

Construction of a nursing care protocol for children in post-hematopoietic stem cell transplantation

Construção de protocolo de cuidados de enfermagem à criança no pós-transplante de células-tronco hematopoiéticas

Construcción de protocolo de cuidados de enfermería para niños después del trasplante de células tronco hematopoyéticas

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ABSTRACT

Objective: To construct a nursing care protocol for children in post-hematopoietic stem cell transplantation.

Method: Methodological research carried out from January to September 2019, in three steps: (a) integrative review (nursing care was identified); (b) theoretical structuring and organization of healthcare based on the Theory of Basic Human Needs and on the International Classification for Nursing Practice (supplementing the review data); and (c) development of a protocol in the three previously mentioned stages. Analysis of the understanding of the protocol's items/care was performed by three specialist nurses.

Results: The care protocol consists of 40 nursing problems and is organized in accordance with the psychobiological, psychosocial, and psycho-spiritual needs of children undergoing transplantation, integrating practical and guidance care.

Conclusion: The care protocol is an important technology for nursing care to transplanted children, aimed to prevent and manage transplantation complications.

Keywords: Nursing methodology research. Hematopoietic stem cell transplantation. Nursing diagnosis. Nursing care. Child. Standardized nursing terminology.

RESUMO

Objetivo: Construir protocolo de cuidados de enfermagem à criança no pós-transplante de células-tronco hematopoiéticas.

Método: Pesquisa metodológica conduzida entre janeiro e setembro de 2019 e, em três etapas: a) realização de revisão integrativa (cuidados de enfermagem foram identificados); b) estruturação e organização teórica de cuidados a partir da Teoria das Necessidades Humanas Básicas e da Classificação Internacional para a Prática de Enfermagem, complementando os dados da revisão; c) desenvolvimento do protocolo, cuja elaboração integrou as etapas anteriores. A análise de compreensão de itens/cuidados do protocolo foi realizada por três enfermeiros especialistas.

Resultados: O protocolo de cuidados é composto por 40 problemas de enfermagem e está organizado de acordo com as necessidades psicobiológicas, psicossociais e psicoespirituais de crianças submetidas ao transplante, integrando cuidados práticos e de orientação.

Conclusão: O protocolo é opção tecnológica para a assistência de enfermagem à criança transplantada, com vistas à prevenção e manejo das complicações.

Palavras-chave: Pesquisa metodológica em enfermagem. Transplante de células-tronco hematopoiéticas. Diagnóstico de enfermagem. Cuidados de enfermagem. Criança. Terminologia padronizada em enfermagem.

RESUMEN

Objetivo: Construir un protocolo de cuidados de enfermería para niños después del trasplante de células tronco hematopoyéticas.

Método: Investigación metodológica realizada entre enero y septiembre de 2019 para construir un protocolo, en tres etapas: a) realización de revisión integradora (fueron identificados cuidados de enfermería); b) estructuración y organización teórica de cuidados a partir de la Teoría de las Necesidades Humanas Básicas y de la Clasificación Internacional para la Práctica de Enfermería, complementando los datos de la revisión; y, c) desarrollo del protocolo, cuya elaboración integró las etapas anteriores. El análisis de comprensión de ítems/cuidados del protocolo fue realizado por tres enfermeras especialistas.

Resultados: El protocolo de cuidados está compuesto por 40 problemas de enfermería y está organizado de acuerdo con las necesidades psicobiológicas, psicosociales y psicoespirituales de niños sometidos a trasplante, integrando cuidados prácticos y de orientación.

Conclusión: El protocolo de cuidados es una opción tecnológica para la asistencia de enfermería al niño trasplantado, con los objetivos de prevención y manejo de las complicaciones del trasplante.

Palabras clave: Investigación metodológica en enfermería. Transplante de células madre hematopoyéticas. Diagnóstico de enfermería. Atención de enfermería. Niño. Terminología normalizada de enfermería.

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INTRODUCTION

Hematopoietic Stem Cell Transplantation (HSCT) is a life-saving therapy used for hematological or bone marrow disorders. Transplant is autologous when the stem cells come from the same person who gets the transplant, i.e. the patient, and allogeneic, when stem cells are from another person, a donor⁽¹⁾.

Allogeneic HSCT, the type of transplant most recommended for and performed in children, involves a high risk of complications and recurrent hospitalizations due to the highly immunosuppressive condition, and other risk factors such as graft versus host disease (GVHD), long duration of neutropenia and long grafting time⁽²⁾.

The treatment lasts at least 100 days, including the pre- and post-transplant phase in which the child is monitored clinically and through laboratory tests, in addition to undergoing a large number of medications and transfusions. During this period, in the first 30 days, on average, patients are hospitalized and on the other 70 days, they are in day hospital care and outpatient care.

HSCT-related mortality, disease-free survival, overall survival, and GVHD (acute and chronic) are concerns in the pediatric post-transplant scenario, with the latter considered the most feared complication of the procedure⁽³⁾. A previous study found that some of the main events and complications that affected transplanted children in the period between hospital discharge and 100 days were pain (60.9%), cough (57.2%), runny nose (47.1%), fever (47.1%), vomiting (46.4%), diarrhea (39.1%), viral infection (37%), nausea (35.5%), GVHD (26.8%) and neutropenia (23.9%)⁽⁴⁾.

Regarding health care, whether in the hospital setting or at home, the various professionals involved must ensure the best possible recovery for patients undergoing this type of transplant⁽⁵⁾. However, due to the characteristics of the care provided by nurses and their constant presence at bedside, they can greatly contribute to the recovery of the patients.

Nurses are supposed to develop and improve their work process in HSCT, using tools and/or technologies supported by evidence that qualify the care provided, and get involved in the prevention and management of complications in post-transplantation, such as the development of a care protocol.

It should be noted that the construction of protocols is a strategy aimed to contribute to improve the quality and safety of care and to increase satisfaction with nursing work⁽⁶⁾, as this tool describes a given care situation, defining operational aspects, the professional responsible for the execution and how the action will be performed. The

protocol includes various procedures, such as care and/or treatment actions, regarding physical, emotional and social aspects, in addition to educational actions. It may also involve the participation of other professionals who integrate the multidisciplinary team⁽⁷⁾.

The care protocol aims to improve assistance, and in the present study, nursing care, favoring decision-making in clinical practice. It is a technology that provides the best care alternative available, as it encompasses actions supported by evidence from research findings. Thus, it is recommended that professional nursing assignments are contemplated by care protocols, ensuring the organization of work and compliance with legislation, especially in critical therapies, such as HSCT⁽⁸⁾.

In view of the above, the justification for this study is that the construction and use of a nursing care protocol, capable of guiding the team's actions, allows for standardization of care, which may vary among the different centers of transplantation. Such a protocol can corroborate the results of therapy and contribute to the patient's recovery, and it can be used in the care of children both on day hospital regime and outpatient care.

Furthermore, the Bone Marrow Transplant Service (BMTS) where the present study was conducted assists Brazilian high-risk pediatric patients. Therefore, transplants that entail major risks for recipients (allogeneic and with incompatibilities) are performed at the referred service, and Nursing Care Systematization (SAE) is not effectively implemented.

Thus, the following question was proposed for the development of the present study: How to develop a nursing care protocol for children in post-hematopoietic stem cell transplantation? The purpose of the study is then the construction of a nursing care protocol for children in post-hematopoietic stem cell transplantation.

METHOD

Study based on the psychometrics theory proposed by Pasquali's methodological reference and that involves two phases. Phase 1 concerns the construction of the care protocol, was carried out from January to September 2019 and is the focus of this study. Thus, the construction of the protocol was performed in three stages, as follows: a) integrative review; b) theoretical structuring and organization of nursing care based on the Theory of Basic Human Needs (TBHN) and the International Classification for Nursing Practice (ICNP®); c) protocol development. Content validation of the protocol constructed will take place at a later stage.

The integrative review aimed to analyze the available evidence about nursing care provided to post-HSCT patients. The care identified comprised the construction of the referred protocol⁽⁹⁾.

Theoretical structuring and organization of the knowledge produced by ICNP® 2017 was then carried out, complementing the care identified in the literature, and also constructing new care based on the main complications identified in a previous clinical profile of the same population for whom the protocol is intended⁽⁴⁾. Nursing diagnoses (in accordance with ISO 18.104) and care, according to the basic human needs affected, were established based on this theoretical structure and organization of knowledge.

In the second stage, a chart was created with MC Word, which integrated and correlated primary basic human needs (those primarily affected), according to TNHB; nursing problems (main events and complications identified in the profile study), human needs affected as a result of primary needs, diagnoses and nursing care. This step was performed by a nurse with practical experience in HSCT for over ten years, who is the author of the clinical profile study and the integrative review.

As far as the ICNP® is concerned, the version used was from 2017 (printed), and uses a terminology that unifies the validated and used worldwide nursing language. The terminology was read in full and exhaustively, in order to reconcile and structure nursing diagnoses and care according to the profile of needs of children undergoing HSCT. Semantic and cross-cultural adaptation was used for some terms, according

to the setting and the health institution - a national BMTS located in a teaching hospital -, so that the protocol could be clearly understood and used by HSCT nurses, maintaining the hierarchy and the original term code.

Subsequently, an initial version of the protocol was developed and assessed for the understanding of the items/care through semantic analysis, as recommended by psychometrics. Thus, four meetings were held with a committee of experts formed by three clinical nurses working in HSCT, randomly selected, and performing their duties in the referred BMTS, with 31, eight and five years of experience. The invitation to participate in the study was made in person, with the signing of the Informed Consent Form (FICF) at the first meeting, and the instrument used was the initial version of the care protocol (printed). The different times of work experience of these professionals were purposely chosen in order to increase diversity and the chances of understanding the vocabulary used in the protocol.

After this step, the content of the protocol was reformulated by the main researcher, and the considerations made by the experts were gathered and accepted. Subsequently, the second version of the protocol will be sent for content validation by Brazilian expert judges. Figure 1, below, shows the process of construction of the care protocol.

The care protocol comprises 40 nursing problems, divided into three spheres, namely: psychobiological, psychosocial and psychospiritual. The tool is aimed at children undergoing HSCT, aged up to 12 years old, hospitalized, in day hospital or in outpatient clinic, with the purpose of being used by nurses

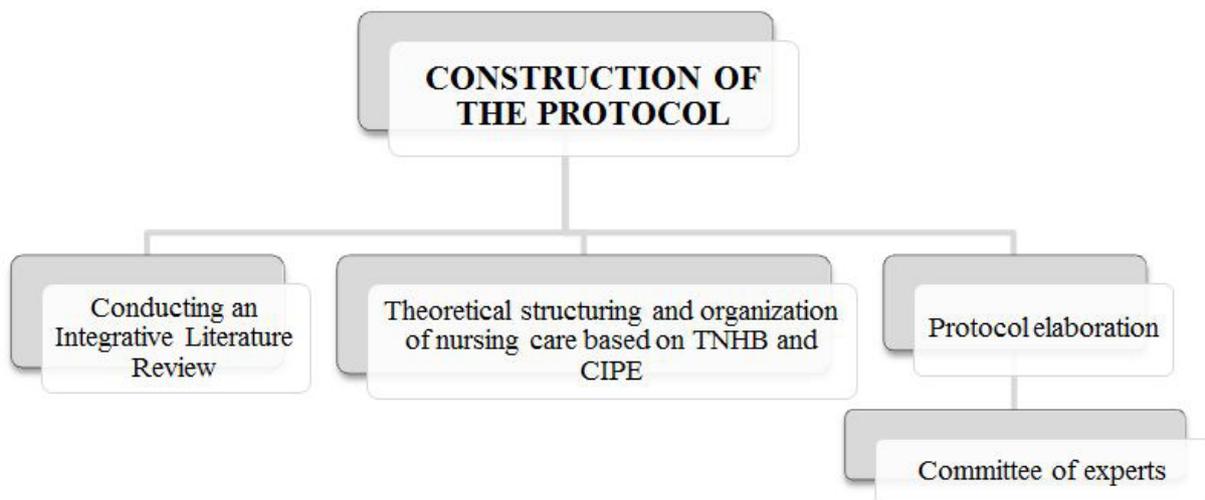


Figure 1 – Theoretical substruction of the steps taken to construct the nursing care protocol for children post hematopoietic stem cell transplantation. Curitiba, PR, Brazil, 2020

Note: BHNT – Basic Human Needs Theory; CIPE –International Classification for Nursing Practice
Source: The authors, 2020

in clinical practice and teaching. An example of a nursing problem, with its respective care, for each of the spheres of affected needs, will be detailed in this study.

The present study observed all the ethical standards of resolutions 466/2012 and 510/2016, such as confidentiality and anonymity, and was approved by the Research Ethics Committee of Hospital de Clínicas da Universidade do Paraná, under protocol number 3.107,127.

RESULTS

In the initial protocol, 30 nursing problems in the sphere of psychobiological needs, seven in the psychosocial sphere and three in the psychospiritual spheres were listed, which comprise the main events and complications identified in children undergoing HSCT. In this tool, for each nursing problem, its respective affected basic human need is presented, as well as ICNP® code, diagnoses and nursing care, the latter being divided into "practical care" and "guidance care", when applicable, both relevant for HSCT nurses.

Nursing problems were presented in each sphere of affected need, with their respective care in Charts 1, 2 and 3. The problems were selected due to the high frequency in which they occur in children undergoing hematopoietic transplantation. It should be noted that the nursing care presented has already been assessed by experts. As mentioned, the protocol developed contemplates 40 nursing problems, and, therefore, its full presentation is impracticable.

DISCUSSION

According to the literature, nurses must be aware of the vulnerabilities of patients undergoing HSCT, of nursing and medical diagnoses and meet the needs of patients and families in different care transitions^(4,10-11), such as hospitalization, outpatient and home care. Thus, the protocol described helps in the systematization of nursing care, given the main complications of treatment, in addition to supporting it scientifically and in the different contexts of care.

Regarding the nursing problems used to exemplify the content and the way the protocol was constructed, in the psychobiological sphere, "infection" was one of the problems included and is a common condition in HSCT. It should be stressed that the treatment for post-HSCT infections involves high health costs, especially fungal infection, and is also a clinical challenge⁽¹²⁾. This reaffirms the need to implement preventive measures, as well as early identification and treatment of the problem. These aspects are highlighted as actions in the aforementioned care protocol.

As for the infections, viral infections are relatively common and impact morbidity and mortality post HSCT. In a previous study with a pediatric population undergoing HSCT, viral infection was the most prevalent (37%), followed by fungal (15.9%) and bacterial (12.3%) infections. As for the viruses, contamination was caused by Herpes simplex virus; Human Herpesvirus 6; Epstein-Barr virus (EBV), and by Rhinovirus, Coronavirus, Influenza, Parainfluenza virus and Respiratory syncytial Virus (RSV)⁽⁴⁾.

Isolation of suspected cases with respiratory symptoms in a hospital environment until complete improvement of symptoms, as well as proper personal hygiene care, is an essential conduct in HSCT. Spreading of infection from the upper to the lower respiratory tract, which may occur in cases of RSV infection⁽¹³⁾, for example, must also be monitored by the nurse through the assessment of the child's clinical condition.

When the protocol highlights aspects for the prevention of infections (such as physical examination and guidance on body and environmental hygiene), early identification (such as controlling body temperature), and treatment (such as early administration of antibiotics, as prescribed by the physician), the relevance of the post-HSCT complication is recognized and an attempt is made to reduce its impact on the recovery process.

Infection accounted for half of treatment-related causes of mortality (53.1%), i.e., in the absence of progressive cancer. This result was demonstrated in a cohort study with children with a cancer diagnosis and mean age of 7.1 years. The follow-up period was five years. However, most infections occurred in the first three months after HSCT (39.5%), with bacteria and fungi, respectively, as the main agents. Some risk factors identified were diagnosis of hematological malignancies, age less than one year at diagnosis and allogeneic HSCT⁽¹⁴⁾.

Since the care protocol can be used for children at different stages of HSCT (inpatient, day hospital care and outpatient care), the tool includes the critical recovery period, that is, the first three months after HSCT, and clinical monitoring of the child is crucial.

The results of the aforementioned study⁽¹⁴⁾ demonstrate the need to prevent infection in populations undergoing transplants. Consequently, information on care related to the prevention of infections was gathered. Environmental care, also included in the protocol, is recommended by post-HSCT infection prevention and control guidelines, in addition to isolation, proper nutrition (cooked food), hand hygiene (health team and patient/caregiver) and evaluation of the pre-HSCT infectious history⁽¹²⁾.

Basic Human Needs (TBHN)	Nursing problem	Basic human needs affected	(ICNP®) Code	Nursing Diagnoses (ICNP®)	Nursing care (literature, ICNP® and experience of specialist nurses)
PSICHOBIOLOGICAL					
Regulation (cell growth and functional development)	Infection (viral, fungal, bacterial)	Regulation (thermal)	10023032	Infection	<p style="text-align: center;">PRACTICAL CARE</p> <ul style="list-style-type: none"> • Assess the persistence of fever and notify the physician; • Keep suspected or confirmed cases of respiratory infections in isolation and advise on the use of a mask; • Monitor vital signs, paying attention to temperature and clinical symptoms; • Perform physical examination; • Administer antiviral, antifungal and/or antibiotic early, as prescribed by the physician; • Follow the recommended interval between prescribed doses of antivirals, antifungals and antibiotics. <p style="text-align: center;">GUIDANCE CARE</p> <ul style="list-style-type: none"> • Advise the caregiver on checking body temperature at home; • Advise the child and caregiver not to maintain contact with other patients if the viral infection is contagious; • Advise the child and caregiver on the importance of following the times of prescribed medications given by mouth; • Reinforce the importance of body hygiene care to prevent infection; • Advise on the cleaning of the environment and the absence of contact with carpets, rugs, teddy bears, plants, animals, works; • Advise on the risk of fungal infection due to the use of immunosuppressants; • Reinforce the importance of a neutropenic diet, with cooked foods.

Chart 1 – Nursing care for children in post-hematopoietic stem cell transplantation regarding the nursing problem - Infection, in the psychobiological sphere. Curitiba,

PR, Brazil, 2020

Source: The authors, 2020

Basic Human Needs (TBHN)	Nursing problem	Basic human needs affected	(ICNP®) Code	Nursing Diagnoses (ICNP®)	Nursing care (literature, ICNP® and experience of specialist nurses)
PSICHOSOCIAL					
Education for health and learning	Self-care/ Care provided by the caregiver	Gregarious communication, Recreation and leisure, Emotional security, Freedom and participation	10027773 10021788 10001647 10038411 10018410 10037230	Caregiver Stress; Stress due to Change (or Transfer) of the Environment; Social isolation; Mental disorder; Social disorder; Risk of Difficulty with Coping	<p style="text-align: center;">PRACTICAL CARE</p> <ul style="list-style-type: none"> • Assess the caregiver’s ability to provide care; • Assess the child’s and caregiver’s psychosocial response to the care plan; • Discuss information from the internet capable of causing distress and/or confusion in the caregiver, not translating the reality of the transplantation process and generalizing the case;; • Talk about shifting the role of the family; adjustment after isolation and hospitalization; common emotional responses; offering support; coping with life after treatment; • Offer motivational support; • Help alleviate child and caregiver anxiety at the time of transition from different levels of care and locations, providing guidance for care; • Promote support for coping with the treatment to the child and caregiver; • Request support and involve the multidisciplinary team in care, including occupational therapy, psychology, social work; • Refer to psychiatric follow-up, if necessary; • Encourage support groups among caregivers, with monitoring by the multidisciplinary team; • Offer social support options available to patient and caregiver.

Chart 2 – Nursing care for children in post-hematopoietic stem cell transplantation, regarding the nursing problem Self-care/Care provided by the caregiver, in the psychosocial sphere. Curitiba, PR, Brazil, 2020

Source: The authors, 2020

Basic Human Needs (TBHN)	Nursing problem	Basic human needs affected	(ICNP®) Code)	Nursing Diagnoses (ICNP®)	Nursing care (literature, ICNP® and experience of specialist nurses)
PSYCHOSPIRITUAL					
Religiosity or spirituality	Hope	Religiosity or spirituality	10018614 10009105	Risk of Spiritual Condition, Impaired; Risk of Hopelessness	PRACTICAL CARE <ul style="list-style-type: none"> • Promote hope through words of comfort; • Promote spiritual support, explaining the importance of spirituality in the illness process, respecting individual beliefs; • Present available social support options; • Support beliefs; • Refer to psychological and/or psychiatric follow-up, if necessary.

Chart 3 – Nursing care for children in post-hematopoietic stem cell transplantation, regarding the nursing problem Spirituality, in the psycho-spiritual sphere. Curitiba, PR, Brazil, 2020
 Source: The authors, 2020

Therefore, the health team, as well as the children and their caregivers must adopt measures aimed at preventing infections and reducing their spread. Infection prevention actions, also at home, were established in the care protocol constructed, as care needs to be continuous, and nurses are supposed to prepare caregivers for care.

In addition to actions to be carried out in home care, the importance of correct and immediate administration, by nursing, of antibiotics, antivirals and antifungals, with the interval recommended between doses followed, is highlighted. Such measures interfere with the effectiveness of the treatment of infections, and hence are covered in the protocol.

In the psychosocial sphere, for the nursing problem “self-care/care provided by the caregiver”, care related to the offer of support, which is part of the educational process, to the assessment of the therapeutic plan of the caregiver and the performance of the multidisciplinary team, was included. In this regard, different strategies must be considered in the process of hospital discharge, in order to facilitate learning, given the large number of guidelines to be made available to the patients.

Regarding the different strategies for the educational process, the authors of the study conducted in the BMTS produced digital videos for patients and caregivers that are

available online to guide care post HSCT⁽¹¹⁾. This strategy facilitated the teaching-learning process, enabling responsible hospital discharge. Understanding the guidelines for care and professional support, in different moments, are actions inherent in the nursing care of children undergoing HSCT.

Nurses must also recognize caregivers as relevant allies, as their involvement and role change the evolution of HSCT. It is known that caregivers take responsibility for the management of symptoms, in addition to monitoring problems and coordinating care, often 24 hours a day⁽¹⁵⁾. Thus, these professionals must be prepared and monitored, and these actions are also covered in the care protocol constructed.

Establishing a standardized approach to the education of HSCT recipients and caregivers, from a teaching perspective, can help understand the expectations associated with quality outcomes. It is also important for nurses to assess the learning needs, as well as the caregivers’ understanding of the information⁽¹⁵⁻¹⁶⁾.

Nurses aware of the unique role of family caregivers of patients undergoing HSCT and facilitate the fulfillment of their obligations, understand the concept of continuity of care⁽¹⁰⁾, crucial in HSCT, especially in care to children.

Moreover, protective isolation, necessary for HSCT, can affect the well-being and psychological aspects of patients⁽¹⁷⁾.

Therefore, these individuals must be prepared and clarified regarding their needs, in addition to receiving psychological support for these actions, which make up the care protocol in the psychosocial sphere.

In the protocol developed, the relevance of the performance of the multidisciplinary team was highlighted, as well as the establishment of support groups, even among the caregivers, as a way to facilitate coping with the transplant process.

In the psycho-spiritual sphere, which includes the nursing problem "hope", it was clearly mentioned that care helps professionals clarify their doubts on how to meet the needs related to this sphere. This was pointed out by the expert committee. Spiritual care and, specifically, the promotion of positive feelings, such as hope, can and should be treated as a competence of nursing. Therefore, some support strategies to be offered by nurses to children and their caregivers were addressed in the care protocol.

Spiritual support is provided regardless of the recipient's religion, and it impacts the well-being and expression of feelings by children and their caregivers. Respecting the beliefs of patients and family members, as well as welcoming the latter, must be part of the aforementioned care. The nursing team must be prepared not only to recognize, but also to offer spiritual care, since spirituality is understood by health professionals as a source of security and serenity⁽¹⁸⁾.

Social support, including family and healthcare team, is an important tool for reducing anxiety and depression, as well as increasing hope in patients undergoing HSCT⁽¹⁹⁾. The impact of such support is perceived as positive and beneficial in the care of children and their caregivers, as HSCT can even affect the beliefs of patients and caregivers. Therefore, comforting, by taking advantage of the actions established in the care protocol, supports nursing care and recovery.

In view of the aforementioned, when the three dimensions of health affected by HSCT are considered, the care protocol can contribute to improving the results of the care provided, not only by including actions targeted to the identification and treatment of clinical signs and symptoms by nurses, but also because it encompasses actions for the preparation of children and their caregivers, for home care, for the provision of information and support. In this regard, technical nursing actions, as well as the health education process, are relevant and essential to care.

CONCLUSION

In the construction of the protocol, the search for evidence in the literature allowed for the gathering of care provided by nursing in the context of HSCT; the establishment

of care based on the ICNP® made it possible to complement assistance, as new types of care were defined, considering the nomenclature and versatility of the classification terminology.

The theoretical support provided by the Theory of Basic Human Needs (TBHN) allowed us to understand the complexity of the needs of children undergoing HSCT, and the study of a previous clinical profile of the population to which the protocol is intended, allowed the identification of nursing problems.

There are few studies on nursing care in the psychosocial and psychospiritual spheres, which, although they are not the base of the pyramid, are affected by the therapy adopted and must be contemplated, as they are interrelated. Therefore, studies that identify, measure and propose actions to meet these needs must be carried out.

The construction of the care protocol is an important technology for HSCT nursing care, for the prevention and management of complications. This technology can assist in professional development in this area of care, improving care and increasing patient safety. It can also be used in the teaching of clinical practice and in management, assisting in the organization of nursing care for children undergoing transplantation.

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