## Coping strategies used during treatment by patients submitted to hematopoietic stem cell transplantation

Estratégias de enfrentamento utilizadas durante o tratamento por pacientes submetidos ao transplante de células-tronco hematopoiéticas

Estrategias de afrontamiento utilizadas durante el tratamiento por pacientes sometidos a trasplante de células madre hematopoyéticas

Ana Paula Szczepanik\*<sup>(D)</sup>; Angela da Costa Barcellos Marques\*\*<sup>(D)</sup>; Mariluci Alves Maftum\*\*\*<sup>(D)</sup>; Rosibeth Del Carmen Muños Palm\*\*\*\*\* Raria de Fátima Mantovani\*\*\*\*\*\* Ruciana Puchalski Kalinke\*\*\*\*\*\*

#### Abstract

Background: Coping strategies in the process of treatment with hematopoeitic stem cell transplantation are crucial to the improvement of the quality of life of these patients.

**Objective:** To describe coping strategies used during treatment by patients submitted to hematopoietic stem cell transplantation. Methodology: Qualitative, descriptive, and exploratory research, with 5 participants, conducted from July to November 2017, in a hospital of reference for this treatment in Brazil. Data were collected by means of semi-structured and self-applied video interview and analysed by the content analysis technique.

Results: Coping strategies such as family support and spirituality were the most used, present in every stage of transplant, followed by the increase of feeling of appreciation of life after overcoming this experience.

Conclusion: Patients develop coping strategies to endure therapy effects. The knowledge of the strategies can contribute to the enlightenment and stimulation of future patients regarding coping with treatment, as well as to the assistance of health professionals, especially nursing teams in care practice.

Keywords: hematopoietic stem cell transplantation; bone marrow transplantation; adaptation, psychological; oncology nursing

#### Resumo

Enquadramento: Estratégias de enfrentamento no processo de tratamento do transplante de células-tronco hematopoiéticas são determinantes para uma melhor recuperação dos pacientes. Objetivo: Descrever estratégias de enfrentamento utilizadas durante tratamento por pacientes submetidos ao transplante de células-tronco hematopoiéticas.

Metodologia: Pesquisa qualitativa, descritiva e exploratória, com 5 participantes, de julho a novembro de 2017, em hospital referência para este tratamento no Brasil. Os dados foram obtidos por vídeo-entrevista semiestruturada, auto aplicada,

e analisados pela técnica análise de conteúdo. **Resultados:** Estratégias de enfrentamento como o apoio fami-liar e a espiritualidade foram as mais utilizadas, estando presente em todas as etapas do transplante, seguido do aumento do senso de valorização da vida após a vivência desta experiência. Conclusão: Pacientes desenvolvem estratégias de enfrentamento para suportar os efeitos da terapêutica. O conhecimento destas estratégias pode contribuir para a elucidação e estimulação de futuros pacientes relativamente ao enfrentamento do tratamento, assim como, para a subsidiação dos profissionais de saúde, em especial, das equipas de enfermagem na prática do cuidado.

**Palavras-chave:** transplante de células-tronco hematopoé-ticas; transplante de medula óssea; adaptação psicológica; enfermagem oncológica

regarding relevant intellectual content.

Resumen

Marco Contextual: Estratégias de enfrentamiento em el proceso de laterapéutica del Trasplante de Células-Madre Hematopoyéticas son determinantes para una mejor recuperación de los pacientes.

**Objetivo:** Describir estrategias de enfrentamiento utilizadas em el tratamiento por pacientes sometidos al trasplante de células madre hematopoyéticas.

Metodología: La investigación cualitativa, descriptiva y exploratoria, realizada con 5 participantes, de julio a noviembre de 2017, en hospital referencia para este tratamiento en Brasil. Los datos fueron obtenidos por video-entrevista semiestructurada, auto aplicada, y analizados por la técnica análisis de contenido.

Resultados: Estrategias de enfrentamiento como el apoyo familiar y la espiritualidad fueron las más utilizadas, estando presente en todas las etapas del trasplante seguido del aumento del sentido de valoración de la vida después de la vivencia de esta experiencia.

Conclusión: Los pacientes desarrollan estrategias de enfrentamiento para soportar los efectos de la terapéutica. El conocimiento de estas estratégias puede contribuir com elucidación de cómo el paciente vive el tratamiento y como estímulo para los pacientes futuros, así como subsidios para profesionales de salud, en especial, el equipo de enfermería em la práctica del cuidado.

Palabras clave: trasplante de células madre hematopoyéticas; trasplante de médulaósea; adaptación psicológica; enfermería oncológica.

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#### Introduction

Hematopoietic stem cells transplantation (HSCT) is considered as one of the treatment options for patients with haematological diseases and is in continuous growth. It is a complex and hard procedure, which requires a long period of hospitalization and exposes the patient to physical, emotional, and social changes, leading to the need to develop coping strategies to face these adversities.

The global demographic and epidemiological transitions show a growing impact in cases of cancer and hematologic diseases in the next decades (Gratwol, Baldomero, & Passweg, 2013), with increasing incidence in Brazil and the world. According to data from the Ministry of Health (MH), in 2017 there were 2,794 HSCTs in Brazil, of which 1,668 were autologous and 1,126 allogeneic, 46 autologous and 155 allogeneic occurring in Paraná (Associação Brasileira de Transplante de Órgãos, 2017).

When the HSCT is performed, there is depression of the immune system that triggers physical changes throughout the patient's daily life. This can be considered as a critical moment in their life because, initially, the patient feels fear and little expectation in relation to the future. Sometimes, these reactions are reinforced by beliefs and fantasies related to this pathology, associating it with the end of life (Andrade, Castro, Soares, & Santos, 2012). Therefore, there is a need to seek coping alternatives and strategies to experience these changes.

Coping strategy was defined by Lazarus and Folkman (1987) as an individual variable depicted by the way people commonly react to stress, driven by personal factors, situational demands, and available resources. That is, they are ways and attempts to preserve life and/or physical and mental health in the face of a stressor moment that will bring consequences into their daily lives.

Considering that studies addressing the coping strategies theme in the treatment can contribute to scientific production for transplant patients and those who, directly or indirectly, experience this process with them, such as family, friends, and health professionals, the patient can benefit from knowledge thereby improving their understanding and, thus, engaging in treatment for a greater success. Family and friends will be able to understand the situation experienced by the patient and help them with special care during hospitalization and at home and to persevere there (Zatoni et al., 2017). The produced knowledge can assist health professionals, especially those in nursing, in understanding how the patient experiences treatment and in benefiting from subsidies to the practice of developed care.

Therefore, the objective of this study was to describe coping strategies used in the treatment of patients undergoing hematopoietic stem cells transplantation.

## Background

The biotechnological development and improvement that therapies for individuals with hematologic diseases have achieved has increased the possibility of prolonging life and even promoting their cure. Thus, the advances brought new possibilities. Attention to health has become as important as survival (Matias, Oliveira-Cardoso, Mastropietro, Voltarelli, & Santos, 2011). In view of this process, studies were started in the scientific community relating to how diseases and treatments affect the lives of patients and their relatives and friends (El-Jawahri et al., 2015).

During the therapeutic process of HSCT, the patient goes through some critical steps in which the complications, such as infection and graft-versus-host disease, may put their lives at risk and negatively affect the perceptions about themselves. The treatment causes symptoms which have temporary disabling potential, like mucositis and fatigue, and will worsen as the severity of symptoms increases (Ovayolu, Ovayolu, Kaplan, Pehlivan, & Karadag, 2014). Considering the patient's situation resulting from the clinical and emotional manifestations of the treatment, they will need strategies that help them to experience this moment in order to endure until the end. The study by Silva et al. (2018), whose objective was to identify the coping strategies of people with HIV, had the highest means related to factors of positive re-evaluation, problem resolution, and escape-avoidance, demonstrating the more frequent use of the forms of coping strategies focused on the problem and the emotion. Their

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study concluded that the family affective context and religiousness can influence coping with the disease in a positive way.

## **Research Question**

What are the strategies that patients use in coping with the treatment by HSCT?

## Methodology

Qualitative, descriptive, and exploratory research, developed in the Bone Marrow Transplantation Service (STMO) of a federal education hospital, a reference for this treatment in Brazil, located in the state of Paraná.

The recruitment of participants was carried out by the researchers, by personal delivery of a folder that included an invitation to participate in the research. 30 patients were invited and treated in the outpatient post-transplant service during the months of July to November of 2017, of which seven accepted the invitation.

The inclusion criteria were: age equal or older than 18 years, submitted to HSCT in the field of this research and with at least 1 year posttransplant. The reason behind the 1 year posttransplant was that with a shorter period the patients would still be undergoing physical and emotional changes, as well as the adaptation to the new stage of life, which could interfere with the quality of their testimonies. However, there was no limitation of post-transplant time since it is believed that the memories of an experience as unique as this that changes globally the individual, family, and social life are not forgotten. Although this is not the object of study, the greatest possible post-transplant time shows the possibilities of survival that the treatment provides to the person.

Patients were excluded who did not show Karnofsky performance status above 70% (evaluation system related to the general condition of the patient, which classifies the participants without scale from 0 to 100, where perfect health corresponds to 100 and death to 0; Cabianca, Menegheti, Bernardi, & Gurgel, 2017), depression diagnosis and/or use of antidepressant medication, and medical records. Thus, two participants were excluded due to the use of antidepressants, constituting a purposeful sample of five patients.

The data relating to sociodemographic characterization were collected through an individual interview carried out by the researcher about the dependences of the ambulatory STMO, in a booked room, provided by the service coordinator, and the clinical characterization data by means of access to medical records. The structured self-applied interview in mp4 video recording format, respecting the choice of the participants, occurred in their homes after they received individually in the outpatient service a guide with questions about their experience during the HSCT therapy. The guide was read individually and all doubts about each issue were addressed. All participants reported having the equipment necessary to carry out the recordings and took on average between two to four weeks to deliver the videos to the researcher, who received them in the outpatient service of STMO, in a booked room, with a timetable arranged by telephone. This research is part of the project of Motivational Communication Tools for Improving the Quality of Life of Hospitalized Patients Undergoing Hematopoietic Stem Cells Transplantation, which was approved by the Research Ethics Committee of the Health Sciences Sector of the Federal University of Paraná, under the opinion number 2,062,046.

The sociodemographic and clinical data were analysed descriptively and expressed in absolute frequency. The reports included in the video recordings were submitted to content analysis (Bardin, 2011), through the stages of pre-analysis, material exploration, results' treatment, and interpretation.

In pre-analysis, a full transcription of the recorded interviews was carried out, with subsequent readings for the transcribed material to become familiar. In the material exploration phase, the raw data of the transcriptions of the interviews were reread repeatedly in order to identify the topics of interest and relevance to answer the question and the research objective. In the stage of results' treatment and interpretation, the relevant data were articulated with the theory and inferences were made for final interpretation and construction of categories.

## Results

The age of the patients ranged between 21 and 52 years; two were male and three female; three declared themselves married or in a stable union. In relation to schooling, one was in high school, two had graduated from high school, and two in college, all of which were economically active. Regarding clinical characterization, two had some type of leukaemia, two had severe aplastic anaemia, and one had Fanconi anaemia. All patients were submitted to the allogeneic SCT. The results generated by the patients' testimonies were organized in three categories: Family support in coping with the disease; Spirituality and religiousness in coping with the disease; and Coping with the disease provides an appreciation of life.

#### Family support in coping with the disease

The presence of the family was reported as the main support in coping with the disease, constituting itself as support at all stages of the transplant. Some patients had to depart from their hometowns, nevertheless, at least one family member followed the therapeutic process, as seen in the testimony of P1 and P4:

> I rented an apartment near the hospital because I needed to go there almost every day while awaiting news of the donor. My father and my mother stayed with me, my wife and children remained in Recife, at that moment it was just me, my father, and my mother, and that made the difference. (P1; July 2017) on the day I received the second bone marrow, it was very exciting, I was very happy, my father, my mother, and my sister, who donated my first bone marrow donor were allowed to stay with me, so it was a joyous, a happy occasion, I was very happy. (P4; September 2017)

The moments of sadness and longing were overcome by the desire to improve these conditions, often motivated by family members. Patients with children (P1 and P2) reported that the faith in that they would be reunited with their families and survive to witness their lives was what inspired them and motivated them to overcome the moments of pain:

> I have four children to support, I want to live to see my children grow, in the

hard days when I thought how difficult it was, I thought about my children, how I would like to see them grow and be beside them. (P1; July 2017)

My son had only two and a half months and I needed to do chemotherapy, I had to be isolated from him, we stayed 33 days away from each other. So I tried to have a lot of faith in something. In my case, my greater faith was really my son . . . he was my inspiration. I always had his pictures around my room, my home, on my cell phone. I always look at his pictures, he really is my inspiration. (P2; August 2017)

# Spirituality and religiousness in coping with the disease

Debilitated by the waiting for a donor and the aggravation of the disease over time, faith in God was often the consolation and motivation to continue. Praying was reported as a means of renewal of faith, of hope, as can be seen in the testimonies of P1 and P2:

I prayed frequently, prayed to God to give me light. One of those endless nights, in my room, I knelt down and talked to God, I said to him: my God! I need to tell the Lord what I am going through here. I have four children to support, I want to live to see my children grow, if the Lord is testing my ability to endure, I can't stand it anymore. So I ask only this. If You think that I should not live anymore, then take me Lord, but on the other hand, if You think that I deserve a chance, I want the Lord to give me light. (P1; July 2017) when I had to go to the hospital, briefly before I went, I reflected a lot, prayed a lot, my son was already one year and a half old at that time, I waited for him to go to sleep and prayed beside him, watching him, asking him to give me strength. (P2; August 2017)

The praying to and the presence of God provided the strength and encouragement to remain in treatment, just as the experience of illness and disease helped to have a greater appreciation of life and everything that surrounds it, as observed in the testimony of the participants P3 and P4. when we are sick or experience a problem in life, we start to value more the real things, that which is invisible to the eyes in the daily life when we are well and healthy. I always talked with God, asked God for much strength, so I could go through the rough days and be well and live to be good to people. (P3; August 2017)

I never asked God: my God, why me? Damn it, I never harmed anyone. I simply looked up and said: God! Let's go then. I'll have to go through this! For me it is a purpose in life, if I have to go through this, I'll go it, I'll do it and I'll win. (P4; September 2017)

#### Coping with the disease provides an appreciation of life

The feelings and perceptions about the period of the disease and present life are reported by patients as gratitude for having managed to overcome this stage. The disease is no longer remembered, the moment was seen as the possibility of reflection and life lesson by participant P1:

> It's been over 7 years since I went through all of this, but my life today is normal, I have my family, my job, I do sports, do everything everyone does. A person who goes through a hematologic disease learns that you can't make a book telling what happens because every person has a story, reacts in a way both clinical and emotional, so much happens that it is difficult to say. Thank God I did not have any serious damage. (P1; July 2017)

The return to a normal and healthy life, to work, and a new sense of coexistence with family, cherishing life, is evident in the testimony of participant P2:

> Today I have a normal life. I am celebrating my five years of transplant. I work, on weekends I hang out with my son, go to the park with him, I live my life. I do everything I have the right to do because at the time of the transplantation I realized how precious our health and our life is. (P2; August 2017)

Taking into account the period of illness and transplantation, and in spite of suffering, the overcoming is evident in the reports of patients as a learning opportunity, highlighting the return to the will to live after a period of perceiving that their lives were being destroyed by disease. After 12 years of transplant, P4 highlights living a normal life, having plans to have children in the future, stating that there has been no subsequent damage, but rather a life lesson. In turn, P5 expressed gratitude for everything that happened, believing that this phase was of spiritual enrichment, getting back the will to live, as their testimony evidences:

"now, looking back, all the suffering you go through is really worth it because now you have a better quality of life, are able to hang out more with your family, your friends, it is very rewarding" (P4; September 2017).

> you will have to go through this, I say this from the bottom of my heart, going through this phase is worth it, because life is made of phases, bad or good. This opportunity will return your will to live, to do what you like, to play with your children and even your pets. Enjoy every moment of your life because it is very valuable. (P5; November 2017)

## Discussion

Discovering the diagnosis of a serious disease like haematological cancer is devastating, since it may represent the possibility of suffering and death. This condition can lead to the collapse of controlling life, impacting significantly in their beliefs, in their culture, in the physical, social, and mental well-being, both the patient's and the family's (Mathias, Girardon-Perlini, Mistura, Jacobi, & Stamm, 2015).

The collapse of controlling life is clearly displayed during the analysis of the demographic profile of patients, when one verifies that, despite the diversity of the mean age, the age range is adults in productive and reproductive phase. For many people, it is the phase of professional ascension and consolidation and, at the same time, the idealization of building a family with reproductive planning occurs. The alienation of these dreams can cause feelings of anguish, fear, decrease of productivity and of functional and sexual performance, taking into account that high doses of chemotherapy can lead to infertility, thus frustrating future dreams and goals of building a family (El-Jawahri et al., 2016).

Other aspects that should be emphasized relate to the marital status and presence of children. For patients who have children, there is the additional concern with the health problem. The distancing imposed by hospitalization creates feelings of anguish and helplessness, especially when the children are dependent. In addition, difficulties with the partner can occur due to the double role that they will play, as companion and home provider, which causes the patient to think that their treatment generates family overload and disturbance (Brice et al., 2017).

When receiving the diagnosis of cancer, the family cluster is affected and a life of uncertainties and expectations about the future begins. At this moment, it is almost impossible to predict exactly the difficulties that will occur with the treatment, increasing the levels of anxiety and fears, inserting the patient and the family in a state of emotional fragility. This unexpected news combines with fear and causes insecurity, consequently making the family union the main source of support and assistance for the patient to face this challenge (Mathias et al., 2015).

It stands out that the caregivers of transplant patients are an essential resource for the patient during the course of the disease, but they are not always acknowledged by health professionals. The care needs are complex for patients with chronic diseases and cover a wide range of potential deficits in all domains: physical, psychological, social, and spiritual care (Silva et al., 2018). Thus, it is important to highlight that the support received from the family, as reported by patients undergoing HSCT in this research, was essential, since they need to feel safe in the initial stages of treatment and, especially, during hospitalization and after hospital discharge, to make sure that they are not alone in this delicate moment of their lives. Therefore, the family constitutes itself as an institution in which the individuals start their processes of training, acknowledging it as the basis of the human being, as part of the culture of our society. It represents a unit in constant movement, composed not only of those linked by blood ties but of all who perceive themselves as a family, linked by affection, who coexist in an organized fashion for a determined period of time and aim to achieve common goals. Thus, it is understood that their members are able to share the experiences of life, providing support and witnessing their adverse moments (Brusamarello, Maftum, Mantovani, & Alcantara, 2018).

In the testimonies of patients, it was possible to verify that the support received from their family and faith gave them the opportunity to appreciate life and face feelings of fear, anguish, and anxiety. The literature emphasizes an increased religiousness during negative events, including the illness. Therefore, the studies conducted in the area of health claim that religiousness is positively associated with indicators of psychological well-being which uses to achieve a positive direction for life (Rocha & Fleck, 2011).

Through religiousness towards transcendence, in its meaning for their existence outside of the objective world, in the reflection on themselves and their relations with the world, in the consciousness of their finiteness and limitations, and for the desire to overcome them, the person can experience spirituality. It is manifested by an intimate sense of existence, by the desire to give meaning to the existence in the world, with depending in the belief in a higher thing or being (Rocha & Fleck, 2011).

Therefore, it appears that the experience of feelings of spirituality and religiousness by the patients of this study seems to help them directly in coping with the disease, making them more confident and optimistic, since they believe they can count on a divine strength of aid to therapy, based on faith in recovery and the fast return to their normal life as a person. Thus, a mobilization of faith is evident in religiousness, causing the person to feel more empowered to face adversity and continue to fight for their life, including the belief that they will be cured. Consequently, faith leads the person to the belief that they will have a supernatural and favourable assistance to the condition of fragility and suffering that they are experiencing (Murakamil & Campos, 2012).

In the study by Wilson, Forchheimer, Heinemann, Warren, and McCullumsmith (2017), which aimed to identify the importance of spirituality in patients with cancer to the coping with the process of illness and treatment, the authors concluded that spirituality can give meaning to the process of illness and suffering, being a coping strategy for the patient and their family in the face of cancer.

The notion of spirituality, in the words of oncolog-

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ic patients, is permeated by relief in difficult moments, giving courage and strength to overcome, improvement in treatment, acceptance, and even resignation, acting as a source of personal balance and retreat in the struggle for the life threatened (Pinto et al., 2015). The exercise of spirituality and religiousness, and the experience during the course of the disease provided to patients the feeling of gratitude for the new opportunity of life after overcoming the treatment.

Patients undergoing HSCT, according to the experience, adopt the attitude of seeking to obtain a new perspective on life (Nenova, Du-Hamel, Zemon, Rini & Redd, 2013). In this study, it is noted that patients refer to a change in the way of seeing and living life based on actions and meanings generated by therapy, so that they start to appreciate their relationships, events, and time; to get involved more positively in their treatment, with more faith; to act more carefully in relation to themselves; and to mature with the experience. According to El-Jawahri et al. (2015), a post-traumatic growth occurs in people who experience this situation.

Because this is a transformative experience, it is believed that achieving a better state of health, in relation to what it was before therapy, became important so that patients learn to balance their needs in accordance with what they experience in each stage of treatment, seeking this balance in what strengthens them the most, be it the belief in something greater, in a loved one, in the appreciation of the life threatened.

It stands out that the shortage of studies, both national and international, on this theme, mainly related to coping strategies in this specific population, as well as the small number of patients, became a limiting condition of this research because they hindered the wide comparison with different results in the literature.

It is believed that new knowledge resulting from this research concerns reports of transplant patients about the experience and strategies which they used to remain in treatment and become now a source of positive stimuli for future patients, families, and health professionals.

#### Conclusion

With this research, it was possible to consider that the coping strategies of treatment by patients undergoing HSCT were the support and acceptance of family, the religiousness, and spirituality.

Taking into account the emotional and psychological context, experienced by patients in transplant centres, from the discovery of the disease until the final stage of the transplant, the testimonies of those who were submitted to transplantation and succeeded can help future patients to overcome this time with more confidence and hope, because it is the exposure of the experience of those who felt, lived, and endured a long and exhausting period of uncertainty and suffering.

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