ASPECTS REGARDING THE PATIENT / FAMILY AND PROFESSIONALS IN THE CONTEXT OF HEMATOPOIETIC STEM CELLS TRANSPLANTATION: A REFLECTIVE ANALYSIS

Abstract

Objective: To present reflections on the triad patient/family and professionals in the context of Transplantation Hematopoietic Stem Cell. Method: A descriptive study, of conceptual and theoretical analysis performed by the reflective process about Transplantation of Hematopoietic Stem Cells. Results: The findings of this reflective process were evidenced in three categories: 1. The context of Transplantation Hematopoietic Stem Cell, 2. The role of family and health care team in the care of patients undergoing transplantation of Hematopoietic Stem Cell and 3. Repercussions of the process of death and dying in Transplantation Hematopoietic Stem Cell. Conclusion: There was the implicit role of the health care team in the task of engaging patients, families and other team members in job attitudes that enable all verbalizing their feelings, identifying sources of aid, that may be inside or outside of their own family. Descriptors: Stem Cell Transplantation; Family; Nursing.

Resumo


Résumé

Objectif: presenter reflexions acerca da triade paciente/familia y los profesionales en el contexto del trasplante de células madre hematopoyéticas. Método: Se realizó un análisis descriptivo, conceptual y teórico realizado por el proceso de reflexión sobre el trasplante de células madre hematopoyéticas. Resultados: Los resultados de este proceso de reflexión se evidencian en tres categorias: 1. El contexto de trasplante de células madre hematopoyéticas, 2. El papel de la familia y el equipo de atención de salud en el cuidado de los pacientes sometidos a trasplante de células madre hematopoyéticas y 3. Repercusión del proceso de la muerte y el morir en el trasplante de células madre hematopoyéticas. Conclusion: fue el papel implícito del equipo de salud en la tarea de involucrar a los pacientes, las familias y otros miembros del equipo en las actitudes de trabajo que permitan a todos los verbalizar sus sentimientos, la identificación de fuentes de ayuda, que puede estar dentro o fuera de su propia familia. Descriptores: Trasplante de Células Madre; Familia; Enfermería.
INTRODUCTION

The Transplantation Hematopoietic Stem Cell is a procedure that aims to restore immune function and spinal cord of patients with various malignant and non-malignant diseases, inherited or acquired. Among the malignant disorders, include some leukemias, lymphomas and myelomas; between non-malignant may be cited aplastic anemia, sickle cell anemia and thalassemia. Transplants can be classified according to the type of graft, autologous, allogeneic related and unrelated and still not myeloablative HSCT.¹

This is a new therapy in the world; the first successful transplant was performed in 1957 by Dr. E. Donnall Thomas. Since then, this is a treatment modality that has been widely used in many countries. Studies indicate that there were some 50 million THSC in the world in 2006.²

In Brazil, the first transplant was performed in 1979, at the Hospital of the University of Paraná. In actuality, this is a procedure performed in more than 60 hospitals in the country. Since the number of transplants has also increased rapidly: in 2002, 870 transplants were performed such as that in 2010 transplants were performed in 1581 in Brazil.³ With the growing demand for HSCT patients, emerges the need of a series of reflections on the factors inherent in living conditions and health of this population and their families.

As we reflect on these issues in the context of HSCT, it is essential to understand that this is a recent therapeutic characterized by aggressiveness of side effects caused by chemotherapy, radiotherapy and other organic effects of the numerous interventions during this process. It should be noted that such patients develop a high potential impairment to multiple organs, besides the inherent immune depression, which can be stressed in accordance with the type of transplant performed.⁴

The experiments in this context leads to a pertinent question: if on one hand new types of treatment are increasingly used to prolong or even cure serious diseases, on the other stand the difficulties faced by patients and their families when they experience the implications of such treatments.

This study aims to present reflections on the triad patient/family and professionals in the context of Transplantation of Hematopoietic Stem Cell.

METHOD

This is a descriptive study, of conceptual and theoretical analysis performed by the reflective processes about Transplantation of Hematopoietic Stem Cell. To support the reflective process, it was used as a source of data collection, articles of databases Lilacs (Latin American and Caribbean Health Sciences), Medline (International Literature on Health Sciences) and sites linked to the ministry health. For discussion of the findings obtained, we sought to categorize into three themes:

♦ The role of family and health care team in the care of patients undergoing HSCT
♦ The context of transplantation of hematopoietic stem cell transplantation (HSCT)
♦ Impact on the process of death and dying in HSCT

DEVELOPMENT

♦ The context of transplantation of hematopoietic stem cell transplantation (HSCT)

Because of the complexity involved in these therapeutic activities of life and health of patients and families become vulnerable to risks early and late. In this perspective, as a result of ignorance of aspects of the disease and treatment, may emerge feelings generated by the resulting fragility of the disease and the situation encountered.

Thus, in the run up to transplant many anxieties and fears may arise. Since, after diagnosis and indication of HSCT than autologous starts a search for potentially compatible donors. These are not always among the family members, making necessary a search for the national registry of bone marrow donors or even search by international donors.⁵ The search for donors is always a constant dilemma potentiatior of psychosocial and socio-familiar.

After this initial phase, should it have a compatible donor will be required to hold a series of clinical and laboratory evidence for the health of both the recipient and the donor involved in this process. At this time, the receiver gets to be prepared to assume the condition of transplanted, and checks with your family and core social possibilities and difficulties you might encounter after completion of the same.

The therapy involves care that goes beyond those that develop in the hospital...
environment. Therefore, the demand for care is quite sharp and lasts for months or even years after HSCT. However, this is not an easy process, since the profile of transplant patients demonstrates the existence of a significant deficit in the spheres of economic support, social and family. As a result, situations arise that demand by the multidisciplinary team, patient and family to establish a trust, credibility and support, in order to overcome the numerous obstacles and barriers that may occur in this process. Aiding decision-making with a focus on preserving the quality of life of patients and their families.

In the next stage, the patient will receive care in hospitals. Thus, it is relevant to highlight the continuity of strategies related to health education of these individuals, favoring the process of meaning construction and interface between therapeutic multidisciplinary team, patients and families. During this period of therapy highlight the numerous side effects arising from conditioning prior to transplantation. Among them, shows a marked neutropenia period, the dietary imbalance, mucositis, diarrhea, electrolyte imbalance, and hospitalizations long and filled countless invasive procedures for diagnosis and rehabilitation functions. Such events act so as to maximize psychological effects, sleep disorders, depression, and social isolation, among others. These require an accurate and steady gaze of the multidisciplinary team in the rapid diagnosis and effective such situations, as well as the development of strategies that may be developed in conjunction with the patient and their caregiver.

After the period of immune recovery and the process of clinical HSCT, the patient and his family enter a phase of preparation for follow-up care at the household level. During this period the team builds possibilities and enables mechanisms to discharge from hospital and maintenance of the other measures of care in outpatient services. Such strategies should prioritize the development of conditions that generate autonomy, self-care and reintegration benefit the core socio-familiar. However, it is known that these require substantial changes in the patterns of life and health, the family routine adjustments, including the removal of the individual from his residence to the vicinity of an HSCT center. This is a process constantly unfinished, as doubts, fears and other situations that occur need to be evaluated continuously by the health team.

It is evident also that these patients and their families are followed for several years after HSCT, and in the first year limitations can be quite severe and should be appropriate in subsequent periods to this readaptation to their daily activities and restoration practices labor, among other schools.

The role of the family and health care team in the care of patients undergoing HSCT

We have experienced increasing investigations focusing on the family as an object of study. Such studies constitute important tools in the construction of theoretical frameworks in order to support the care the family who experiences moments of illness of one of its members.

In this context, chronic degenerative diseases, like cancer, can bring serious inconvenience to patients and their families. Regardless of the outcome, the initial diagnosis of cancer is still perceived by many people as an event that frightening threat, making them vulnerable.

Whereas the families throughout the life cycle are vulnerable to crises, although moments of instability, it makes them evolve as an institution; noting that in situations of imbalance, this also ends up suffering significant changes.

One study sought to describe the imbalance that the diagnosis of juvenile cancer causes in families and highlight the representation of diagnosis in children, adolescents and families involved as well as the behavior of the nursing staff in their perception. It was concluded that this disease process interferes with the whole family structure, causing an imbalance in this structure.

These changes in family dynamics caused by the diagnosis of cancer should not only physical aspects caused by the disease, but also refer to the psychosocial and financial demands on the lives of patients and their families, thereby generating, disorders that are not only obtained the disease, but increased by caregiver burden, creating imbalance in social and family life.

Noteworthy is the fact that caregivers/family members are often not prepared to face the implications of HSCT, such as the restructuring of the family routine, seeking funding, the emergence of emotional disorders such as anxiety, depression, anxiety.

Both psychosocial and psycho-emotional aspects of the patient and family can interfere in any way in the treatment. These may influence positively or not, and this
variable will be conditioned by previous experiences, inter-relationships with the staff and the forms of support that this can take hold in this period.

It is noteworthy that the patient who performs HSCT goes a long way and its arrival at the health service key to the creation of links with health professionals who will accompany you in this process. The health team fits the valuable task of engaging patients, families and other team members in this action.

The communication strategy developed in a positive way can be an important ally of health professionals in patient care/family in HSCT. Adding to this practice a close eye to the uniqueness of the subject, which means personalized attention directed to the construction of a therapeutic process that takes into account the particularities of each situation. Therapeutic communication developed with the family may favor the establishment of bonds, obligations and responsibilities in order to integrate harmoniously patients, families and professionals. Building strong ties is an essential part of the processes of change, implying a contractual relationship of rights and duties among all parties involved.12

Among the many possible health actions deemed necessary to provide comprehensive care to these patients, stand out, the availability, the attitude of acceptance, listening and creating/maintaining a therapeutic environment that promotes the welfare and care.

In this context, a recent Brazilian study also notes that for many users of cancer care services, the provision of health care is not yet seen as a labor action, which characterizes the assistance offered more as a good action than as a care.13

As we reflect on this practice, everything suggests that the decision making of health professionals, has not always taken into consideration the wishes of the family and the right to receive a call quality, which are prioritized relevant aspects for all involved this relationship, even the professionals do not come sufficiently reflecting on their work and the implications of passivity and disengagement to interact, educate the family, causing them to establish themselves as actors in the exercise of their care actions based on solid principles and technical scientific and ethical.

Health professionals working in oncology are confronted daily with situations of suffering, pain and loss. Diagnostic investigations, treatment and face all its vicissitudes, along with the uncertainty of healing and the possibility of death, are activities that put the professional face of emotionally charged situations.14 However, the sources of gratification occur by the outcome of patient care and the establishment of effective linkages, that help professionals find satisfaction and pleasure in activities they perform.15

The host and humanization patient’s family in HSCT should consist of job attitudes that create spaces that allow everyone to verbalize their feelings and value them, identifying sources of assistance that may be inside or outside the family itself.16

Health professionals should be aware of issues related to the host and links developed in the context of HSCT, seeking understanding of the educational process is able to promote the restructuring harmonic physical capacity, intellectual and moral. Thus, the patient care in HSCT may be more effective as an educational process in full for all patients/families/health professionals.

Repercussions on death and dying in HSCT

The care of patient’s family in HSCT reveals all its complexity, as it involves a variety of physical, psychological, social, cultural, spiritual and economic; once these patients are often faced with the possibility of failure of therapy and death. Often in a slow and gradual one observes the patient’s terminal illness beyond cure.

The goal of palliative care is to improve the quality of life of patients and their families in coping with the problems associated with life-threatening illness. Such an approach is through the prevention and relief of suffering by means of early evaluation and needs, beyond the treatment of pain and other problems, physical, psychological and spiritual15 Nevertheless, the evaluation of palliative care begins with establishing a relationship with patients and their families by checking the common goal. This point should be to assess the physical and psychological care involved to minimize the discomforts of the same, taking into consideration that some measures should be avoided as those that do not prioritize the comfort and dignity.17

Health professionals must now take into account the host and humanization of care the patient’s family in HSCT. Investing in job attitudes that create spaces that enable all verbalizing their feelings, identifying sources of aid, that may be inside or outside of their
own family, so this way the patient can have a dignified end and with minimal discomfort can.

**FINAL REMARKS**

The process of HSCT is undoubtedly a broad and complex process, permeated by numerous issues that move between the concepts and practices developed. In this context, the link established between the patient, family and health professionals need constant maintenance, as it can take on different nuances according to the stage, clinical status and outcome of the process of HSCT.

In the process of HSCT, especially in the post-transplant, these patients have significant changes in their habits of life, and may suffer from reduced production capacity and even the loss of some social and family roles. Such situations require great demand supportive care, to be offered subsidies to encourage the promotion of health rehabilitation and re-integration of these in society.

After discussing issues relevant to the roles developed by patients, families and health professionals is implied the need to highlight the dynamics and functioning together they develop in the period they are allied around a common goal: the process of HSCT and their implications. Thus, we must embark on this triad a look that is able to understand the collective taking into account in this process the dimension and integral elements of subjectivity involved. Once these have characteristics, experiences and ways of thinking that lodge in the lived realities individually but with direct repercussions on the collective.

It is understood that mutual respect and cooperation in the formation of a body of knowledge and practices specific to each patient and family and the incorporation of technical knowledge by the health team can translate into a beneficial feedback, where all perceive and share lessons.

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