



ADHERENCE TO NURSING GUIDELINES IN RELATION TO HOME CARE OF BONE MARROW TRANSPLANTEES IN THE ECOSYSTEM PERSPECTIVE

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ABSTRACT

Objective: to analyze adherence to the nursing guidelines for home care of bone marrow transplant recipients from an ecosystem perspective.

Method: descriptive, exploratory study with a qualitative approach, using Content Analysis for data analysis, with theoretical and philosophical ecosystem support. The interviews, carried out in bone marrow transplant services, in Brazil and Spain, were guided by an instrument developed by the researchers which contained 25 closed and ten open questions. 40 users participated who met the inclusion criteria. Data collection was carried out from July 2016 to October 2017.

Results: the Orientations category emerged from the data which then gave rise to the subcategories: Interactive relational actions; and, actions and behaviors that interfered in the success of the transplant. Some users, due to excessive information at the time of discharge, were unable to assimilate or carry out the guidelines received; others, during the hospitalization phase, apprehended them and absorbed them in order to use them in the home ecosystem space after transplantation.

Conclusion: part of the users followed only the guidelines that best adapted to their daily lives and, for others, after hospital discharge, they caused doubts and insecurities regarding the care to be performed at home. It is necessary for the user to identify the constituent elements of their home ecosystem and learn, through communication and information, how they interfere in post-hospital discharge care. Therefore, it is necessary to create communication and information mechanisms that enable the dynamic process between the constituent elements of the ecosystem, biotic and abiotic, so that they have interaction and sustainability and can be practiced by the user.

DESCRIPTORS: Transplantation. Bone marrow. Nursing care. Adherence to treatment. Housing. Ecosystem.

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ADESÃO ÀS ORIENTAÇÕES DO ENFERMEIRO PARA CUIDADO DOMICILIAR DO TRANSPLANTADO DE MEDULA ÓSSEA NA PERSPECTIVA ECOSISTÊMICA

RESUMO

Objetivo: analisar a adesão às orientações do enfermeiro para o cuidado domiciliar do transplantado de medula óssea na perspectiva ecossistêmica.

Método: descritivo, exploratório, com abordagem qualitativa, utilizando-se para a análise dos dados a Análise de Conteúdo, com apoio teórico-filosófico ecossistêmico. As entrevistas, realizadas em serviços de transplante de medula óssea, no Brasil e Espanha, foram norteadas por um instrumento elaborado pelas pesquisadoras, contendo 25 questões fechadas e dez abertas. Participaram 40 usuários que cumpriram os critérios de inclusão. A coleta de dados foi realizada de julho de 2016 a outubro de 2017.

Resultados: a categoria Orientações emergiu dos dados e originou as subcategorias: Ações relacionais interativas; e, ações e comportamentos que interferiram no sucesso do transplante. Alguns usuários, por excesso de informações no momento da alta, não conseguiram assimilar e desempenhar as orientações recebidas; outros, no transcorrer da fase de internação, as apreenderam absorvê-las para o cuidado no espaço ecossistêmico domiciliar no pós-transplante.

Conclusão: parte dos usuários seguiu somente as orientações que melhor se adaptaram ao seu cotidiano e, para outros, no pós-alta hospitalar, ocasionaram dúvidas e inseguranças em relação ao cuidado a ser praticado no domicílio. Faz-se necessário que o usuário identifique os elementos constituintes do seu ecossistema domiciliar e conheça, por meio da comunicação e informação, como interferem no cuidado pós alta hospitalar. Portanto, é preciso criar mecanismos de comunicação e informação que possibilitem o processo dinâmico entre os elementos constituintes do ecossistema, bióticos e abióticos, para que tenham interação e sustentabilidade e possam ser praticados pelo usuário.

DESCRITORES: Transplante. Medula óssea. Cuidados de enfermagem. Adesão ao tratamento. Habitação. Ecossistema.

ADHERENCIA A LAS DIRECTRICES DE LA ENFERMERA PARA EL CUIDADO EN EL HOGAR DE LA TRANSPLANTACIÓN DE MÉDULA ÓSEA DESDE LA PERSPECTIVA DEL ECOSISTEMA

RESUMEN

Objetivo: analizar el cumplimiento de las directrices de la enfermera para el cuidado domiciliario de los receptores de trasplante de médula ósea en una perspectiva ecossistémica. Método: descriptivo, exploratorio, con un enfoque cualitativo, utilizando el análisis de contenido para el análisis de datos, con soporte teórico y filosófico del ecosistema. Las entrevistas, realizadas en los servicios de trasplante de médula ósea, en Brasil y España, fueron guiadas por un instrumento desarrollado por los investigadores, que contenía 25 preguntas cerradas y diez abiertas. Participaron 40 usuarios que cumplieron con los criterios de inclusión. La recolección de datos se realizó entre julio de 2016 y octubre de 2017.

Resultados: la categoría Orientaciones surgió de los datos y originó las subcategorías: acciones relacionales interactivas, acciones y comportamientos que interfirieron en el éxito del trasplante. Algunos usuarios, debido a la información excesiva al momento del alta, no pudieron asimilar y llevar a cabo las pautas recibidas, otros, en el curso de la fase de hospitalización, los detuvieron para absorberlos para su atención en el espacio del ecosistema del hogar en el pos trasplante.

Conclusión: parte de los usuarios siguió solo las pautas que mejor se adaptaron a su vida diaria y para otros, después del alta hospitalaria, causaron dudas e inseguridades con respecto a la atención que se practica en el hogar. Es necesario que el usuario identifique los elementos constitutivos del ecosistema de su hogar y aprenda, a través de la comunicación y la información, cómo interfieren en la atención hospitalaria posterior al alta. Por lo tanto, es necesario crear mecanismos de comunicación e información que permitan el proceso dinámico entre los elementos constitutivos del ecosistema, bióticos y abióticos, para que tengan interacción y sostenibilidad y puedan ser practicados por el usuario.

DESCRIPTORES: Trasplante. Médula ósea. Cuidados de enfermería. Adherencia al tratamiento. Vivienda. Ecosistema.

INTRODUCTION

The expansion of life expectancy in the prognosis of people with serious illnesses, especially chronic illnesses, is a reality related to new technological health treatments, which are increasingly more efficient. In this scenario, the Hematopoietic Stem Cell Transplantation (HSCT) process is included, whose therapy has grown in recent decades for hematological diseases, as well as in its application for autoimmune diseases and hematopoietic organ reconstitution.¹

Currently, the progenitor cells used in HSCT may come from bone marrow, peripheral blood and umbilical cord blood. Thus, HSCTs are divided into autologous, when the cells are the user's own and allogeneic, when the cells are from a donor. When the donor is a relative, it is called Relative HSCT, if it is from a non-family donor it is called Allogeneic Unrelated HSCT.¹

The HSCT process requires great care with the general health of the user and also the risk relationships that may occur and the possible and uncertain benefits to be achieved must be considered.² HSCT care has specific characteristics in each phase. The user and his or her caregiver require guidance, mainly, in relation to care in the post-transplant period in the home context.² In this aspect, the nurse has an important function, due to their attribution of care, from the moment of indication and accomplishment of the transplant, as well as, during all the stages of the treatment, as well as in the post-transplant phase and in the preparation for the hospital discharge.

At this level, planning for hospital discharge includes the nurse's guidance on various aspects of care to be practiced at home. Due to the range they cover, they need to start before the day of discharge itself, so that the user and caregiver have time to assimilate the information that must be inserted into their daily routine and in the care activities that need to be continued after discharge.³ However, many doubts may arise, both from the user and the caregiver, regarding the best adaptations of the guidelines and health requirements in their specific household and their due adjustment to provide greater efficiency and minimization of complications in the post-hospital discharge.

Hospital discharge is a complex process, which involves the entire team that was responsible for direct care to the user and caregiver during the hospitalization stage. This moment of transition needs to become a learning period, with focus and attention on the user and the caregiver, as it requires ample clarification on the continuity of care at home. In order to instrumentalize them, it is recommended to provide written material regarding home care which can be consulted when in doubt.⁴ Therefore, it is necessary to continuously maintain an open communication channel with the HSCT team if at any time of the day and/or night the user needs to return to the service.

The circumstances to be faced in the home space, considered here as a home ecosystem, become real and, often, not adequate for the needs and orientations received, emphasized and warned in the hospital discharge stage. Therefore, it must be remembered that health actions need to consider the environments where the user is aggregated and their network of interactions and relationships, i.e., the principles of their ecosystem. The word ecosystem is composed of the word *eco*, which derives from the Greek *oikos*, space, and system that means a set of elements that interact, are interconnected forming a totality/unit that influence each other and are interdependent.⁵

The ecosystemic principle of the interaction of all the elements that make up the user's space, is highlighted in bone marrow transplant recipients. These users, who generally have low immunity are subject to multiple adverse risk factors that can be avoided. In this sense, the nurse's orientations, in an ecosystemic perspective, need to understand that the human being is part of and constitutes one of the elements of nature, but that the set, the totality of factors inherent to the space it occupies, influences and interferes, procedurally, in the prevention, promotion and recovery of health for the professional competence of nurses in relation to user guidance.⁵⁻⁷

Environmental variations influence a person's continuous changes and naturally lead to temporary health changes.⁸ Thus, in order to plan the nursing care procedures for hospital discharge, technical knowledge related to the procedure and its complications is not enough, but indeed, it is necessary to examine and understand the home ecosystem in which the user will return to live in and coexist.

This conception⁸⁻⁹ leads to an assessment of all the elements that make up the user's home ecosystem and to verify how they interact and how they can influence the health of bone marrow transplant recipients. The perception of totality/unity of the real space allows nurses to assist the user and their caregiver, in their adaptation to the care requirements at home, which may arise during and after hospital discharge, based on ecosystem principles.

Ecosystem principles are complementary to each other, helping to understand being, living and existing in an environment, in this case, of care, and it is important to understand that this interdependence and interaction of ecosystem principles with each other, among other variations, allows constant adaptations to disturbances and fluctuations in ecosystems allowing the user to self-organize.⁹⁻¹⁰

Based on this perception, for the discussion of the theme of this article, the theoretical-philosophical framework of the ecosystem paradigm was chosen as it emphasizes that a person's health condition always depends, to a high degree, on their environment, in this case the ecosystem at home, where they live and recover from bone marrow transplantation intervention.

Based on this context, the present study aims to analyze adherence to the nursing guidelines for home care of bone marrow transplant recipients in an ecosystemic perspective.

METHOD

A descriptive, exploratory research, with a qualitative approach, using the Content Analysis (AC) method.¹¹ This method is applicable because it is a planned study, capable of evaluating how the HSCT user, who is already discharged from the hospital and is at home, follows the guidelines received from nurses during hospitalization. Data collection was carried out from July 2016 to October 2017. The data analysis process began by the transcription of the interviews, with subsequent fluctuating reading of these data in order to assess whether all transcripts could be included in the research *corpus*.

The results rely on data extracted from interviews conducted with 40 participants during the outpatient consultation. In order to be included in the research, the HSCT user needed to be on an outpatient basis and living at home for at least 30 days and at most two years. Four users of the HSCT service from Santa Maria - Rio Grande do Sul, 12 users of the HSCT service from Curitiba - Paraná (BR) and 24 users of the HSCT service from Murcia, Spain were selected. Understanding the socioeconomic differences of the two countries, we sought to conduct research in public hospitals in both Spain and Brazil, emphasizing that the vast majority of Brazilian users receive transplantations in public hospitals regardless of their socioeconomic status.

In Spain, data were collected during the researcher's Doctoral Sandwich, made possible by the Coordination for the Improvement of Higher Education Personnel (CAPES) program, in a reference HSCT service in the Hospital *Morales Meseguer* located in Murcia City.

The inclusion criteria for participant selection was: being over 18 years old; having only undergone one transplant; perform outpatient follow-up in one of the services surveyed. In order to preserve the anonymity of the participants, they were identified by letters and numbers: BR1 and BR2, respectively, for the services investigated in Brasile, ES for the service investigated in Spain, and Arabic numbers, according to the order in which the interviews took place: BR1.1, BR2.1, ..., and ES1, ES2, ..., ES24.

The interviews were guided by an instrument developed by the researchers, containing 25 closed and ten open questions, which covered the nursing guidelines that were carried out during hospitalization, together with the bone marrow transplant, for home care, in an ecosystemic perspective.

The data collection instrument listed the sociodemographic data in order to characterize users in their territorial, social and economic differences. Clinical data, such as the primary disease that led to HSCT and the source of stem cells, were also investigated. Finally, the guidelines received during hospitalization and their respective practice in the home ecosystem were investigated, such as: avoid contact with domestic animals, use sunscreen, avoid places with many people, avoid touching soil and plants, avoid using sharp tools, avoid cleaning the house, have sex with condom, family and friends were advised that they needed to avoid contact with people with fever, cough, flu, among others. In open questions, users were asked about the professional who performed the guidelines; if they missed any guidance after arriving at their home and changes that occurred in life after HSCT.

RESULTS

The category “Guidelines for users, during the hospitalization period, performed by the nurse”, gave rise to two subcategories. The first, Interactive relational actions that affect adherence to the nursing guidelines for post-HSCT home care in an ecosystemic perspective, which reported how they received the information and how they applied it in their daily lives or how they tried to resolve their doubts. The second subcategory encompassed the Actions and Behaviors that interfere with adherence to the nursing guidelines for home care after HSCT from an ecosystem perspective, with the purpose of verifying how the user followed the guidelines received during hospitalization, regarding ecosystem care in the post-HSCT.

Interactive relational actions that affect adherence to the nursing guidelines for home care post- HSCT, from an ecosystem perspective

When HSCT users reported “prolonged conversations”, “I was well informed”, “I did not miss the guidance”, “I consulted the written material provided” and “I made contact with the service by phone”, demonstrated how interactive relational guidance actions were carried out by nurses and how they were received by the user, according to the statements: [...] *the nurse, cleared up any doubts, and was very patient, she came again because I was unable to take it all in during the first orientation* [...] (BR1.2); [...] *I was well informed both me and my daughter who lives with me and we followed the guidelines very well* [...] (BR1.3); [...] *I was well oriented, nothing was missing, both food and hygiene everything, everything* [...] (BR2.7); *I got all the information, I was very well advised, with great affection* (ES13); “[...] *when I got home I was safe, I felt like I received all the orientations* (ES19).

Expressions about the importance of the guidelines dedicated to clearing up doubts during the period of hospitalization: [...] *I even read again what nursing told me, at home, to make sure I was doing it right, it was very important what the nursing has given me, it was very complete, it was all there* [...] (BR1.2); *“I knew the changes could happen. I received the guidance from the whole team, they gave me a sheet and guided me. It was clear, I stayed at home safe* [...] (ES6); *Nothing was missing* [...] *I managed to follow all the guidelines at home, I had written material, but there was no need to read it* (ES11).

The provision of printed material with more detailed information, figures and explanations, which can eliminate momentary doubts, was valued by the user as one of the efficient guidance methods, which gave them a sense of safety at home: *I had doubts, so I called, when I worried, I called, I called two or three times* (BR1.4); [...] *I come for review consultations and whenever I had a question I could contact the service by phone* (ES1).

In the subcategory Interactive relational actions, in addition to the positive points, some participants stated that the guidelines for post-discharge from hospital caused doubts and insecurities regarding the care to be practiced at home: *The day I went home, I was very overwhelmed because there were a lot of people talking to me, a doctor, a nutritionist, even the girl from the pharmacy. I didn't miss guidance, except that on the first night at home I slept very little because I didn't take the sleeping pill because they didn't have the prescription there [HCST Center] and I had bought it and had finished and worried about cleaning; was she right? Is it correct? but then it was quiet (BR2.9); [...] it wasn't something very interesting but I was insecure, it was about food if I could eat or not and cleaning the house, if I could do it, I would talk to the nurses, but it was the food I was afraid about (BR1.4); The guidance that was missing or we didn't remember, is that I had the flu symptom, cough, runny nose and I didn't come to the hospital on the day, I only came on the day of the appointment. It started on Friday and I came only on Monday when I had an eye consultation. Then the doctor said he couldn't, I had to come on Friday, to collect the exams, that was the case. Thank God nothing happened (BR2.4).*

Actions and behaviors that interfere with adherence to the nursing guidelines for home care post-HSCT, from an ecosystem perspective

Although the user and the caregiver are influenced by their home ecosystem, the guidelines are always indispensable and can serve as guides when making decisions, as stated: *I managed to follow the guidelines at home, I insist that I am meticulous, if I have to do exercises, I do them, if I have to eat something, I will eat it (ES10).*

Discipline and the follow-up of all guidelines were not very frequent in this research, since users were able to follow some guidelines and others were not, as can be seen in this statement: *[...] I do not use sunscreen when I come to the hospital because it is the only day that I go out, I never used it [...] (BR1.4); I only use factor 50 sun screen when it's very hot, I don't have the habit of going for a walk, I just come to the hospital, I went to the market and stayed in the car. I only use sunscreen on the parts that are exposed to the sun (BR2.9); I don't use sunscreen, I don't sunbathe and I just walk in the shade (ES14); [...] I use sunscreen, but not always, but they tell me to always use it (ES24); I managed to follow the guidelines except for the sunscreen ... [laughs] (BR2.6).*

The use of sunscreen is essential in post-HSCT in order to avoid skin complications, resulting from Graft Against Host Disease, which can lead to user death. Even so, it was observed that users showed resistance to using it.

In addition to the lack of use of sunscreen, other aspects were not observed: *[...] I do not use a condom because I have a steady partner (BR2.10); "I already had sex after the transplant, I didn't use a condom and I took care of the exams if they were okay to be able to have sex (ES17); I have had sex after the transplant, my husband uses a condom, with controlled blood tests (ES8).*

A small number of users who reported already having sex post-HSCT. The others do not for fear of complications or for lack of physical conditions. Users who have resumed sexual activity are reluctant to use condoms.

I was not able to follow 100% of the guidelines, for example, I read the guidelines for food, I do not eat everything that is written there. I only eat polenta, chicken, for example, I did not want to adapt to cleaning with vinegar on fruits and vegetables, but I don't eat those things (BR2.9); I didn't manage to follow all of them, all the guidelines ... [laughs], there is a bit of stubbornness, sometimes you forget something, more or less within the ideal, it was not 100%, but about 70% to 80% (BR2.4).

Finally, the difficulty and resistance to follow all the guidelines was highlighted, even though users stated that they had been oriented in relation to such care.

DISCUSSION

Adherence to user guidelines is not only based on specific learning of a theme, but on their knowledge as a totality/unit, involving their experiences, their perception of the universe, their experiences, their knowledge, and their ecosystem as a whole.

Based on this ecosystemic thinking, the guidelines for HSCT users need to be contextualized, appropriate to their home ecosystem, as successful adherence involves all these aspects. The home ecosystem, made up of biotic (living) and abiotic (non-living) elements are interdependent, interact and influence each other forming an immense and intricate network of relationships, forming a totality/unit.⁵⁻⁶

However, it is considered that the human being is the only living being that can consciously choose the direction of its actions. Through attitudes you can demonstrate the power of your thoughts. Thus, attitudes occupy an important space in life, and can influence decisions and behaviors, which are shaped by the relationship of people with their environment, both physical and social.⁹ The choices made by the users of the research demonstrated that some decisions led them to not follow the guidelines and expose themselves and possibly damage their health.

Data similar to those found in the present investigation were observed in the research carried out with seven adult patients who underwent HSCT, in a public hospital in the interior of Minas Gerais.¹² This study reported that the new way of looking at life, after HSCT, structuring in the midst of a diversity of feelings.

When the user is discharged, there is an expectation, on the part of the nurse and the multidisciplinary team, that the patient, upon returning to the home ecosystem, will take the necessary actions to continue the treatment, living with physical, social, dietary restrictions, among others imposed by treatment. For that, it is necessary to consider the user's age, their learning capacity and their socioeconomic aspects, understanding that this process does not happen immediately, and requires monitoring and reorientation during nursing consultations.¹² In this context, one research considered that human behavior is not only based on the learning processes, but on the knowledge of the lived experiences and perceptions of the human being from their universe, i.e., from their ecosystem.¹³

Therefore, to understand the human being, it is necessary to understand the space in which he/she is reinserted, his/her ecosystem, his/her interrelationships, so that he/she can observe the condition of following the guidelines discussed for hospital discharge in the context of the HSCT user.

The decisions made by the participants during this period were analyzed in order to understand how the guidelines given by the nurse, during the hospitalization of the HSCT user, were practiced at home in the post-hospital discharge, in an ecosystemic perspective. This analysis resulted in two subcategories: Interactive Relational Actions and Actions and Behaviors that interfere in the success of HSCT. Interactive Relational Actions, between the nurse and the user, represent possibilities for the HSCT user to assimilate or not assimilate the guidelines, during hospitalization, for home ecosystem self-care. Care that is necessary to perform for a prolonged time after hospital discharge. It was investigated whether the guidelines received during the hospitalization period were sufficient or not, and why many needed to be reinforced and expanded in outpatient follow-up care. In this context, research carried out in Minas Gerais, highlights that individualized care plans, during hospitalization, can support and prepare the user and their caregiver/family member for the necessary care after hospital discharge.¹³

When identifying the importance of providing informative material and a telephone contact where he can answer questions in the speech of the users, it is recognized that there are interrelations and interdependence between the elements of the home ecosystem of the HSCT user and the nurse, perhaps for a certain confidence at the time of some need or care. In addition to the material received, the value given to the participation of their caregiver during guidance, together with the

user was also identified. These relationships demonstrate the link that is formed with the nurse and the multidisciplinary health team of the transplant service. Users and caregivers seek to maintain a network connection, which remains even after hospital discharge.

This thread, ecosystemically speaking, represents communication, the dialogue that links the professional, the user and their caregiver, the multiprofessional team, the family, friends and other elements of their social circle. Thus, the network is not only comprised of the biotic (living) and abiotic (non-living) elements that participate in it, represented by the network nodes, but also the filaments that unite the elements, through communication and information.¹⁰

Similar data⁴ are found in one research, which interviewed 21 family caregivers of post-HSCT children at a reference Bone Marrow Transplant Service in the Southern Region of Brazil. In addition to these participants, 25 nurses who worked during hospitalization and provided guidance to these users were also interviewed. In addition, 12 professionals from the multiprofessional team were interviewed, all linked to the inpatient unit. The results are similar to those of the present research, highlighting that the complex process of hospital discharge in HSCT requires that the multiprofessional team, involved in direct assistance to the user and caregiver, are responsible for making this transition a period rich in learning, instrumentalizing them for the continuity of care at home.

According to another study,¹³ carried out in a public hospital in southern Brazil, an international reference in HSCT, with 18 participants divided into three groups: the first group, composed of ten family members/caregivers of post-HSCT children, who lived in Transitional Support Houses (TSHs); the second group, included five family members who performed care at the TSHs, but were already with the child at home; and, finally, three professionals who worked at TSH were interviewed. The results of this research are similar to those of the present research, when they mention that hospital discharge guidelines must happen during the entire hospitalization, and not only at the moment of discharge. According to the users' statements, receiving the information in a concentrated matter at the time of discharge was not a good experience.

Corroborating these findings, another research⁹ stated that the guidelines provided in the last moments before hospital discharge do not allow the professional of the team that is providing the orientations to clear up doubts or difficulties, which can negatively influence the user in post-HSCT recovery.

Based on the ecosystemic paradigm, the most important step is to make the user aware of the nature and extent of his/her imbalance. This user awareness encompasses an effort by the multiprofessional team to plan care, in order to involve the user and his family in this care.⁹ Therefore, the user and the family member/companion, aware and involved in the care during HSCT, leads to treatment adherence and better recovery.

Ecosystem thinking instigates and proposes the participation and cooperation of the entire group in the activities of the reality in which it is inserted, using a dialogical form of communication. The dialogue must be openly provided, in order to lead to joint decisions, contributing to the interconnection of the elements of the web of relationship and providing opportunities for energy exchanges in the development of knowledge, respecting individual knowledge and collective characteristics to understand the whole, assisting in the personal and collective formation of the totality/unit.⁵

The HSCT user, based on the principles of ecosystem thinking, needs to dynamically organize themselves in non-equilibrium situations, with dissipative structures emerging in the ecosystem, which will generate new possibilities through bifurcations,⁹⁻¹³ leading the user to adapt to the lack of information. As a consequence, the doubts that may arise in the home ecosystem, after discharge, there is the possibility of leading to the search for guidelines that were not provided or were not captured by the user during the hospital discharge guidelines.

Building a shared vision for the success of HSCT, among the elements of the user's ecosystem, may possibly contribute to the occurrence of actions and behaviors that favor adequate post-HSCT recovery. The relationships that human beings assume in their ecosystem context include an essential element, called care. This is shown as an essential condition, expressed in the form of commitment, effort and dedication, allowing the individual to interact with the other and with the ecosystem, maintaining a connection with the elements around him.¹²

In analogy, in a theoretical-philosophical reflection, authors discussed health, its conditioning factors and determinants, from the perspective of ecosystem thinking.¹² In relation to human beings and their health, it is possible, by similarity, to interpret the relationships of the HSCT user, their caregiver and the supervisor for hospital discharge, the orientations received and, as a consequence, analyze how he complies with these guidelines to stay healthy. The convergences of this reflection consist of emphasizing the importance that the user and their caregiver are able to perceive the connection between the guidance received and the benefits of their practice. This connection between what is proposed and what is necessary to practice at home, in order to stay healthy and achieve success in HSCT, needs to be understood as the interconnection between these two moments and the benefits they can generate to stay healthy.

By recognizing the interdependence of actions and the commitment of all elements, it will be easier to understand the benefits or even the losses arising from the practice or not of the guidelines. Therefore, it can be said that following the guidelines received for post-HSCT care goes beyond the domain of competencies and skills to develop care and self-care, but it also includes believing in the importance of each guidance for a successful outcome of the HSCT.

Thus, following the guidelines involves attitudes and behaviors shown by some users as a way to remain confident that the HSCT will have a good result. Such guidelines require responsibility and a decision to participate in their compliance.

In order to discuss non-compliance with the guidelines in the home ecosystem context of post-HSCT, an agreement with a leading author in the management area was sought,¹² to try to understand the mental models that people have rooted and that influence the way they act and see the world. The author, stating that the human being acts as he thinks, i.e., according to his mental model, which, seen in this understanding, represents something highly personal and is related to what he assumes, thus causing the differential for understanding the orientated questions.

When users stated that they did not use sunscreen as they were instructed, did not use condoms during sexual intercourse, cooked and used sharp tools, had contact with domestic animals, i.e., not following the guidelines, even confirming that they were instructed to avoid health risks, awakens the professional to reflect when reading these statements. Therefore, it is confirmed, that hospital discharge preparation needs to start during the treatment period, and avoiding giving these guidelines in a concentrated manner at the time of discharge.

Another research,¹⁴ carried out by means of a literature review with 18 articles extracted from the Latin American and Caribbean Center for Health Sciences Information (BIREME) website and the Scientific Electronic Library Online (SciELO) indexing bank, observed the descriptors: Hospital Discharge, Care Plan and Post-discharge Guidelines. The results corroborate those of the present research, when identifying that the anticipated guidelines for hospital discharge, avoiding the abrupt realization of these on the day of discharge, provided moments of observation in relation to the level of apprehension by the user and the family member/caregiver.

The nurse has a fundamental role during the planning and execution of the discharge process, through constant involvement with the user and caregiver, due to being present during the daytime in the hospital. This fact promotes a relationship of trust between professionals and users, allowing more opportunities for professionals to orientate post-discharge care.⁴

One research, carried out in a pioneering reference hospital in Brazil for HSCT, with pre- and post-HSCT users, followed up at the outpatient clinic of the HSCT Unit, over a period of one year, had similar results to those of this research, by highlighting that the greatest difficulty found to resume life is the demand for eminent health care, given the limitations resulting from the procedure, needing to be attentive to body care, obeying medical prescriptions, internalized as rigid rules of conduct, leading many users to confess that they reacted aggressively to these impositions, often refusing to carry out all the prescribed self-care activities.¹⁵

The findings of a research carried out at the Brazilian reference hospital for hematopoietic stem cell transplantation, with 25 users in the pre- and post-HSCT phase, in outpatient follow-up at the HSCT Unit, within a year, referred to limitations such as wearing a mask daily, not being able to drive, not being able to expose themselves to the sun, not having sexual relations, among other prescriptions, caused the quality of life of the HSCT user to be limited.¹⁵ These data are similar to those of this research, when some users demonstrated resistance to sunscreen, not being able to follow all the guidelines and not using a condom. Such findings reflect this exhaustive phase of post-HSCT, where the user needs to obey strict guidelines that will only show their benefits one year after HSCT.

The educational action of the multiprofessional team, especially the nurse, is understood as necessary when looking for mechanisms to achieve effectiveness in their guidelines for care and self-care, which need to be exercised at home after hospital discharge. It is necessary to remind the user and their caregiver, at the time of discharge guidance, that the entire recommended procedure is interdependent with the other elements of their home. Such elements include the structure of the house, water, rain, winds, animals, flies, mosquitoes, garbage, friends, relatives, food, among many others, whether biotic or abiotic elements. It is always important to remember, that he himself is one of the elements of this ecosystemic context. Seen in this way, it is easier to understand that interrelationships, mutual influences and the success of the transplant, depend, in large part, on the strict observation of the guidelines received from the multiprofessional health team at the Transplant Center.

CONCLUSION

Based on the ecosystem reference, it can be stated that, in order to understand the dimension of the guidelines for HSCT users and their caregivers for post-discharge, it is necessary to understand the elements, biotic (living) and abiotic (non-living) , the ecosystem in which he will reintegrate and of which he is one of the elements. In this understanding, the contextualized guidelines become more effective and are more likely to be successful in bone marrow transplantation.

The results showed that HSCT users who follow the guidelines are the ones who best adapt and understand the importance of the care they need to follow. On the other hand, some users have shown resistance to follow-up care, such as the use of sunscreen and the use of condoms, among others. This situation reflects the exhaustive phase of post-HSCT, where the user needs to obey strict guidelines, the result of which, positive or negative, is usually manifested after one year of HSCT. Such aspects need to be emphasized in the guidelines.

It should be noted that some users did not assimilate the guidelines provided during hospitalization or on the last day at hospital discharge. Therefore, the importance of assessing the attention capabilities of the user and their family member/caregiver is identified, while the guidelines are being carried out, in order to detect whether they were understood, or whether they need to be reinforced. Providing feedback after the orientation is recommended, so that the user and caregiver can demonstrate the level of perceived understanding of the guidance that was provided.

It is worth noting the continuously open communication channel between the Transplant Center and the user and the caregiver after hospital discharge, which can be accessed by phone, e- email, chat chats or other social media.

Thus, it is considered that adherence to the nursing guidelines, for home care of bone marrow transplant recipients, depends on the self-organization, dynamics and non-balance that emerge in the ecosystem of the HSCT user, taking advantage of ecosystem principles, the effects of the dissipative structures effects that arise in the post-transplant recovery process, generating possibilities for recovery and success in the process as a whole.

Further studies on this important theme are encouraged, as a way to improve the guidelines provided by nurses, when preparing the HSCT user for hospital discharge and reintegrating into their home ecosystem.

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NOTES

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