Original article

SUGGESTIONS FOR THE IMPROVEMENT OF GUIDANCE AT THE HOSPITAL DISCHARGE OF CHILDREN IN POST HEMATOPOIETIC STEM CELL TRANSPLANTATION*

Débora Cristina Paes Zatoni[1], Maria Ribeiro Lacerda[2], Ana Paula Hermann[3], Ingrid Meireles Gomes[4], Jaqueline Dias do Nascimento[5], Jéssica Alline Pereira Rodrigues[6]

ABSTRACT: Qualitative descriptive study with suggestions for the improvement of guidelines for hospital discharge of children in post- hematopoietic stem cell transplantation. The study was conducted in a public service specialized in bone marrow transplantation in southern Brazil, with 58 participants, including professionals of the multidisciplinary team and family caregivers, interviewed in the January 2014-March 2016 period. Thematic content analysis was used. The possibilities of improvement identified here are as follows: training of the professionals involved in care, construction and implementation of discharge planning by the multidisciplinary team, guidance provided also to the patients (children), use of various ways to guide and prepare the appropriate teaching materials. The discharge process is complex, and the staff that supports patients and caregivers is responsible for turning this moment of transition of care from hospital to home into a period of learning, assisting them in home care.
DESCRIPTORS: Hematopoietic stem cells transplantation; Patient discharge; Nurse; Multidisciplinary team.

SUGESTÕES DE ORIENTAÇÕES PARA ALTA DE CRIANÇAS NO PÓS-TRANSPLANTE DE CÉLULAS-TRONCO HEMATOPOIÉTICAS

RESUMO: Estudo qualitativo descritivo com sugestões de aprimoramento de orientações para a alta hospitalar de crianças no pós-transplante de células-tronco hematopoiéticas. Realizado em serviço público de transplante de medula óssea do sul do Brasil com 58 participantes, entre eles profissionais da equipe multiprofissional e familiares cuidadores, entrevistados de janeiro de 2014 a março de 2016. Utilizou-se a análise de conteúdo temático categorial. As possibilidades de aprimoramento são capacitação dos profissionais envolvidos no cuidado, construção e aplicação de planejamento de alta pela equipe multiprofissional, inclusão da criança na orientação, utilização de formas variadas para orientar, e elaboração de material didático apropriado. O processo de alta hospitalar é complexo e a equipe envolvida na assistência ao paciente e cuidador é responsável por tornar esse momento de transição um período de aprendizagem, para auxiliá-los nos cuidados em casa.
DESCRITORES: Transplante de células-tronco hematopoiéticas; Alta do paciente; Enfermeiro; Equipe multiprofissional.

SUGERENCIAS DE ORIENTACIONES PARA ALTA DE NIÑOS EN EL POS TRASPLANTE DE CÉLULAS MADRES HEMATOPOYÉTICAS

RESUMEN: Estudio cualitativo descriptivo que trae sugerencias de perfeccionamiento de orientaciones para el alta hospitalar de niños en el pos trasplante de células madres hematopoyéticas. Fue realizado en el servicio público de trasplante de médula osea en sur de Brasil con 58 participantes, entre profesionales del equipo multiprofesional y familiares cuidadores. Estos fueron entrevistados de enero de 2014 a marzo de 2016. Se utilizó el análisis de contenido temático categorial. Las posibilidades de perfeccionamiento son capacitación de los profesionales participantes en cuidado, construcción y aplicación de planeamiento de alta por el equipo multiprofesional, inclusión del niño en la orientación, uso de formas distintas para orientar y elaboración de material didático adecuado. El proceso de alta hospitalaria es complejo, y el equipo integrado en la asistencia al paciente y cuidador es responsable por ayudar en los cuidados en casa y para que ese momento de transición sea un periodo de aprendizado.
DESCRIPTORES: Trasplante de células madres hematopoyéticas; Alta del paciente; Enfermero; Equipo multiprofesional.

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[1]Nurse. Master om Nursing. Nurse at the Intensive Care Unit of Complexo Hospital de Clínicas da Universidade Federal do Paraná. Curitiba, PR, Brazil.
[2]Nurse. PhD in Nursing. Professor at the Postgraduate Course in Nursing of Universidade Federal do Paraná. Curitiba, PR, Brazil.
[3]Nurse. PhD in Nursing. Nurse Supervisor at the Diagnostic Examination Unit Unidade de Exames Diagnósticos do Complexo Hospital de Clínicas da Universidade Federal do Paraná. Curitiba, PR, Brazil.
[4]Nurse. PhD in Nursing. Nurse in a Bone Marrow Transplant unit of Complexo Hospital de Clínicas da Universidade Federal do Paraná. Curitiba, PR, Brazil.
[5]Enfermeira. PhD Student in Nusing. Nurse of the Laboratory of Nursing Practices of Universidade Federal do Paraná. Curitiba, PR, Brazil.
[6]Nurse. PhD in Nursing. Nurse in a Bone Marrow Transplant unit of Complexo Hospital de Clínicas da Universidade Federal do Paraná. Curitiba, PR, Brazil.

Corresponding author:
Débora Cristina Paes Zatoni
Universidade Federal do Paraná
R. Wanda dos Santos Mullmann, 1266 - 83323-123 – Pinhais, PR, Brasil
Email: debypz@gmail.com

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INTRODUCTION

Hospital discharge (HD) occurs after a period of hospitalization for the treatment of a particular disease, and in some cases, ongoing care will be needed at home. During this period, patients and/ or family caregivers, when present, may experience fear and concern about the transition of care as the patients move from the hospital to home [1].

Regarding guidance at the hospital discharge of children who underwent hematopoietic stem cell transplantation (HSCT), a multidisciplinary approach is essential to ensure proper guidance to the children, their families and caregivers on the ongoing care that will be needed by the these patients at home (e.g. related to dietary restrictions and other specific care) [2].

However, it was found that such guidance is usually provided just before discharge from hospital of these patients. There are several reasons for this practice, e.g. lack of personnel and work overload of the multidisciplinary team. Family caregivers are unable to assimilate the information received and expose their doubts and difficulties in such a short period of time. An unsuccessful care transition process at HD has a negative impact on the recovery of these children in the post discharge period [2].

Specific recommendations and guidance on hospital to home transition, which have many important implications, are transmitted at discharge from hospital. Ideally, such recommendations and guidance should be provided during all the stages of the treatment [3].

The most effective strategy related to guidance at HD is the use of educational components and records of such guidance. Discharge planning should be the focus of nursing care from the admission of patients to the unit until discharge, to minimize their anxiety and clarify their doubts [4].

Actions aimed to improve guidance on care at hospital discharge are therefore needed to prepare family caregivers for home care, contributing to reduce complications and avoidable readmissions.

Given the importance of the guidance provided at hospital discharge, this article introduced the category "Aprimoramento das orientações para a AH de crianças no pós TCTH" (Improvement of guidance regarding the discharge process of children in post HSCT, one of the categories identified in the master's dissertation entitled Guidance regarding the discharge process of children in the immediate post hematopoietic stem cell transplant period (HSCT). This study is part of the project "A vivência de pais de crianças submetidas ao TCTH" (The experience of the parents of children who underwent HSCT) funded by the National Council for the Scientific and Technological Development – CNPq, through Edital Universal CNPq no 14/2012.

The present article aimed to present suggestions for the improvement of guidance at the discharge process of children in post HSCT.

METHOD

Descriptive and qualitative study conducted in a large public teaching hospital in southern Brazil. The pioneer service is a national reference in hematopoietic stem cell transplant, used in the treatment of hematological, oncological, and hereditary immunological disorders.

The study included 21 caregivers of children in the immediate post HSCT period, i.e. up to 100 days after transplantation, 25 nurses working in the inpatient hospital setting (from pre to post HSCT period, who delivered direct care to children at the Bone Marrow Transplant Unit (STMO) and have been performing their professional activities for more than six months; and 12 professionals that integrate a multidisciplinary team, including professionals in training (psychology and dentistry residents) who have been performing their activities for at least six months, all of them attached to the inpatient unit or outpatient unit of the referred STMO.

The selection of the participants was based on the topic of the study, which concerns actions inherent to professionals who develop direct care to children. The group of family caregivers was included in the sample because they are the main recipients of the guidance delivered at hospital

discharge. Therefore, their participation is essential for the achievement of the treatment goals.

For data collection, semi-structured instruments were used to interview the 58 participants. For the arrangement of the date and time of the interviews, the subjects were contacted by phone or approached personally. Data was collected from January 2014 to March 2016, and the interviews were recorded and transcribed in full.

Table 1 shows the number of participants according to respondents' class and coding.

Table 1 – Number of participants and coding used during the interviews. Curitiba, PR, Brazil, 2016

Classes of participants		**Coding in the interview**	**Total per class**
Nurse		E	25
Family caregiver		FC	21
Multidisciplinary team	Nutritionist	N	12
	Physician	M	
	Physiotherapist	F	
	Occupational Therapist	TO	
	Social Worker	AS	
	Psychologist	P	
	Dentist	O	
Total number of participants		--	58

Thematic Content Analysis (TCA) was used in data processing, which allows handling messages, allowing some inferences about reality (5-6). TCA systematizes data analysis through the procedures described below, guiding the researcher to achieve the results (6).

First there is a free floating reading of the transcripts of the interviews, followed by formulation of the hypotheses that can be accepted or rejected at the end of the study. During determination of the record units, excerpts from the statements of the participants are listed and the units of meaning are defined. These are grouped by similarity. Subsequently, thematic analysis of the units of meaning is performed, followed by category construction, as shown in Table 2.

Table 2 – Category construction considering the grouping of units of meaning and the total number and percentages of record units per unit of meaning. Curitiba, PR, Brazil, 2016

Category	**Units of Meaning**	**Total number of *URs**	**URs%**
Improvement of the guidance at hospital discharge of children in post HSCT	Suggestions for improvements	193	74
	Nurse as a link between the team and the family caregiver	69	26
	TOTAL:	262	100

*URs – Record Units

The project was approved by the Research Ethics Committee of Setor de Ciências da Saúde of Universidade Federal do Paraná, under statement no 398.957.

RESULTS

"Improvement of guidance at hospital discharge of children in the post HSCT period "contains two units of meaning that are related to the need for improvements in guidance at HD, mentioned by the participants, and the relevance of the actions of nurses, who provide a link between the multidisciplinary team and the family caregiver in the process of hospital discharge, as shown in Table 2.

Some suggestions for improvement follow:

1. Standardization of the hospital discharge process through the development of a protocol or checklist that improves guidance, recommends its continuity throughout the hospital stay and that involves day and night shift teams, and not only the day shift team, as it was the case in the health service in this study.

Record and document all the steps that must be followed, because sometimes we forget to include an item. A checklist to assess all the steps taken during the day would be interesting. (E20)

2. Staff training, addressing the context of each profession involved, to ensure effective multidisciplinary work.

Oh, I think we must learn. Like I said, I was looking for information on the internet, like that little manual. (P2)

3. Early guidance at the beginning of the treatment, to prevent the accumulation of information in the few days before hospital discharge

[...] permanent guidance on the discharge process, and not only at the end of the treatment, to reinforce the importance of these recommendations throughout the hospitalization period. (TO)

During the entire hospitalization period [...] we could discuss all the recommendations of the hospital discharge process [...] transmitting the information more slowly, gradually, so that it could be better assimilated. (N1)

4. Child and family caregiver monitoring by the same health professional until hospital discharge. This favors the establishment of closer ties between health professional and patient – caregiver, corroborating the recommendation of a more customized discharge process.

[...] In my opinion, guidance at hospital discharge should be provided by the nurse assigned to give care for the patient during most of the patient's stay and responsible for the admission process, as this professional is more aware of the weaknesses of the patient and his/her family. (E20)

5. Use of a child health record, as the health service analyzed in this study already counts on material targeted to adults. Both health records must be constantly updated and use easy to understand language, pictures and including recommendations from all the different health professionals.

[...] We considered the creation of a manual targeted to children, but it didn't work [...] maybe the design needs to be improved, or maybe we should have the manual revised by a professional, an early childhood educator, in order to make it more accessible to children (E10)

6. Practical guidance that encourages the family caregiver and the child to develop the necessary care under the supervision of a professional, e.g. workshops for family caregivers during hospitalization.

[...] During the caregiver's stay at the Bone Marrow Transplant Unit (STMO), he/she should receive appropriate guidance on home care, or participate in a workshop or course for caregivers, in order to be prepared for the hospital discharge process. This process must take into consideration the characteristics of each individual, level of understanding, among other aspects. And this should be performed throughout the entire hospitalization period. (E18)

I think the patient's parents should be asked to discuss the subject, provide examples. (FC7)

7. Professional who provides guidance during the process of hospital discharge. In the pre-transplant phase, in order to become familiar with the patient's routine and be able to provide more accurate

guidance, and in the post-transplant phase, for follow- up, clarification of doubts and verification of compliance with the guidelines received during hospitalization.

I believe that a visit to the child at the home setting, prior to hospital admission, would give us greater insight on the conditions of this patient, enabling us to provide guidance customized to the individual needs of patients and caregivers (E12)

A professional, nurse or social worker, could visit the patient at home to monitor the post-discharge period. (E8)

Regarding the nurse's role as a link between the health staff and family caregivers, the statements reinforce the importance of this professional in the context of the multidisciplinary team, providing direct and uninterrupted care to children who underwent HSCT.

Because of their close contact with the patients and family caregivers, nurses are a link between the patients and the other members of the multidisciplinary team, being responsible for clarifying doubts of these professionals related to their specific areas, e.g. on nutritional care.

The success of the transplant depends on the nursing professionals. The family members have much more contact with us than with the other health professionals... so sometimes when they [family caregiver] has doubts about nutrition, we call the nutritionist, and so on. We mediate all the contacts here. (E15)

Family caregivers and the other health professionals identify the nurse as the reference point, a link between the team and the family caregiver in various situations related to hospitalization, including the process of hospital discharge.

I realize, for example, that nursing is essential in guidance [...] regarding personal hygiene and house cleaning [...] they often ask [...] about this matter, and we tell them to ask the nursing staff about it. (N2)

In this regard, when asked about the professional to whom they would turn to if they had any doubts during the post hospital discharge period, the first professional mentioned by family caregivers was the nurse.

If I had any questions, I asked the nurses ... they are always around [...] nurses are closer to us than other professionals. (FC15)

DISCUSSION

The health professionals frequently expressed their concern with the standardization of the discharge process, since a discharge planning protocol is needed in the health facility where the study was conducted. The literature stresses the importance of a properly designed discharge planning, with the cooperation and participation of all the professions involved in direct patient care to ensure that the caregiver and the patient are gradually involved in home care activities .According to a study on hospital discharge in Iran, the structuring of a discharge plan will also improve adherence to treatment and reduce the number of readmissions[7].

In the United States, the United Kingdom and in Australia, discharge planning has been a priority for decades. These countries have policies and procedures that were formulated through a multidisciplinary approach, which favor the implementation of the discharge process. In the past few years, the rates of preventable readmissions have been considered a hospital care quality indicator [7].

Corroborating this issue, a study conducted in the US reinforces the recommendation that hospital discharge processes are constantly improved. And these processes are more and more perceived as a priority in the national agenda, as a way to reduce preventable readmissions. The referred study also emphasizes the importance of adequate discharge planning to the promotion of continuous assertive care[8].

Therefore, discharge planning ensures the quality of care from the moment of hospital admission, significantly reduces hospital readmission, reduces hospital costs, favors continuity of responsible

home care, improves the mental health of patients and family members, in addition to ensure patient safety[9]. The reduction in the number of readmissions, through the adoption of best practices of discharge planning, can generate considerable savings [10].

Regarding the need for staff training, the nurses said that training and capacity building of health professionals are needed to ensure a proper discharge planning. According to a study on nutritional guidelines in the community context, in addition to exposing the precariousness of the health system structure, the nurses said that the professionals needed more in-depth knowledge on the theme to develop the discharge planning [11]. Permanent training is necessary to ensure the professionals are constantly updated on new technologies and treatments.

Nurses must constantly seek to improve knowledge on their specific area to provide reliable care to the patients and their families. The identification of potentialities and vulnerabilities daily experienced during contact with patients and family members aims to guide health promotion actions in the hospital setting [12].

The empowerment of human resources through the acquisition of knowledge is vital for the proper implementation of the discharge plan, with evidence pointing to the benefit of professional training for practice [11].

The need for early guidance is based on studies on the subject, aimed to promote direct interaction of family caregivers since the beginning of the hospitalization period. Corroborating the aforementioned, even today, caregivers of patients in palliative care are not perceived as key actors in the care process[13].

Moreover, the discharge planning should be a priority in the nursing care process, starting when the patient is admitted to the hospital, involving interaction with the family members and seeking comprehensive care [14].

Regarding the appropriate teaching materials, the professionals suggested these materials can be adapted for children to facilitate the discharge process. A study on the hospital discharge process carried out in Iran, which found that lack of professional training and of adequate teaching materials are obstacles to the hospital discharge process, supports this suggestion [7]. The use of tools in the discharge planning can help standardize the process steps and ensure that all steps are completed before the patient leaves the hospital[15].

Therefore, the teaching materials must be based in the scientific literature comprising the biological, psychosocial and spiritual needs of the patients and families, in order to minimize any possible doubts and anxieties about care practices, favoring adherence to home treatment. The use of structured tools and appropriate teaching methods to support the discharge planning is valid for the standardization of this process [8,16-17].

Regarding guidance through practical actions, it is known that hospital discharge should be approached as an action plan of the multidisciplinary team since hospital admission. This approach promotes a more humanized interaction with the families and patients, favoring the learning necessary to a safe hospital discharge process. An educational intervention for the patient and family, even if it is short is an effective way of empowering these individuals [11,18].

The professionals who participated in this study emphasized the importance of the presence of a health professional monitoring the post-discharge period and attentive to the way in which the patient and his/her caregiver implement the guidance received, in order to clarify doubts, facilitate the adaptation of the patient and his/her family to the new situations experienced.

Studies on issues related to the performance of nurses responsible for guidance to patients with diabetic foot, at hospital discharge, during the transition of care from hospital to home, showed that telephone calls or home visits may improve post-discharge clinical outcomes. The studies also detected significant differences in the rates of readmission on the 84 days after hospital discharge, which were associated to the telephone calls [16,19].

Nurses were described as the main reference during the hospitalization period, often considered the link between the child, the family caregiver and the multidisciplinary team responsible for care, which corroborates the literature. The nurses of the STMO can deliver competently and effectively all

the care inherent to the patients who underwent HSCT, ensuring comprehensive assistance [20].

In the hospital setting, the doctor is legally responsible for patient discharge. However, the nurse is responsible for the coordination of discharge planning because, as aforementioned, this professional interacts with the patients and family members throughout the entire hospitalization period. The nurse's presence conveys integrity and reliability, which is a valuable asset in health promotion [8,11-12].

However, the nurse must maintain close ties with the patient and family members to assess their level of preparedness and willingness to promote care, enabling them to develop home care. Discharge planning requires the nurse's ability to promote adherence. While the patient is in a critical stage, the nurse can identify educational aspects that should be introduced in the hospital routine. Health education can be used to nurses to enable the patient and his/her family to promote home care [1,12].

One limitation of this study is the small sample size, as it was conducted in only one hematopoietic stem cell transplantation center.

CONCLUSION

The hospital discharge process is complex, and the staff involved in direct care to the patient and the caregiver is responsible for turning this process into a period of learning, in order to prepare the caregiver and patient for transition of care from hospital to home.

The multidisciplinary team should be constantly trained, and the different professionals involved in care should plan hospital discharge, through a process that ensure the family caregiver and the child are capable of properly and safely developing the necessary care at home.

The interaction between the multidisciplinary staff and caregivers allows the clarification of doubts during hospital admission, as well as treatment adherence, assisting family caregivers in the delivery of care in the home setting.

The role of nurses during the planning and execution of the discharge process is emphasized here The expertise and the permanent involvement of these professionals with patients and caregivers allows the establishment of a relationship of trust that favors the clarification of possible doubts about the treatment and guidance.

The present study intends to contribute to the elaboration of healthcare strategies and health education actions targeted to children undergoing HSCT and their families.

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