CORRELATION BETWEEN ADDITIONAL CONCERNS AND PERSONAL PERFORMANCE WITH THE QUALITY OF LIFE IN HOSPITALIZATION FOR HEMATOPOIETIC STEM CELL TRANSPLANTATION¹

Celina Angélica Mattos Machado* Angela da Costa Barcellos Marques* Bruna Eloise Lenhani*** Dabna Hellen Tomim**** Paulo Ricardo Bittencourt Guimarães***** Luciana Puchalski Kalinke******

ABSTRACT

The objective was to correlate the additional concerns and personal performance with the general/global quality of life of adult patients with hematologic cancer hospitalized for autologous and allogeneic hematopoietic stem cell transplantation. A longitudinal, observational and analytical study was carried out in a public hospital in the south of Brazil with 55 patients. Data collection took place between September 2013 and November 2015. The sociodemographic and clinical questionnaires, Quality of Life Questionnaire Core-30 and the Functional Assessment of Cancer Therapy - Bone Marrow Transplant were used. The data were evaluated using the software Statistical 7.0. The mean age for autologous transplantation was 45 years, with a prevalence of multiple myeloma diagnosis; for the allogeneic was 31 years with predominance of leukemia. The general/global quality of life, personal performance and additional concerns characterized by body image, fatigue, sexuality and appetite presented significantly lower mean values in the period of pancytopenia than baseline, with a gradual improvement in the hospital pre-discharge period. It is concluded that transplantation is a therapy with potential curing role, however, it has negative impacts on the domains of quality of life, personal performance, additional concerns and the life experience of the recipients.

Keywords: Quality of Life. Hematopoietic Stem Cell Transplantation. Hematologic Neoplasms. Nursing Oncology. Hospitalization.

INTRODUCTION

The gradual increase of chronic-degenerative diseases, among them cancer, has become a public health problem in Brazil and in the world. According to the National Cancer Institute José Alencar Gomes da Silva (INCA), the estimated incidence of the disease for the 2018/2019 biennium is 600.000 cases for each year. Excluding non-melanoma skin cancer, there will be 420,000 cases; regarding to hematological cancer, it is estimated the occurrence of 23,510 new cases each year⁽¹⁾.

In other developed or developing countries, the picture is similar. According to the International Agency for Research on Cancer (IARC) of the World Health Organization (WHO), there is a 2025 outlook for more than 20 million new cancers, and it is estimated that by 2030 the occurrence of 13.2 million related deaths⁽²⁾.

Cancer is a disease with the potential to influence negatively the quality of life (QoL) of patients,

because their diagnosis is often received with apprehension and fear. These feelings, which lead to the interference of family dynamics, which cause additional concerns, qualified by interferences in body image, fatigue, sexuality and appetite, as well as in personal performance, characterized by the ability to perform daily tasks⁽³⁾.

Patients with hematologic cancer may have the therapeutic indication of the hematopoietic stem cell transplantation (HSCT), a consecrated and highly complex procedure, which requires the participation of professionals from different spheres of health, among them, nursing, which acts actively at all stages. The treatment is relatively long, involving risks that predispose the patient to a broad spectrum of complications, which need to be managed in order not to threaten his life or affect his/her survival and $QoL^{(4)}$.

The hospitalization period is the phase of treatment in which the patient suffers the greatest changes in QoL and experiences social isolation in a

¹The article is original extracted from the dissertation: Changes in the quality of life of patients submitted to hematopoietic stem cell transplantation during the hospitalization period, Federal University of Paraná, 2017.
*Nurse. Master in Nursing. Hospital Clinic Complex of Paraná Federal University. Paraná (CHC-UFPR). Bone Marrow Transplant Service (BMTS). Curliba, Paraná, Brazil. E-mail: celina.utpr@gmail.com ORCID iD: http://oroid.org/0000-

[&]quot;Nurse. Master in Nursing. CHC-UFPR. BMTS. Curitiba, Paraná, Brazil. E-mail: angebarenf@yahoo.com.br ORCID iD: http://orcid.org/0000-0003-1442-0308.

^{**}Nurse. Master in Nursing. Erasto Gaertner Hospital. Curtiba, Paraná, Brazil. E-mailt brulenhan i@gmail.com. ORCID iD: http://orcid.org/0000-0002-6009-3400.

[&]quot;Nurse. Master in Fisiology, Federal University of Paraná (UFPR). Curtiba, Paraná, Brazi. E-mait dabnatomin/@gmail.com. ORCID ID: http://orcid.org/0000-0003-3199-0740.
""Statistician. Dodor of Forestry Engineering. UFPR. Professor of the Department of Statistics. Curtiba, Paraná, Brazil. E-mait guimaraes.ptb@gmail.com ORCID ID: http://orcid.org/0000-0002-9852-67777.
"""Nurse. Post-Dodor in Health Sciences. UFPR. Professor of the Graduate Program in Nursing. Curtiba, Paraná, Brazil. E-mait Jucianakalinke@yahoo.com.br. ORCID ID: http://orcid.org/0000-0003-4868-8193..

scathing way due to the immune system being compromised and will be at high risk of acquiring infections. Although all steps are considered relevant and permeated by changes, it is noticed that the phases of conditioning, cell infusion, pancytopenia and medullary "hold" become the milestone for a series of modifications that will accompany the patient throughout the course treatment and even life.

In the hospitalization phase, the patient is faced with a stressful environment, with the imposition of norms and routines that are often not implemented with a humanized eye. There is loss of privacy and freedom, exposure to invasive and unpleasant procedures, which can lead to insecurity and dependence. It is necessary to search for the balance between the biologicist and the humanized model, since the treatment of cancer requires the use of highly technical care⁽⁵⁾.

This way, the objective of this research was to correlate additional concerns and personal performance with the general quality of life of hospitalized adult hematologic cancer patients for autologous and allogeneic hematopoietic stem cell transplantation.

METHOD

This is a quantitative, observational and analytical study, developed in the Bone Marrow Transplantation Service (BMTS) of a federal teaching hospital in Curitiba, a national reference in HSCT.

The sample was composed by a non-probabilistic sampling procedure but based on the number of patients who underwent HSCT in the years 2010 to 2012, plus 50% due to the possibility of losses of participants due to the treatment characteristic. Fifty-five patients were invited to participate in the study. The inclusion criteria were: to be older than 18 years, diagnosis of hematologic cancer and hospitalization to be submitted to HSCT. Patients who did not have the physical conditions to complete the questionnaires were excluded. It was defined that if the patients withdraw their consent, if they undergo a new procedure or if they died, they would be discontinued from the research.

The data collection period comprised the months of September 2013 to November 2015, through the following steps: Pre-transplantation - to establish a baseline level; HSCT - Period 1 - Period of

pancytopenia; HSCT - Period 2 - Prehospital discharge. Socio-demographic and clinical data were collected with their own instrument in pre-HSCT. The Functional Assessment of Cancer Therapy - Bone Marrow Transplant (version 4.0) (FACT-BMT) from the Functional Assessment of Chronic Illness Therapy (FACIT)⁽⁶⁾ evaluating the quality of life of cancer patients (QLQ C30) of the European Organization for Research and Treatment of Cancer (EORTC)⁽⁷⁾ used to evaluate the quality of life of cancer patients in general, both validated for the Portuguese-Brazil.

The use of the FACT-BMT instruments and the QLQ C30 was authorized and made available via download directly to the researcher through registration of the research project.

The information obtained from the questionnaires was entered spreadsheets in the Microsoft Exce^{1®} 2010 program and then processed by descriptive statistical procedures with the results expressed in simple and absolute frequency (%) and then analyzed using Statistical 7.0 software.

The Friedman non-parametric test was used to analyze the scores obtained in each step, complemented by the least significant difference test of multiple comparisons (p value) in which the significance level of 5% was applied to results with p value below of 0.05, being considered significant (p <0.05). The application of the non-parametric tests is justified by the lack of normality of the data, attested by the Shapiro Wilk test.

This research is part of the thematic project "Quality of life assessment of patients with haematological malignancies submitted to hematopoietic stem cell transplantation", approved by the Research Ethics Committee of the Health Sciences Sector of the Federal University of Paraná under the opinion no. 411,548.

RESULTS

Regarding the sociodemographic and clinical data expressed in Table 1, it was possible to observe that the mean age in the allogeneic group was 31 years, with a discrete difference for males in both groups. Regarding the diagnosis, 92.32% (n = 36) of the patients who underwent allogeneic HSCT presented some type of leukemia.

Table 1. Sociodemographic and clinical data of patients submitted to autologous and allogeneic hematopoietic

stem cell transplantation - Curitiba, PR, Brazil,2015 (n=55).

Variables	Autologous n=16(%)	Allogenic n=39(%)
Average age	45 years	31 years
Gender		
Female	07 (43.75)	19 (48.72)
Male	09 (56.25)	20 (51.28)
Marital Status		
Singles	03 (18.75)	20 (51.28)
Married or consensual union	11 (68.75)	19 (48.72)
Separated or divorced	02 (12.50)	-
Number of children		
None	05 (3.25)	20 (51.28)
1 to 3 fchildren	10 (62.50)	16 (41.02)
4 or more	01 (6.250)	03 (7.70)
Education		
Primary school	07 (43.75)	11 (28.20)
High school	06 (37.50)	18 (46.15)
Undegraduate school	03 (18.75)	10 (25.64)
Diagnosis		
Leukemias	-	36 (92.32)
Lymphomas	08 (50,00)	02 (5.12)
MultipleMyeloma	08 (50,00)	-
Myelodysplasia	-	01 (2.56)
Tipo de transplante		
Allogenic related	-	18 (46.15)
Allogenic not related	-	21 (53.85)
Autologous	16 (100.00)	-
Cell source		
Bone marrow	-	27 (69.23)
Peripheral blood	16 (100.00)	12 (30.77)

Source: the authors

Regarding to the FACT-BMT questionnaire for specific QoL assessment for patients submitted to HSCT applied in the three stages of the study in the total sample, it was possible to observe in Table 2 that in the comparison

between the first and second stages and between the first and third stages, there was a significant difference in the domain of additional concerns.

Table 2. Comparison of Additional Concerns with General Quality of Life, between treatment stages - FACT-BMT -Curitiba, PR. Brazil, 2015 (n = 55).

Biri Cuitiba, FR, E		Averages (SD)			(p-value)	
FACT Domains	1 st Stage Basal n=55	2 nd Stage Pancytopenia n=50	3 rd Stage Prehospital discharge n=49	1 st x 2 nd	1 st x 3 rd	2 nd x 3 rd
Additional Concerns	27.78 (6.14)	22.88 (4.30)	23.90 (4.38)	p<0.05*	p<0.05*	-
General quality of life	108.40 (21.04)	90.70 (15.07)	95.89 (17.35)	p<0.05*	p<0.05*	-

Fonte: as autoras

Table 3 shows that for both groups, the domains additional concerns and General QoL showed significantly lower mean values in the pancytopenia

period than in the basal group with a gradual improvement in the hospital pre-discharge period.

^{*} escores significativos.

Table 3. Comparison of Additional Concerns with General Quality of Life in autologous (Au) and allogenic (Al) - FACT-BMT transplants, Curitiba, PR, Brazil, 2015 (n = 55).

	Averages (SD)			(p-value)		
	1st Stage	2 nd Stage	3 rd Stage			
FACT	Basal	Pancytopenia	Prehospital discharge	1st x 2nd	1st x 3rd	$2^{nd} \; x \; 3^{rd}$
Domínios	Au (n=16)	Au (n=16)	Au (n=16)	1 × X Z	1 × X 3	
	Al (n=39)	Al (n=34)	Al (n=33)			
Additional (Additional Concerns					
Au**	27.50 (4.12)	22.63 (4.63)	24.75 (4.65)	p<0.05*	-	-
Al***	27.90 (6.84)	23 (4.21)	23.48 (4.25)	p<0.05*	p<0.05*	-
General qua	lity of life					
Au**	107.70 (18.34)	91.47 (16.40)	98.97 (16.68)	p<0.05*	-	-
Al***	108.68(22.26)	90.33 (14.65)	94.40 (17.73)	p<0.05*	p<0.05*	-

Source: the authors

With the EORTC QLQ-C30 questionnaire, the QoL assessment of cancer patients, which was also applied in the three stages of the study, in the total sample, corroborates with data from the FACT-BMT questionnaire. It was observed in Table 4 that the means

of global QoL and personal performance are lower in the pancytopenia stage, with significant differences between the first and second stages for both domains and between the second and third stages for the global OoL domain.

Table 4. Comparison of the Additional Concerns with the General Quality of Life between the treatment stages - QLQ C30, Curitiba, PR, Brazil. 2015 (n = 55)

	Averages (SD)			Comparison of stages (p-value)			
QLQ C30Domains	1 st Stage Basal n=55	2 nd Stage Pancytopenia n=50	3 rd Stage Prehospital discharge n=49	1 st x 2 nd	1 st x 3 rd	2 nd x 3 rd	
General quality of life	76.82 (17.69)	56.67 (20.27)	69.05(19.17)	p<0.05*	-	p<0.05*	
Personal Performance	79.09 (29.44)	44 (29.69)	58.50 (32.12)	p<0.05*	-	-	

^{*}significant scores.

Table 5 shows for both groups (Au and Al) that the Global QoL domains and personal performance presented significantly lower means in the period of

pancytopenia than in the basal period with a gradual improvement in the pre-hospital discharge period.

Table 5. Comparison of Additional Concerns with General Quality of Life in Au and Al-QLQ C30 transplants. Curitiba, PR, Brazil. 2015 (n = 55).

	Averages (SD)				(p-value)		
QLQ C30	1st Stage	2 nd Stage	3 rd Stage	=			
Domain	Basal	Pancytopenia	Prehospital	1st x 2nd	1st x 3rd	$2^{nd} \times 3^{rd}$	
	Au (n=16)	Au (n=16)	discharge				
	Al (n=39)	Al (n=34)	Au (n=16)				
			Al (n=33)				
	General quality of life						
Au	70.83 (16.39)	59.38 (19.21)	73.96 (15.18)	-	-	p<0.05*	
Al	79.27(17.82)	55.39 (20.91)	66.67 (20.62)	p<0.05*	-	-	
Personal Performance							
Au	79.17 (30.12)	50.00 (36)	52.08 (37.45)	p<0.05*	p<0.05*	-	
Al	79.06 (29.55)	41.18 (26.35)	61.62 (29.31)	p<0.05*	p<0.05*	p<0.05*	

Source: the authors

^{*}significant scores, ** Autologous, *** Allogenic.

^{**} significant scores, ** Autologous, *** Allogenic.

DISCUSSION

The diagnosis of hematologic cancer affects the QoL of patients, relatives and close relatives. The struggle against disease, uncertainty about the future, difficulties in confronting reality and possibilities presented at the same time bring hope and distress. Within this mix of situations and emotions, the hospitalization stage negatively potentiates personal performance and causes additional concerns such as body image, which leads to a decrease in QoL.

In order to plan for changes in the different functions that HSCT can affect, the characteristics of the assisted population must be considered. In this way, knowing the socio-demographic and clinical profile, as well as the needs and factors that alter the QoL can help in the assistance, coexistence, effectiveness and adherence to the treatment. The QoL presents a multidimensional concept that includes physical, psychological and social domains. It is essential to relate these aspects in order to evidence factors that may influence their improvement or worsening.

In the present study, mean age of patients submitted to autologous HSCT was 45 years and for allogeneic HSCT 31 years. Despite the diversity of mean age and patients in the study, the age group is the same, e.g. adult patients in productive performance.

This phase of life is for many to rise and consolidate in their profession and moving away from their work activities can lead to feelings of anguish, fear, falling productivity and personal performance, among other psychic disorders and directly impact on therapy and QoL.

There are also issues related to the challenges that the patient will face when returning to work, such as weak physical and psychological conditions to cope with the workload he/she has previously had. It is incumbent upon nursing to assist in managing these fragilities, to guide them as early as possible in the preparation for discharge, to talk about subjects that may cause anxiety and fear in the future, to explore the potentialities of the patient and the family, as well as to refer them with their family to psychological care in order to strengthen it and prepare it to face reality.

In this study, patients who underwent autologous HSCT were predominantly married and in a consensual union; for patients in allogeneic HSCT, the prevalence was single. Regardless of marital status, the presence of a person who gives them emotional and social support is of fundamental importance for coping with the procedure and promotion of QoL. It is worth

emphasizing that the nursing team has an important role to stimulate its existence⁽⁸⁾.

However, the opposite must be evaluated when the companion or the person who could give him/her more support does not present an affective and empathetic behavior, this can cause feeling of solitude and distress, since in that period the patient is debilitated due to the therapeutics. In addition, family disruption can also occur simultaneously to complications after HSCT and should be investigated to provide concrete data and subsidize nursing interventions that may help in coping with the crisis⁽⁹⁾.

For patients who have children there is an additional concern about the health problem. The distance imposed by hospitalization generates feelings of anguish and impotence, especially when the children are dependent. The patient may be frustrated by the difficulty in playing his role in the family axis, which can cause difficulties to the spouse or close person, due to the double journey that will perform, to be companion and to provide the home, leading him to think that their treatment generates a family burden⁽¹⁰⁾. It is up to the nursing team that is in continuous follow-up to the to promote moments of discussion, conversations with the sick and the family that address issues related to how to face and overcome the healthdisease process in order to extract positive points of this moment of life, practicing the resilience (11-12).

The negative impact of a disease affects several areas of patients' lives, including financial (also considered an additional concern). For families in which the affected member is economically active and the provider of the home, these difficulties are verified as causing concern with consequent social, family and personal injury. Although the treatment is financed by the Unified Health System (SUS), expenses are required, such as stay and transportation of the companion when the patient and family do not reside in the city of treatment, buying prescribed and nonstandardized medication, among others. The difficulties that may impact on the continuity of treatment after HSCT, since the follow-up and the specific care needs are fundamental to prevent complications due to the high rate of morbimortality related to the therapy.

The predominance of allogeneic transplantation in this research may be related to the place where it was performed, a reference for this modality in Latin America due to the high technical capacity of the professionals who work there, as well as the adequate structure. Allogeneic HSCT can be considered of greater technical complexity when assessing the question of

donor and recipient compatibility, graft rejection risk and the development of graft versus host disease (GVHD). However, both modalities present their peculiarities, in the case of autologous HSCT, it is necessary to consider the predominant age group of the population that performs it, which may constitute a risk factor for its accomplishment or for the development of complications.

Other factors should be taken into consideration when comparing the modalities of HSCT, such as: comorbidities, diagnosis time between transplantation, stage of disease in the indication of transplantation, clinical conditions in diagnosis, among others. A cohort study that evaluated the nursing workload in hematopoietic stem cell transplantation⁽¹³⁾ showed that for both autologous and allogeneic HSCT, the degree of severity was similar in the conditioning period, infusion day, and in the medullary "hold", however, patients submitted to autologous presented greater severity in the period of pancytopenia in relation to those submitted to allogeneic. Other studies evaluating QoL suggest that there is no significant difference between the transplantation modalities performed⁽¹⁴⁻¹⁵⁾.

During hospitalization the patient several disorders, both those caused by chemotherapeutic toxicity and those related to the social isolation necessary at this stage, since it is a period in which the immune system is weakened, and the patient is susceptible to a series of infections which may aggravate his/her condition. Cut off from daily activities, family and friends can lead to loneliness and depressive symptoms. It is up to the nursing team to carry out the situational diagnosis and promote measures for social well-being, as well as to promote discussions in support groups among patients, family members and health staff, to stimulate the use of technologies to bring social contact closer together that can also be a support tool that can benefit you at this stage.

The care of critical patients, such as the case of those who undergo HSCT, requires the nurse's willingness and balance to provide a care that comforts and goes beyond basic health care⁽¹⁶⁾, and emphasizes that these care needs to comprise the patient's admission to the HSCT service and to extend to the discharge and home⁽¹⁷⁾.

The additional concerns item, evaluated by FACT BMT, which encompasses questions such as body image, fatigue, sexuality and appetite, presents lower averages in the period of pancytopenia. A study in Massachusetts suggests that patients' experiences during

hospitalization represent a traumatic event and may implicate long-term outcomes and necessitate interventions focused on minimizing the burden of symptoms during hospitalization with a view to improving QoL in the short and medium term⁽¹⁸⁾.

The personal performance assessed by QLQ-C30, which includes items such as ability to perform daily tasks, fun and leisure activities, pleasure in living, satisfaction with QoL, presented lower means during pancytopenia. According to the study conducted in the western US⁽¹⁹⁾, this functional disability may make patients more prone to depression. Similar results were found in another US study of 90 patients who assessed QoL, depression, anxiety, and risk factors for developing post-traumatic stress disorder after HSCT⁽¹⁸⁾.

Concern about delayed recovery from full functional performance may lead to feelings of uselessness and physical weakness beyond the emotional discomfort. The hospital pre-discharge stage is the moment in which the nursing team can favor the autonomy of the patient in the search for a better confrontation of the post-discharge reality. Stimulating the patient in actions that he can perform such as feeding himself, getting dressed and going to the bathroom, will assist him in the post- HSCT moment, outside the hospital.

It is important to emphasize that the studies are sensitive to alterations for both autologous and allogenic HSCT, although allogeneic patients may be more symptomatic, general QoL does not differ significantly in relation to the modality, therefore, the same attention should be given both for autologous and allogeneic HSCT. Study carried out in Spain corroborates these data when it is concluded that transplantation modality does not influence the health-related QoL at any given time⁽¹⁵⁾, as well as the US study⁽²⁰⁾, which found that the decline in QoL, fatigue and psychological symptoms do not differ by type of transplant.

The nurse needs to know all the domains that can be affected in the patient who underwent HSCT, as well as to know the factors that can influence them in order to promote orientations and referrals of the cases needed for specific professionals. It should also provide moments of experience exchange between patients and their families in a systematic way and under the supervision of trained professionals to assist in the comfort and improvement of the altered domains. Nursing has the role of surveying the problems found and to propose measures to amend them, interventions that are possible at this stage that may favor the improvement of QoL in the domains involved. The

partnership and the continuous exchange of information with the multiprofessional team can assist and facilitate the decision making and the planning of the assistance and the sum of forces can potentiate the plan of individualized care.

In this research, the small number of participants was a limiting factor. This may be related to the number of beds available for HSCT at the hospital where it was performed; difficulty in finding a compatible donor; prolonged hospitalization until the reconstitution of hematopoiesis does not allow the comparison of the results found with other studies. Another limiting factor is the small number of studies that perform the QoL assessment in the hospitalization period and the comparison by HSCT modality.

CONCLUSION

HSCT has a potential role in curing and increasing survival for various hematological cancers; however, it is also a challenging therapy with an impact on QoL domains and life experience of HSCT receptors.

In view of the changes caused by therapy, it is important to evaluate the quality of life of these patients.

Using the questionnaires to evaluate the patient's perception of his QoL, it was possible to observe that he considers his QoL good at the beginning of the treatment, however, when reaching the period of pancytopenia, between D + 5 and D + 10, scores on the evaluation of general QoL (FACT-BMT), Global QL (QLQ-C30), item additional concerns and personal performance, for both modes of HSCT. When the hospital pre-discharge period approaches, the values reach a gradual increase, but without reaching the baseline values. Changes in the domains evaluated may be related to the cytotoxic effects caused by chemotherapy, together with the effects hospitalization, which imply physical, emotional, social and functional fragility.

In this sense, the research may contribute to the deepening of the topic, decision making and best practices, especially in the hospitalization period - identified as a critical treatment phase. It is important to carry out studies that consider the correlation of sociodemographic and clinical variables with the domains of QoL in order to subsidize the planning and implementation of interventions aimed at improving QoL, according to the specific needs.

CORRELAÇÃO ENTRE PREOCUPAÇÕES ADICIONAIS E DESEMPENHO PESSOAL COM A QUALIDADE DE VIDA NA HOSPITALIZAÇÃO PARA O TRANSPLANTE DE CÉLULASTRONCO HEMATOPOIÉTICAS

RESUMO

Objetivou-se correlacionar as preocupações adicionais e o desempenho pessoal com a qualidade de vida geral/global dos pacientes adultos com câncer hematológico, hospitalizados para o transplante de células-tronco hematopoiéticas autólogo e alogênico. Estudo longitudinal, observacional e analítico, realizado em hospital público do sul do Brasil com 55 pacientes. A coleta de dados foi realizada entre setembro de 2013 e novembro de 2015. Foram utilizados os questionários sociodemográfico e clínico, Quality of Life Questionnarie Core-30 e o Functional Assessment of Câncer Therapy – Bone Marrow Transplant. Os dados foram avaliados com o auxílio do software Statística 7.0. A média de idade para o transplante autólogo foi de 45 anos, com predomínio do diagnóstico de mieloma múltiplo; para o alogênico foi de 31 anos com predomínio da leucemia. A qualidade de vida geral/global, o desempenho pessoal e as preocupações adicionais caracterizadas pela imagem corporal, fadiga, sexualidade e apetite apresentaram médias significativamente menores no período de pancitopenia em relação ao basal, com gradativa melhora no período pré-alta hospitalar. Conclui-se que o transplante é uma terapêutica com potencial papel de cura, no entanto, acarreta em impactos negativos nos domínios da qualidade de vida, desempenho pessoal, preocupações adicionais e na experiência de vida dos receptores.

Palavras-chave: Qualidade de vida. Transplante de células-tronco hematopoiéticas. Neoplasias hematológicas. Enfermagem oncológica. Hospitalização.

CORRELACIÓN ENTRE PREOCUPACIONES ADICIONALES Y DESEMPEÑO PERSONAL CON LA CALIDAD DE VIDA EN LA HOSPITALIZACIÓN PARA EL TRASPLANTE DE CÉLULAS MADRE HEMATOPOYÉTICAS

RESUMEN

El objetivo fue correlacionar las preocupaciones adicionales y el desempeño personal con la calidad de vida general/global de los pacientes adultos con cáncer hematológico, hospitalizados para el trasplante de células madre hematopoyéticas autólogo y alogénico. Estudio longitudinal, observacional y analítico, realizado en hospital público del sur de Brasil con 55 pacientes. La recolección de datos fue realizada entre septiembre de 2013 y noviembre de 2015. Fueron utilizados los cuestionarios sociodemográfico y clínico, *Quality of Life Questionnarie Core-30 y el Functional Assessment of Câncer Therapy – Bone Marrow Transplant.* Los datos fueron evaluados con la ayuda del *software Statística* 7.0. El promedio de edad para el trasplante autólogo fue de 45 años, con predominio del diagnóstico de mieloma múltiple; para el alogénico fue de 31 años con

predominio de la leucemia. La calidad de vida general/global, el desempeño personal y las preocupaciones adicionales caracterizadas por la imagen corporal, fatiga, sexualidad y apetito presentaron promedios significativamente menores en el período de pancitopenia si comparado al basal, con mejoramiento gradual en el período de pre alta hospitalaria. Se concluye que el trasplante es una terapéutica con potencial papel de cura, sin embargo, conlleva impactos negativos en los dominios de la calidad de vida, desempeño personal, preocupaciones adicionales y en la experiencia de vida de los receptores.

Palabras clave: Calidad de vida. Trasplante de células madre hematopoyéticas. Neoplasias hematológicas. Enfermería oncológica. Hospitalización.

REFERENCES

- 1. Brasil. Ministério da Saúde, Instituto Nacional de Câncer José de Alencar Gomes da Silva (INCA). Estimativa 2018: incidência de câncer no Brasil. Rio de Janeiro. [citado em 15 out 2018]. Disponível em: http://www.inca.gov.br/estimativa/2018/estimativa-2018.pdf.
- 2. The Global Cancer Observatory. All Cancers. 2018;876:1–2. Available from: https://gco.iarc.fr/today/data/factsheets/cancers/39-All-cancers-fact-sheet.pdf.
- 3. Assis CL, Alves GF. Vivências e estratégias de enfrentamento em uma família com doente crônico com câncer. Rev. Psicol. Saúde [online].2015 [citado em 2018 Nov]; 7(2): 142-151. Disponível em: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S2177-093X2015000200008&lng=pt.
- 4. Marques A da CB, Proença S de FFS, Machado CAM, Guimarães PRB, Maftum MA, Kalinke LP. Quality of life in the first six months posthematopoietic stem cell transplantation. Texto Contexto Enferm. [on-line]. 2017[citado em 2018 Nov]; 26 (3): e5040016. doi: http://dx.doi.org/10.1590/0104-07072017005040016.
- 5. Silva MEDC, Silva LDC, Dantas ALB, Araújo DOR, Duarte IS, Sousa JFM et al. Nursing care to cancer patients in the hospital. Rev Enferm UFPL[on-line]. 2013[citado em 2018 Nov].2:69-75.doi: https://doi.org/10.26694/reufpi.v2i5.1359.
- Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: Properties, applications, and interpretation. Health Qual Life Outcomes. [on-line].2003[citado em 2018 Nov];1 (79):1–7. doi: https://doi.org/10.1186/1477-7525-1-79.
- 7. Fayers PM, Fayers P, Aaronson NK, Bjordal K, Groenvold M, Curran D, Bottomley A.EORTC QLQ-C30 Scoring Manual. 3rd ed. Brussels: European Organisation for Research and Treatment of Cancer, 2001. Available from: http://www.eortc.be/qol/files/scmanualqlq-c30.pdf.
- 8. Rocha V da, Proença S de FFS, Marques A da CB, Pontes L, Mantovani M de F, Kalinke LP. Social impairment of patients undergoing hematopoietic stem cell transplant. Rev. Bras. Enferm. [on-line]. 2016[citado em 2018 Nov];69(3):484-491. doi: http://dx.doi.org/10.1590/0034-7167.2016690310i.
- Matsubara TC, Carvalho EC de, Canini SRM da S, Sawada NO.
 Family crisis in the context of bone marrow transplantation: an integrative review. Rev. Latino-Am. Enfermagem [on-line]. 2007 [citado em 2018 Nov]; 15(4):665–670. doi: http://dx.doi.org/10.1590/S0104-11692007000400022.
- 10. Brice L, Gilroy N, Dyer G, Kabir M, Greenwood M, Larsen S, et al. Haematopoietic stem cell transplantation survivorship and quality of life: is it a small world after all? Support Care Cancer [on-line]. 2017 [citado em 2018Nov];25(2):421–7. doi: http://dx.doi.org/10.1007/s00520-016-3418-5.
- 11. Rosa BVC, Girardon-Perlini NMO, Begnin D, Rosa N, Stamm B, Coppetti LC. Resilience in families of people with cancer colostomy: a look from the belief system. Ciênc., Cuid. Saúde. [on-line]. 2016 [citado 2018

Nov]; 15(4): 723-730. doi: http://dx.doi.org/10.4025/cienccuidsaude.v15i4.34739.

- Rodrigues FSDS, Polidori MM. Enfrentamento e resiliência de pacientes em tratamento quimioterápico e seus familiares.
 Rev.Bras.Cancerol. [on-line]. 2012[citado em 2018 Nov];58(4):2–9.
 Disponível em: http://www1.inca.gov.br/rbc/n_58/v04/pdf/07-artigo-enfrentamento-resiliencia-pacientes-tratamento-quimioterapico-familiares.rdf.
- Da Silva JB, Póvoa VCO, De Melo Lima MH, Oliveira HC, Padilha KG, Secoli SR. Nursing workload in hematopoietic stem cell transplantation: A cohort study. Rev.Eesc.Enferm. USP. [on-line]. 2015 [citado em 2018 Nov];49: 93-100. doi: http://dx.doi.org/10.1590/S0080-623420150000700014.
- 14. Sirilla J, Overcash J. Quality of life (QOL), supportive care, and spirituality in hematopoietic stem cell transplant (HSCT) patients. Support Care Cancer [on-line]. 2013 [citado em 2018 Nov];21(4):1137–1144. doi: http://dx.doi.org/10.1007/s00520-012-1637-y.
- 15. Ruiz Seixas M, Rodríguez LL, Praena Femández JM, Vázquez Moncada M, Quijano-Campos JC. Calidad de vida relacionada con la salud en pacientes con trasplante de progenitores hematopoyéticos. Index Enferm [on-line]. 2014 [citado em 2018 Nov];23(4):209–213. doi: http://dx.doi.org/10.4321/S1132-12962014000300004.
- 16. Monteiro P de V, Almeida ANS de, Pereira MLD, Freitas MC de, Guedes MVC, Silva L de F da. When body care is not enough: the emotional dimension of nursing care. Reme. [on-line]. 2016[citado em 2018 Nov]; 20: e957. doi: http://www.dx.doi.org/10.5935/1415-2762.20160026.
- 17. Zatoni DCP, Lacerda MR, Hermann AP, Gomes IM, Nascimento JD, Rodrigues JAP. Suggestions for the improvement of guidance at the hospital discharge of children in post hematopoietic stem cell transplantation. Cogitare Enferm. [on-line]. 2017 [citado em 2018 Nov];(22)4:e50265. doi: http://dx.doi.org/10.5380/ce.v22i4.50265.
- 18. El-Jawahri AR, Vandusen HB, Traeger LN, Fishbein JN, Keenan T, Gallagher ER, et al. Quality of life and mood predict posttraumatic stress disorder after hematopoietic stem cell transplantation. Cancer.[on-line]. 2016 [citado em 2018 Nov]; 122(5):806–812. doi: http://dx.doi.org/10.1002/cncr.29818.
- 19. Grant M, Cooke L, Williams AC, Bhatia S, Popplewell L, Uman G, et al. Functional status and health-related quality of life among allogeneic transplant patients at hospital discharge: a comparison of sociodemographic, disease, and treatment characteristics. Support Care Cancer[on-line]. 2012[citado em 2018 Nov]; 20(11): 2697-2704. doi: http://dx.doi.org/10.1007/s00520-012-1389-8.
- 20. El-Jawahri A, Traeger L, Kuzmuk K, Eusebio J, Vandusen H, Shin J, et al. Quality of Life and Mood of Patients and Family Caregivers during Hospitalization for Hematopoietic Stem Cell Transplantation. Cancer [online]. 2015 [citado em 2018 Nov]; 121(6):951–9. doi: http://dx.doi.org/10.1002/cncr.29149.

Corresponding author: Celina Angélica Mattos Machado. Complexo Hospital de Clínicas da Universidade Federal. Rua Gen. Carneiro, 181 – Alto da Glória, Curitiba – Paraná, Brasil. Telefones: 41 998015086, 41 3360 1082. E-mail: celina.ufpr@gmail.com.

Submitted: 13/08/2018 **Accepted:** 19/11/2018