in this process so that the discharge is effectively planned. The information and the support provided by the health professionals must be suitable to their specific needs, in order to enable their comprehension about clinical decision-making, and empower them for the decision-making in the management of the health-disease process. The promotion of active listening, the clarification of the doubts and fears of the parents, the verification of their knowledge about the disease, the care they have to provide, the teaching, support and supervision of the care, is part of the professional practice of the nurses and enhances the excellence of care and the efficient preparation to returning home.

The preparation for discharge, shouldn't, therefore, coincide with the moment of discharge, nor end in the time to go home. Parents should have access to an information and support network so that they can feel more confident in providing their child care at home. For that, other resources should be available, like telephone lines and home visits¹³. For even if all the information is provided, in oral and written form, the vulnerability of who faces this disease in a child, may hamper the understanding of its content, or eventually restrain the capacity to retain or even adapt the information to its own situation. This way, the possibility of clarifying doubts, through a phone call and the support provided in the course of a home visit are, without a doubt, promoters of parental self-confidence.

To ensure continuity of care it is mandatory the collaboration of all health professionals and that all pursue the same goals, focusing on the particularities and needs of each child and their parents / caregivers, in order to acquire knowledge and competences to deal with the new experience, living with cancer.

Is undeniable that, oncologic disease in a child is responsible for profound physical changes, emotional and psychological, both for the child / adolescent, as well as for the parents / caregivers and family. This way, the present study emerges as a corollary of the reflexions provided by the practice. This appears in order to fill an important aspect on the cares provided to the child / adolescent with oncologic disease and their parents / caregivers and family, who manifest insecurity in the return home and due to the scarcity of investigation about the subject in Portugal.

This investigation aims to identify the preparation for discharge performed to the parents / caregivers of children / adolescents with cancer submitted to chemotherapy treatment and to identify the strategies of preparation for discharge.

Research methods

The study is based on the qualitative paradigm, of exploratory, descriptive and transversal nature. The population was constituted by the parents of children with cancer undergoing chemotherapy treatment, in a specialized Hospital Center, located in the north of Portugal, after the return home. The non-probabilistic intentional sample was consisted of 11 parents. The participants were selected by the investigator according to the following inclusion criteria:

- Parents of children with cancer submitted to a chemotherapy treatment,

independently of the number of cycles, in the Hospital Center.

- Parents of children with cancer 48 hours after returning home. It was considered that this time interval would be necessary, so that the participants would obtain a minimal perception about the experience of caring for the child at home, after completing chemotherapy treatment;

- Accepted to be in the study.

As exclusion criteria was defined: participants who don't speak Portuguese fluently.

For this study, the interview script was selected as a data collection instrument, and a semi-structured interview as technique, in order to acknowledge the experiences and needs of the parents of children with cancer.

The investigation obtained a positive consent from the Ethics Committee and the Board of Directors of the institution where it was held. The participants were contacted during the period their children were in hospital and signed an informed consent document.

Between January and June 2016, 10 interviews were conducted at the participants' homes, in a room at the Pediatric Oncology Day Hospital or other location, according to the wishes expressed by the parents. Mostly they took place in the presence of the children, being these entertained to draw or color drawings, provided by the investigator. They took place in one single session with the participation of one of the parents, in only one of the sessions both parents participated. The interviews lasted an average of 58 minutes and were recorded on audio support. They were later transcribed, respecting the language used by participants, including laughs, hesitations and silences, as suggested by Bardin¹⁴.

As a technique to analyse the content, the thematic or categorical modality was chosen, which consists in a transformation of the text in regis-

tration units and categories, being this technique the most commonly used by the content analyses^{14,15}.

The ethical questions were considered from the beginning, in choosing the theme, the type of study, participants' selection, data collection and its interpretation.

With the aim of safeguarding the participants' anonymity and confidentiality, identification codes were used and were recognized by E1 to E10.

Findings

From the content analysis of the interviews the domain "The Return Home" emerged, which aggregates the category "Preparation for Discharge" and its subcategories "Oral Information", "Written Information", "Comprehensibility of the Information" and "Information Content" (figure 1).

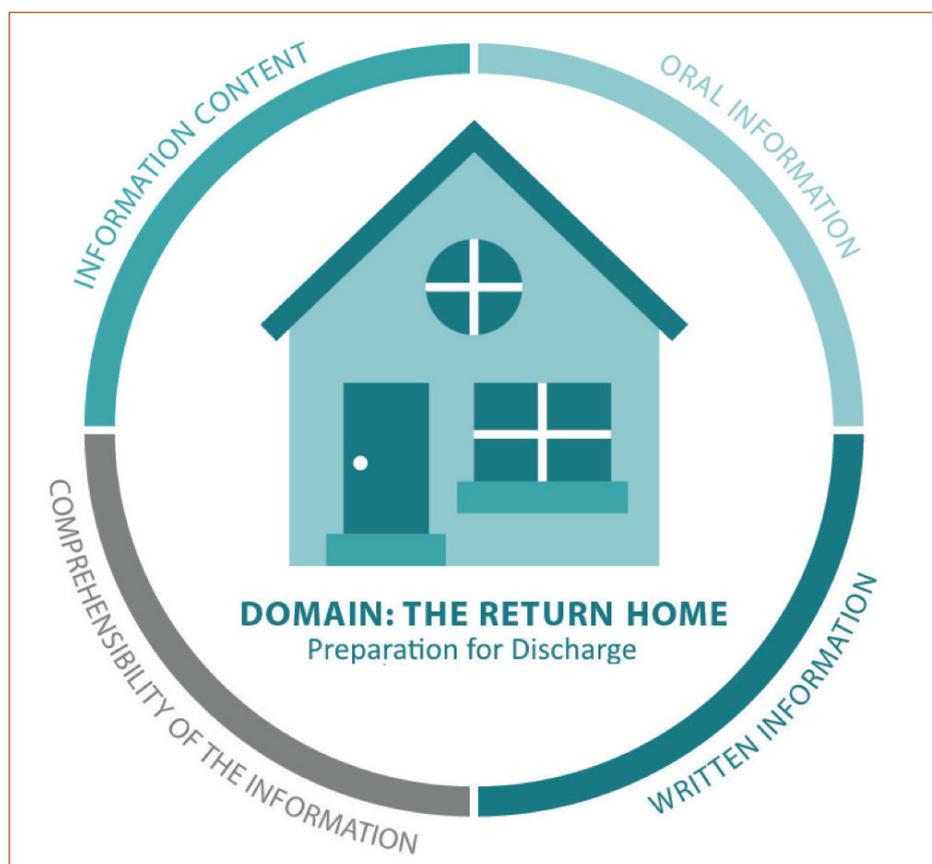


Figure 1. The Return Home

Preparation for discharge

An adequate preparation for discharge requires the participation of the entire multidisciplinary team, doctors, nurses, nutritionists, psychologists, social workers and parents, with the goal of assessing the needs of the child and parents. In order to plan discharge, one must take into account the individual characteristics of the family, and the care inherent with the condition of the child and the treatment they will need to perform at home.

All the process of preparation for discharge is based on communication between the stakeholders and requires information transmission, which may and should be conducted both orally and written. It is necessary to evaluate if the parents understood the transmitted information and if they have doubts, since the information will only be useful if it is understood.

The information transmitted to parents by health professionals is impor-

tant because it is based on anticipatory care, which helps them know what to expect, how to care for and how to deal with side effects that may arise. In addition, the information / guidance of parents promotes their empowerment, the perception of greater self-control and effectiveness of the exercise of their parental role, which will enhance health gains.

Oral information

Parents who participated in the study reported that one of the routes used by health professionals to transmit information was oral:

... before we leave they come [nurses] to ask if we have any questions [...] (E2).

... [provided the information] orally [...] (E3).

Written information

In the participants' testimony is, also, evident the use by different professionals of written information as a way of information transmission:

... in the beginning they gave us a leaflet about the effects of chemotherapy [...] it explained effectively the side effects [...] the doctors gave us that sheet, guided us [...] (E2).

... in writing [...] the nurse there in, in the hospital, printed a, a leaflet with contraindications [drug], they are very accessible actually (E3).

... the nutritionist who came to answer our doubts, gave us a paper with everything that she can and cannot eat [...] (E6).

The participants highlighted the relevance of the complementarity of oral information with the written in pediatric oncology:

... were verbal orientations [...] but the information is all very general like that, isn't it? It is an information that is verbally said and is very general not, is not explicit in terms of detail [...] I think

that, for example, should be written, [...] I think the cares should be given to parents written, so that there are no second interpretations to be in detail what it is [...] (E4).

... because to be talking about everything, half of it passes by, perhaps the information not be so verbal, we are so tired, that things are forgotten very easily, be one more information, those prospects and so (E10).

Comprehensibility of the information

In the participants' speech, it was possible to perceive the difficulty in the comprehensibility of the information, given the quantity of the same, and the vulnerability in which they live:

... they [nurses] clarify us without a doubt, but after is so much information at the same time that we almost become disorientated, without knowing very well what it is, what do we do. [...] it's a lot of information, lots of information and we cannot assimilate half of it, and then stays..., we get a get a bit lost. [...] we are so disorientated that really no, I couldn't, I couldn't understand (E2).

Sometimes we get confused, because the head is completely exhausted, isn't it? And it is not easy to assimilate everything (E10).

After the initial shock cause by the diagnosis of cancer, parents do not have the capacity to understand the information provided:

... parents, first have an emotional shock, in the first appointments, this is one thing, at the time I couldn't even speak, so, as you can see, they could sometimes say somethings and I wouldn't even listen, so, we have a very strong emotional shock (E4).

Content of the information

In the parents discourse it was possible to perceive the content of information provided by the health professionals, during the period in which the child was hospitalized, being the nutrition the most pronounced area:

... [nurses] always alert us about the care to be taken in the feeding part [...] (E2);

... not to eat raw food, [...] if he wants to eat sausages, have to open the sausage can and give to the child, at the time, can't give it raw, has to cook it. Ham has to buy those packages of ten slices of ham and give him one or two slices if open at the time, if after is already opened can't give him anymore [...]. This is not advisable because he is a child who is immunosuppressed (E7).

... be more... be more careful with the food could only eat fruit with hard skin, wash very well the food before cooking it, [...] (E8).

Cook the food well, [...] defrost in the fridge, [...], those small bottled water [...], not eat much sugar [...] (E9).

The infection prevention measures were another topic of information transmitted by the health professionals:

... the cares, also, to avoid, avoid, that he contracted diseases, infections, basically that (E1).

What we were told initially was that it wasn't appropriate for her to be in public places, with lots of people, closed spaces, [...] can go out, can go to a park [...] (E2).

If the parents have a cold, put a mask [...] careful about visitors, that cannot be with people with colds [...] (E4).

The hygiene, always clean the house, the house must be always well cleaned, [...] not to dry the clothes outside, ah more... clean very well and disinfect everything very well, the toys, everything that can be disinfected really well [...] not to use public transports [...] (E6).

They said that carpets and everything have to be shaken, outside and vacuumed [...] (E8).

The nurse said it was not recommendable to have stuffed toys and things like that (E10).

The study participants reported that health professionals taught and instructed parents to recognize and treat fever:

... has fever, immediately to the hospital [...] (E6).

In the parents speech it is possible to perceive that nurses teach about the Central Venous Line cares:

[nurses] teach the dressings [...] what you should do, if it comes out. The disinfection, the disinfectant itself, everything that is material that might be needed [...], they provided me, helped me and explained me how to do it (E5).

The cares to have, they spoke about the line, that could not get wet, had to be careful not to pull it (E10).

Teaching about medication administration at home, was also mentioned by the interviewees:

They [nurses] said what was the dose I had to inject it, [...], taught me how I should do to give the vaccine to the girl (E8).

It's easy, because you [nurses] taught me well [medication] [...], I saw there doing it and after they told me and putted

it in a sheet. And it is easy (E9).

... medication, to give the medication always on time (E10).

The participants of the study mentioned that they were informed about the need to contact the health professionals, in case of secondary effects or questions that could emerge:

If I see him pale, because the platelets may drop now, vomits, anything different to go to the Hospital [...] (E9).

Ah they talked about the fact that if he had any pain, any discomfort we could call there [hospital] or else take him there [hospital]. In case of doubts take him and go, better to go and be nothing, than not go and then be (E10).

Discussion

An adequate preparation for discharge is the continuity of cares base, which leads to a more adequate management of the disease process, increasing the caregivers' satisfaction and decreasing the need for readmissions¹³. All the process of preparation for discharge is based on communication between the stakeholders and requires information transmission, which may and should be conducted both orally and written. It is necessary to evaluate if the parents understood the transmitted information and if they have doubts, since the information will only be useful if it is understood.

The information transmitted to parents by health professionals is important because it is based on anticipatory care, which helps them know what to expect, how to care for and how to deal with side effects that may arise. In addition, the information / guidance of parents promotes their empowerment, the perception of greater self-control and effectiveness of the exercise of their parental role, which will enhance health gains.

The discharge from the hospital requires clarity in the transfer of information by health professionals, and verification of its understanding by the parents / caregivers. The training of the parents and the child, when they are old enough for care, will allow better self-management of the disease, reducing adverse events and avoiding unnecessary re-hospitalizations. Health professionals, especially nurses, will be able to assume a relevant roll in all this process, due to the longer stay with children and parents, which will allow them to build a relationship of trust. The oral information should be provided during the hospitalization in a clear and simple way, adapted to each child / family.

From the participants' discourse analysis, we conclude that the preparation for discharge differed according to the professional group, doctors and nutritionists, besides the transmission of information orally, resorted to the written information, providing leaflets. On the other hand, there is reference to the availability of nursing professionals to research and print adequate information to the parents' needs.

The results obtained corroborate those of other researchers who concluded that parents reported that nursing team shows availability to clarify questions, verbalizing that the information was transmitted orally¹⁰. The majority of families underlined the importance of written information and mentioned that rarely the information transmitted was only verbal¹⁶ and that oral information should be supported by written information^{9,17,18,19}.

The comprehensibility of the information is an essential component to the continuity of child cares at home. As information is being provided, knowledge and needs should be assessed, and encourage parents to express

their doubts¹⁸. The study participants highlight that the oral information is excessive, which associated with tiredness makes it difficult to understand it, which may lead to periods of insecurity / doubts at home.

Other authors as well verified that parents express the need for more time to understand and assimilate the information, preferring that this is provided in a phased manner¹⁶. Also refer that the fatigue and lack of sleep lead to a lack of concentration and perception about the information transmitted⁸.

The content of information transmitted to parents should address: the prevention and management of secondary effects of chemotherapy such as nausea, vomiting, fatigue, alopecia, diarrhea and mucositis; the food; the prevention of infection; the management of medication and when and who to contact regarding changes in the child's health condition²⁰.

Considering the statements of the participants, we conclude that health professionals emphasize the use of a neutropenic diet as a crucial tool, given the susceptibility to infection.

Scientific evidence emphasizes that the potential benefits of a neutropenic diet are very limited. However, it is still prescribed in many institutions, with the aim of preventing infections originated by food and / or bacteremia in patients with neutropenia²¹.

Nowadays, the Safe Food Diet is defined by the United States of America Agriculture Department, by the Food and Drug Administration and by the Centers for Disease Control and Prevention as the main method to prevent diseases related with food in immunosuppressed patients²¹. This diet emphasizes the same hygiene and security rules in the food preparation and confection, the big difference is the possibility of ingestion of raw food and vegetables, that should be carefully washed^{21,22}.

Neutropenia occurs between seven and twelve days after the chemo-

therapy treatment. This period, called NADIR, can vary according to the chemotherapy drug and its dose. Therefore, mainly in this timeframe, parents and children should observe carefully the signs and symptoms of infection and minimize the risk of its appearance^{7,23}.

The infection prevention measures and the recognition and treatment of fever were another topic of the information transmitted by the health professionals. The fever is the main sign of infection, and sometimes the only, in an immunosuppressed child, so it should be treated as an emergency situation. Health professionals should teach and instruct parents to recognize it and treat it²³.

The administration of therapy, the responsibility previously assumed by nurses, on the child's return home, transits to the parents. However, the occurrence of errors in medication administration at home is a reality²⁴. This way, health professionals play a key role in the parental competencies acquisition, in the administration of medication, to avoid that mistakes happen, both in the preparation and administration.

The participants of the study reported that they were informed about the need to contact the health professionals regarding changes in the child's health condition or questions that could emerge. These results corroborate those obtained by other researchers²⁵, who recognized the importance of informing and instructing in an individualized way, to optimize the management of everyday life at home.

The information transmitted to parents about the cares they will have to provide on the return home, as well as, the contact with the health professionals, 24 hours a day, promotes feelings of security and confidence in parents, who return home with their child with a new health condition and needs new cares.

The nursing team assumes a relevant role in the patient and family education^{26,27}. However, when it is not effective, the probability of occurrence of adverse events as the error in the administration of medication and the difficulty of recognizing emerging situations increases⁹. Teaching, instructing, training and supervising parents about their child treatment and disease, promotes the development of knowledge and competencies to provide the necessary care at home. Nevertheless, the effectiveness of discharging presupposes the continuity of support at home, which must be flexible according to the needs. Thus, the availability of a telephone contact, as already mentioned can contribute to make parents feel safer, as well as support through the home visit. Social networks, forums can be a support strategy, as long as there are health professionals to give this support.

Conclusion

The return home is experienced by the child and their family as one of the most awaited moments. However, the new condition of the disease, of the child, the responsibilities in the management of the family social life, the feeding, the body hygiene, the susceptibility to infection, the medication, the chemotherapy effects, the worry and continuous monitoring to prevent and identify possible emergent situation, potentiate feelings of uncertainty and insecurity in parents. This way, the return home should be adequately and timely prepared by all the multidisciplinary team, through oral information complemented by written information, which contemplates all the cares to provide and contacts of the institution. In addition, other support resources should be available, taking into account unpredictable situations that may arise at home.

The moment when the information about the disease and the cares inherent to it is provided, as well as, how it is transmitted, affect the comprehensibility e consequently the preparation for discharge and return home. The information comprehensibility is this way a condition to which the capacitation of the parents is actually effective.

bility e consequently the preparation for discharge and return home. The information comprehensibility is this way a condition to which the capacitation of the parents is actually effective.

We conclude that the majority of issues was addressed by the multidisciplinary team, highlighting the concern and recognition of the need of parents and children to have enough knowledge and competencies to deal with the new condition of the child's illness at home. However the speech encountered some difficulties, that drive the need for better discharge planning and the creation of a professional support to assist the management of unusual situations that arise in everyday life at home.

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