

<http://dx.doi.org/10.1590/0104-07072017005040016>

QUALITY OF LIFE IN THE FIRST SIX MONTHS POST-HEMATOPOIETIC STEM CELL TRANSPLANTATION

Angela da Costa Barcellos Marques¹, Sibéli de Fátima Ferraz Simão Proença², Celina Angélica Mattos Machado³, Paulo Ricardo Bettencourt Guimarães⁴, Mariluci Alves Maftum⁵, Luciana Puchalski Kalinke⁶

¹ Master's student. Post-graduate Nursing Program, *Universidade Federal do Paraná* (UFPR). Curitiba, Paraná, Brazil. E-mail: angebarendf@yahoo.com.br

² M.Sc. in Nursing – Professional, *Universidade Federal do Paraná/Complexo Hospital de Clínicas e Maternidade Vitor Ferreira do Amaral*. Curitiba, Paraná, Brazil. E-mail: sibeliffsimao@hotmail.com

³ Master's student, Post-graduate Nursing Program – Professional, UFPR. Curitiba, Paraná, Brazil. E-mail: celina.machado@hotmail.com

⁴ Ph.D. in Agricultural Sciences. Professor, Statistics Department, UFPR. Curitiba, Paraná, Brazil. E-mail: guimaraes.prb@gmail.com

⁵ Ph.D. in Nursing. Professor, Post-graduate Nursing Program, UFPR. Curitiba, Paraná, Brazil. E-mail: maftum@ufpr.br

⁶ Ph.D. in Health Sciences. Professor, Nursing Department, UFPR. Curitiba, Paraná, Brazil. E-mail: lucianakalinke@yahoo.com.br

ABSTRACT

Objective: to evaluate the quality of life of adult patients with hematologic cancers undergoing hematopoietic stem cell transplantation in the first six months and comparing the transplant modalities.

Method: an observational longitudinal study with 55 participants followed during pre-transplantation, after 100 days, and after 180 days in a reference teaching hospital for this treatment in Brazil. Two international instruments were used for the evaluation, both validated and translated into Portuguese (Brazil): *The Quality of Life Questionnaire-Core 30* and the *Functional Assessment Cancer Therapy-Bone Marrow Transplantation*.

Results: The results showed that the average age of the participants was 36 years old; 65% (n=36) had a diagnosis of leukemia, and 71% (n=39) underwent allogeneic transplantation. Regarding the *Quality of Life Questionnaire-Core 30* instrument, social function and fatigue were significant results, while the functional well-being and treatment outcome evaluation index for the *Functional Assessment Cancer Therapy-Bone Marrow Transplantation* questionnaire had significant domains between the first and the second stage.

Conclusions: despite transplantation being a complex and aggressive treatment, it can be noticed that patients generally perceive their quality of life as satisfactory throughout the therapeutic process. The findings of the study show that a significant portion (69% of patients) recover their quality of life after the first six months of treatment.

DESCRIPTORS: Quality of life. Hematopoietic stem cell transplantation. Bone marrow transplant. Hematologic neoplasms. Oncological nursing.

QUALIDADE DE VIDA NOS PRIMEIROS SEIS MESES PÓS-TRANSPLANTE DE CÉLULAS-TRONCO HEMATOPOÉTICAS

RESUMO

Objetivo: avaliar a qualidade de vida dos pacientes adultos com câncer hematológico submetidos ao transplante de células-tronco hematopoéticas nos primeiros seis meses e comparar entre as modalidades de transplante.

Método: estudo observacional, longitudinal, com 55 participantes, acompanhados nas etapas pré-transplante, pós 100 dias e pós 180 dias, em um hospital de ensino, referência no Brasil para este tratamento. Para avaliação foram utilizados dois instrumentos internacionais, ambos validados e traduzidos para a língua portuguesa (Brasil): *Quality of Life Questionnaire-Core 30* e *Functional Assessment Cancer Therapy-Bone Marrow Transplantation*.

Resultados: os resultados evidenciaram que a média de idade dos participantes foi de 36 anos, 65% (n=36) possuem diagnóstico de leucemia e 71% (n=39) foram submetidos ao transplante alogênico. Quanto ao instrumento *Quality of Life Questionnaire-Core 30*, foram resultados significantes a função social e fadiga, e no questionário *Functional Assessment Cancer Therapy-Bone Marrow Transplantation* os domínios bem-estar funcional e índice de avaliação de resultado do tratamento foram significantes entre a primeira e a segunda etapa.

Conclusões: apesar do transplante ser um tratamento complexo e agressivo, percebe-se que os pacientes consideram sua qualidade de vida geral satisfatória ao longo do processo terapêutico. Os achados do estudo evidenciam que uma parcela significativa, 69% dos pacientes, recupera sua qualidade de vida após os primeiros seis meses de tratamento.

DESCRIPTORIOS: Qualidade de vida. Transplante de células-tronco hematopoéticas. Transplante de medula óssea. Neoplasias hematológicas. Enfermagem oncológica.

CALIDAD DE VIDA EN LOS PRIMEROS SEIS MESES POST-TRANSPLANTES DE CÉLULAS-TRONCO HEMATOPOÉTICAS

RESUMEN

Objetivo: evaluar la calidad de vida de los pacientes adultos con cáncer hematológico sometidos al trasplante de células madre hematopoyéticas en los primeros seis meses y comparar entre las modalidades de trasplante.

Método: estudio observacional, longitudinal, con 55 participantes, acompañados en las etapas pre-trasplante, después de 100 días y después de 180 días, en un hospital de enseñanza, referencia en Brasil para este tratamiento. Para la evaluación se utilizaron dos instrumentos internacionales, ambos validados y traducidos a la lengua portuguesa (Brasil): *Quality of Life Questionnaire-Core 30* y *Functional Assessment Cancer Therapy-Bone Marrow Transplantation*.

Resultados: los resultados evidenciaron que el promedio de edad de los participantes fue de 36 años, el 65% (n=36) tiene diagnóstico de leucemia y el 71% (n=39) fueron sometidos al trasplante alogénico. En cuanto al instrumento *Quality of Life Questionnaire-Core 30*, fueron resultados significativos la función social y la fatiga, y en el cuestionario *Functional Assessment Cancer Therapy-Bone Marrow Transplantation* los dominios bienestar funcional y índice de evaluación de resultado del tratamiento fueron significantes entre la primera y la segunda etapa.

Conclusiones: a pesar de que el trasplante es un tratamiento complejo y agresivo, se percibe que los pacientes consideran su calidad de vida general satisfactoria a lo largo del proceso terapéutico. Los hallazgos del estudio evidencian que una proporción significativa, el 69% de los pacientes, recupera su calidad de vida después de los primeros seis meses de tratamiento.

DESCRIPTORES: Calidad de vida. Trasplante de células madre hematopoyéticas. Trasplante de médula ósea. Neoplasias hematológicas. Enfermería oncológica.

INTRODUCTION

Cancer is currently a significant public health problem both in developed and in developing countries throughout the world.¹ Data released by the International Agency for Research on Cancer (IARC) from the World Health Organization (WHO) reported a forecast of overall occurrence of more than 20 million new cases for 2025. The Union for International Cancer Control (UICC) estimates the occurrence of 13.2 million deaths for 2030.²

In Brazil, the estimate for the 2016-2017 biennium predicts 420,000 new cases, disregarding non-melanoma skin cancer. Among hematological cancers, estimates point to the occurrence of 22,780 cases; 12,210 in men and 10,570 among women.¹

Cancer is one of the diseases that interferes in patients' quality of life (QoL), leading to difficulties in developing family roles, work capacity, and social interaction; even when treated successfully, it can result in physical and psychological consequences. These difficulties during treatment can negatively impact on their lives.³⁻⁴ Assessing QOL is an important indicator in studies aimed at cancer patients at various stages of their therapeutic program, since it points to changes that occur in different areas and that have the potential to impact their life.⁵

Among the various definitions of the term "quality of life", the original from WHO is highlighted as: "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".^{6,1} Such a definition expresses the amplitude and multidimensional

dimensionality of the construct that involves social, health or economic parameters.⁷

Hematologic cancer patients have the possibility of hematopoietic stem cell transplantation (HSCT). This is a treatment that has already been accepted as contemporary, despite its complexity. Its implementation requires the participation of professionals from different spheres of health with nursing among them, which stands out for dynamically acting in all treatment stages.

Patients experience critical periods throughout the therapeutic process in which possible complications put their life at risk or significantly affect their QoL, potentiating psychological conflicts, as well as feelings of anxiety and tension.⁸⁻⁹ The conditioning phase can be highlighted among the decisive steps throughout the HSCT process, in which the patient receives chemotherapy and/or radiotherapy to cause medullary aplasia and induce immunosuppression with the purpose of avoiding rejection of the new grafted bone marrow.¹⁰⁻¹¹ At this stage, the patient suffers from symptomatology arising from the administered drugs, and gastrointestinal disorders are common.

Another important stage is the pancytopenia period when the patient is vulnerable and susceptible to infections; hyperthermia is common, and is a symptom that must be handled quickly by introducing antibiotic therapy so as not to put their life at risk.¹¹⁻¹² At this stage, mucositis can be intensified causing pain and discomfort, making speech and swallowing difficult. These symptoms have disabling potential and weaken the patient, negatively interfering in their QoL. However, a significant portion of patients recover after these

critical stages of treatment and can return to their normal life.¹³

Nurses need to understand the demands that the patients are exposed to throughout the different treatment stages in their care process in order to intervene in an efficient way, eliminating or minimizing their discomfort.¹⁴ They are the health professional team who is closest to the patient and accompany them throughout the HSCT, witnessing physical or emotional transformations that patients go through daily; and by understanding these changes, they have the opportunity to assist them in their therapeutic course.

Therefore, it can be inferred that helping these patients during the different stages of treatment and trying to improve their QoL should be a constant concern of the professionals involved in this scenario. To that end, studies that address this theme become indispensable tools to deepen knowledge in the area and to provide specialized and effective care, seeking to ensure better QoL and survival.

However, there is a lack of national and international studies investigating or evaluating the QoL of patients who undergo such a complex treatment. In this context, the objective of this study was to evaluate the QoL of adult hematologic cancer patients submitted to HSCT in the first six months and to compare the transplant modalities.

METHOD

This study is part of the thematic project: "Evaluating the quality of life of patients with hematologic cancer submitted to hematopoietic stem cell transplantation", submitted to the Research Ethics Committee of the Health Sciences Sector of the Universidade Federal do Paraná under CAAE 19714013.9.0000.0102, and approved under number 411,548. Participants were invited and presented to the study, and then accepted to participate by signing the Informed Consent Term (ICT).

The use of the questionnaires was authorized by registration in the European Organization Research Treatment of Cancer (EORTC) and the Functional Assessment of Chronic Illness Therapy (FACIT), who provided the questionnaires via direct download to the researcher.

This constitutes as a longitudinal and observational study developed in the Bone Marrow Transplantation Service (BMTS) of a teaching hospital in Curitiba, being a national reference for HSCT, from September 2013 to May 2016.

The sample consisted of 55 participants, which corresponds to all patients who met the following inclusion criteria between September 2013 and November 2015: being aged 18 years or older, having hematologic cancer and being submitted to HSCT. Participants who did not meet the physical conditions to complete the questionnaires were excluded from the study. Three patients were lost due to follow-up loss, 12 died before completing 100 days of HSCT, and two before completing 180 days.

Data were collected in the inpatient ward and the BMTS outpatient clinic in three stages of HSCT: pre-HSCT, post 100 days and post 180 days. Sociodemographic and clinical data were collected using our own pre-HSCT instrument. The questionnaires applied at the three stages were the *Quality of Life Questionnaire-Core 30* (QLQ C-30) - version 3.0, in Brazilian Portuguese, designed by EORTC; and the Functional Assessment Cancer Therapy - Bone Marrow Transplantation (FACT-BMT) - version 4.0 in Brazilian Portuguese designed by FACIT. QLQ C-30 is subdivided into functional and symptom scales; its results were calculated according to the EORTC Scoring Manual.¹⁵ The FACT-BMT is subdivided into domains (physical well-being, social/family well-being, emotional well-being, functional well-being, additional concerns). The results were calculated as described in the FACIT Scoring Manual.¹⁶

Sociodemographic and clinical data were descriptively analyzed and expressed as absolute and relative frequency. Data from the QOL questionnaires were organized into tables and analyzed according to EORTC and FACIT guidelines, expressed as mean (M) and standard deviation (SD).

The Mann Whitney test was applied to compare the transplantation types, while the Friedman test was used to compare the stages, supplemented by the Significant Minimum Difference Test of Multiple Comparisons (*p* value), with a significance level of 5%. Thus, results with *p* value below 0.05 were considered significant (*p*<0.05). The calculations were performed by a statistics professional, and Statistica v.7.0 software was used for analysis.

RESULTS

Sociodemographic and clinical characterization of the sample (Table 1) show that the mean age was 36 years, 53% (n=29) are males, and 55% (n=30) are married or declared a stable union. Regarding the diagnosis, 65% (n=36) presented some type of leukemia and 38% (n=21) underwent an unrelated allogeneic HSCT.

Table 1 - Characterization of the sample of patients submitted to hematopoietic stem cell transplantation. Curitiba, PR, Brazil, 2013-2015. (n=55)

Sociodemographic and clinical variables	n	%
Gender		
Male	29	53
Female	26	47
Marital status		
Single	23	42
Married or consensual union	30	54
Separated or divorced	2	4
Education level		
Complete elementary/primary education	17	31
Complete middle/secondary education	24	44
Complete higher education	14	25
Occupation		
Economically active (employed and self-employed)	35	64
Retired	5	9
Housewife/homemaker	5	9
Students	10	18
Diagnosis		
Leukemia	36	65
Lymphoma	10	18
Multiple myeloma	8	15
Myelodysplastic syndrome	1	2
Type of transplantation		
Related allogeneic	18	33
Unrelated allogeneic	21	38
Autologous	16	29
Source of cells		
Bone marrow	27	49
Peripheral blood	28	51

Data related to the overall QoL of the total sample (autologous and allogeneic) measured in the QLQ-C30 presented the following means: 76.82, 74.39 and 76.97 for pre-HSCT, 100 days and 180 days post-HSCT, respectively. A lower performance was observed post-100 days when compared to the baseline stage; however, the average recovered after 180 days. A similar performance was achieved regard-

ing the general QoL measured by the FACT-BMT, in which the means were 108.40, 108.14 and 112.45 for the three stages of the study. It was observed that the average obtained for the post 180-day period was superior to that of the pre-HSCT stage.

The results expressed in table 2 show significant scores between the autologous and allogeneic groups for the three stages of the study. We found

that both groups recovered their physical and social function 180 days after transplantation when compared to the baseline stage, suggesting an improvement in these domains throughout the treatment.

Table 2 - Significant Quality of Life Questionnaire - Core 30 and Functional Assessment of Cancer Therapy Bone Marrow Transplantation scores for autologous and allogeneic patients obtained at the three stages of the study. Curitiba, PR, Brazil, 2013-2016. (n=55)

Scores	Autologous			Allogeneic		
	pre-HSCT (n=16) Mean	post 100 days (n=13) Mean	post 180 days (n=12) Mean	pre-HSCT (n=39) Mean	post 100 days (n=28) Mean	post 180 days (n=26) Mean
<i>Quality of Life Questionnaire - Core 30</i>						
Physical function	72.92	82.56	79.44	77.09	74.76	80.51
Social function	62.50	71.79	86.11	52.14	52.98	67.95
Fatigue	22.22	26.50	27.78	21.37	28.97	24.79
Pain	30.21	20.51	18.06	14.10	17.26	13.46
Loss of appetite	20.83	5.13	16.67	16.24	27.38	16.67
<i>Functional Assessment of Cancer Therapy Bone Marrow Transplantation</i>						
Functional well-being	18.94	20.23	18.67	19.54	16.25	18.65
TOI*	67.44	73.62	73.75	69.79	64.98	70.46
FACTG†	80.20	84.45	84.14	80.79	77.57	82.09

*TOI: treatment outcome assessment index (physical well-being/functional well-being/additional concerns); †FACTG: General evaluation (physical well-being; social/family well-being; emotional well-being; functional well-being).

Comparing the significant scores of the total sample between the three stages of the study (Table 3), it is possible to observe that fatigue symptom had a statistically significant difference ($p=0.006$) between baseline and the post 100 days periods.

Table 3 - Significant scores of Quality of Life Questionnaire- Core 30 and Functional Assessment of Cancer Therapy - Bone Marrow transplantation between the three stages of the study. Curitiba, PR, Brazil, 2013-2016. (n=55)

Scores	p value	1 st stage	1 st stage	2 nd stage
		x	x	x
		2 nd stage	3 rd stage	3 rd stage
<i>Quality of Life Questionnaire- Core 30</i>				
Physical function	0.26	-	-	-
Social function	0.03*	$p<0.05^*$	-	-
Fatigue	0.006*	$p<0.01^*$	-	-
Pain	0.92	-	-	-
Loss of appetite	0.96	-	-	-
<i>Functional Assessment of Cancer Therapy - Bone Marrow transplantation</i>				
Functional well-being	0.001*	$p<0.01^*$	-	-
TOI†	0.02*	$p<0.05^*$	-	-
FACTG‡	0.15	-	-	-

Friedman's test; *Statistically significant data; †TOI: treatment outcome assessment index (physical well-being; functional well-being; additional concerns); ‡FACTG: General evaluation (physical well-being; social/family well-being; emotional well-being; functional well-being).

Overall and general QoL means measured by QLQ-C30 and FACT-BMT expressed in figures 1 and 2, respectively, show a similar performance among patients undergoing autologous and allogeneic HSCT in the three study stages.

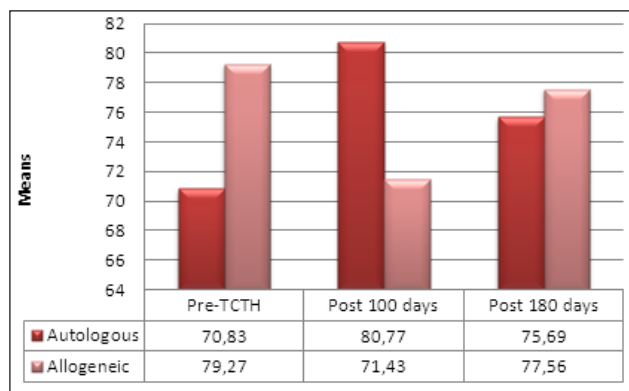


Figure 1 - Overall quality of life means on the Quality of Life Questionnaire-Core 30 of patients submitted to autologous and allogeneic hematopoietic stem cell transplantation at the three stages of the study. Curitiba, PR, Brazil, 2013-2016. (n=55)

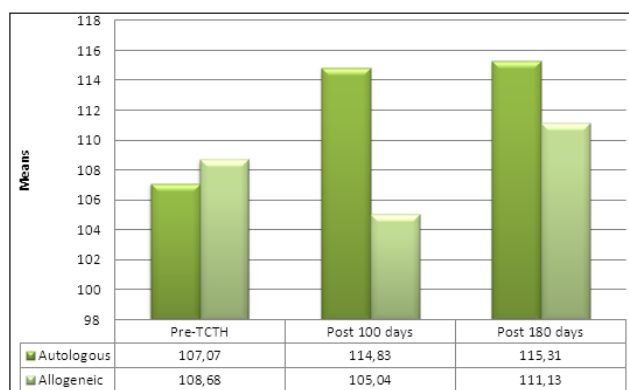


Figure 2 - Overall QoL means in the Functional Assessment of Cancer Therapy Bone Marrow Transplantation of patients submitted to autologous and allogeneic hematopoietic stem cell transplantation at the three stages of the study. Curitiba, PR, Brazil, 2013-2016. (n=55)

DISCUSSION

The disease severity as well as the aggressiveness of the treatment demand extreme care, in order to avoid the occurrence of diseases that predispose the patient to risk of death. Fourteen (14) patients (25.45%) died during the study before completing six months post-transplantation, in which 85.7% of these occurred before completing 100 days. This data suggests that the first 100 days post-transplantation represent a critical treatment period, with physical impairment on QoL, susceptibility to the occurrence of infections and other acute complications, and reflect the risk of mortality involved.

A patient with hematologic cancer submitted to HSCT is part of a specific population who demand the support and care of all the multidisciplinary team to cope with the disease health process due to the disease and the administered therapy. It is essential to understand the profile and the changes in each stage of treatment, thus favoring establishing actions in planning individualized and effective care aiming at a better QoL.

The sociodemographic analysis of this study revealed that the differences between females and males are small, given the fact that according to the national average, 54% of cases of hematological cancer will most likely occur in male patients.¹ Both men and women can be affected by blood cancers, and when they are subjected to a complex treatment such as HSCT they suffer from the effects and conditions of this therapy; thus, the impact on their QoL is inevitable, not only affecting the patient, but also their entire family. Moreover, 54% of the patients in the present study reported not being married or in a consensual union; data which are similar to those found in studies conducted in Brazil and abroad.^{5,17-19}

Family support is essential for patients who undergo HSCT, since they need to feel secure in the early stages of treatment and especially during hospitalization, and to be sure that they are not alone in this delicate moment of their lives.

Another important social fact/data that may contribute to better or worse QoL is education level: 44% of the patients reported having secondary education, and 25% higher education. Studies conducted in the Netherlands and the United States with adult patients confirm this result.¹⁹⁻²¹ Higher education fosters understanding questions related to treatment, especially with regard to the guidelines during hospital stay and after discharge. It is essential that this understanding occurs, making the patient predisposed to developing self-care and active participation in their attempt for succeeding in their therapeutic path and to recover their life activities.

Regarding clinical data, the study shows that the most frequent diagnosis was leukemia, being present in 65% of the cases. According to the *Instituto Nacional de Câncer José Alencar Gomes da Silva* (INCA), leukemia is among the most frequent hematological cancer in Brazil, with a predicted occurrence of 10,070 new cases in 2016, with 55% of which among men.¹ Similar results were observed in a study con-

ducted in Anatolia, Turkey, with 82 adult patients undergoing allogeneic HSCT, in which 44% had a diagnosis of leukemia.²² It is important to note that the diagnosis of a malignant disease negatively affects the life of any person due to the uncertainty of what will happen in the future, of how their body will react to treatment, which ultimately interferes with QoL.¹⁴

In 51% of HSCTs, the predominant source of stem cells was peripheral blood, which corroborates other studies.²³⁻²⁶ Regarding the type of transplant, the study shows that allogeneic HSCT occurred in 71% of the cases. This is similar to the results found in other studies in adults and elderly in Brazil and in the United States, in which 61% and 72% of the patients, respectively, underwent allogeneic HSCT.²⁷⁻²⁸ On the other hand, this differs from the results found in studies conducted in Spain and India, where 59% and 70% of HSCT were autologous, respectively.²³⁻²⁴ The fact that HSC are derived from a related or unrelated donor may increase the risk of complications such as GVHD, resulting in changes in the QoL domains.

It should also be taken into account that the place where this study was carried out is a worldwide reference hospital due to the number of allogeneic HSCTs performed annually, thus this is a differential of this service in Brazil and in the world. It is known that the allogeneic HSCT modality has greater complexity in terms of variables to be controlled. There is concern regarding the necessary compatibilities between donors and receivers; however, both HSCT modalities involve high-complexity demands considering their peculiarities which significantly interfere in QoL recovery.

The QoL domains measured by applying the QLQ-C30 and FACT-BMT questionnaires in the present study made it possible to identify the changes that occur throughout the therapeutic process. The findings show that the overall QoL measured by the QLQ-C30 had relatively high averages in the total sample during the first six months after transplantation. The averages remained above 74 points in the three stages of the study, which indicates satisfactory performance. This was also true for the general QoL measured in the FACT-BMT, which presented averages above 108 points for all three stages, suggesting that patients perceive their overall health as good. It is noteworthy that the averages achieved after six months of transplantation are higher than those measured in the pre-HSCT stage; therefore, the results demonstrate that overall QoL improves six months after HSCT.

This result is confirmed by a review of 38 articles comprising 2,804 adult patients submitted to autologous and allogeneic HSCT at transplantation centers in Germany, Denmark, Finland, Norway, Sweden, Canada, Taiwan and the United States, using QLQ-C30 before and after transplantation. This study found that overall QoL is reduced during hospitalization, but it recovers to the baseline level up to one year after transplantation.²⁹

In Spain, a study that evaluated the QoL of 39 adult patients submitted to HSCT at the baseline, post two months and post nine months showed that general QoL is worse at two months compared to at baseline; however, it improves at nine months, thereby confirming a positive evolution throughout the therapeutic process. This same study makes a comparison between autologous and allogeneic HSCT, concluding that the type of transplantation did not influence QoL in the three stages. Nevertheless, a significant difference between the groups was observed on the physical scale.²³

The physical function and social function domains on the QLQ-C30 scale presented results with higher average values six months after transplantation than those at baseline for both groups. It is highlighted that the greatest difference between averages was evidenced in the social domain function. When comparing the autologous and allogeneic group, it is observed that the means of the autologous group are slightly superior to the allogeneic group. Improvement in social performance is an expected result, since the patient remains isolated in the hospitalization period and their only face-to-face contact is often with the family member who accompanies him or her, in addition to the team that assists them. It is natural that they return to the social life they had before starting treatment after the hospitalization period when they recover.

The statistical analysis evidenced a gradual improvement in the physical function domain over the six months of post-transplantation period. The averages were high, meaning above 70 points in all stages. It should be noted that the maximum score is 100, which suggests that good physical recovery occurs over time with an average at the stage post 180 days recovered and higher than those at baseline. According to the literature,²⁹ pre-transplantation levels are reached between seven and 12 months after transplantation. However, it is important to preserve the patient's physical function during the hospitalization period. Nursing should assist and supervise exercise, encourage the patient to leave the bed frequently and use an armchair for watch-

ing television, or for simple reading. The practice of regular physical activity performed by the patients submitted to HSCT, in addition to improving their aptitude, can also reduce symptoms and contribute to a better QoL and increase survival.³⁰

Regarding fatigue, the autologous group in this study showed statistically significant scores ($p=0.006$) between baseline and the stage post 100 days, demonstrating a significant increase in symptoms between those stages compared to the allogeneic group. It is important to note that the patient is still under the residual effects of the drugs received from the conditioning period in the first 100 days after transplantation, and many of these have side effects or adverse effects with potential to increase the symptomatology. Observation of the symptom scale results provides an indication to the nurse of the affected areas at certain moments of the treatment and allows for implementing actions aimed at reducing those symptoms that have high incapacitating potential and negatively interfere in QoL.

Symptoms such as fatigue, insomnia and loss of appetite interfere with physical, emotional, cognitive and social functions, relating treatment side effects to a reduction in patients' QoL.^{3,5,31} A study conducted in Turkey points out that fatigue, pain, and loss of appetite become more intense after HSCT when compared to the pre-transplantation period, and that patients should be individually evaluated for all QoL domains. They add that nursing should assist patients in coping with symptoms with effective interventions based on QoL assessment.²²

In Brazil, studies using the QLQ-C30 indicate prevalence of fatigue, insomnia and loss of appetite, with fatigue being the most present and persistent symptom over time.^{3,29}

Loss of appetite was more intense in the autologous group in the pre-HSCT stage and in the allogeneic group in the post 100-day stage. However, the averages become equal in the post 180-day stage. Some reported studies^{3,5,22,29} suggest loss of appetite as one of the most common symptoms manifested by patients undergoing HSCT. The care team should not delay in implementing actions that reverse this situation at the first signs of this, since the patient may become malnourished in a short period of time and their clinical condition could evolve negatively, thus compromising their health and QoL.

Another prevalent symptom in cancer patients is pain. The averages were higher in the autologous

group in the three research stages in this study, but there was no significant difference between the groups. However, a reduction is observed over the six months after transplantation in both groups. This result is confirmed by a study²¹ carried out in Massachusetts, which showed the symptom of pain as one of the most frequently reported during treatment in both patients undergoing allogeneic and autologous HSCT, with no statistically significant differences between the HSCT types.

Several occurrences can cause this symptom in the patient during treatment, especially in the hospitalization period. Clinical conditions such as mucositis and abdominal pain, among others, are frequent and cause discomfort and suffering, thus lowering QoL. Pain management in HSCT should be performed effectively, and each patient should be evaluated individually. Nursing should detect factors that may be contributing to and potentiating this symptom. Pharmacological measures are important, however introducing non-pharmacological measures associated with care may bring comfort to the patients and contribute to improving their QoL.

Regarding the evaluation of the treatment outcome index (FACT TOI), which encompasses physical well-being, functional well-being and additional concerns, the averages were similar between the groups in the pre-HSCT stage and post 180 days; however, a better performance is observed in the autologous group at the post 100-day stage, with a significant difference in relation to the allogeneic group.

For the general FACTG assessment that encompasses physical well-being, functional well-being, social/family well-being, and emotional well-being domains, high averages reflect good performance and patient satisfaction during the first six months post-transplantation. The averages were similar for the autologous and allogeneic groups, and an analysis of the results did not confirm significant differences between the groups.

Setting aside the clinical differences, autologous and allogeneic transplantations show similar alterations in QoL, however there is a shortage of studies in the literature that aim to evaluate the QoL differences between patients submitted to these HSCT modalities over time.³² Nursing has the prerogative to be the team that is closest to and actively participates in treatment in its different phases. Thus, it should seek to fill this gap by inserting itself more and more into research that addresses this issue.

CONCLUSION

This study allowed us to show changes in the QoL of adult patients with hematologic cancer submitted to HSCT during the first six months of treatment.

The results demonstrate aspects that go beyond the classic symptomatology derived from administered therapies, thereby making it possible to understand pertinent questions that encompass the care need dimensions of patients submitted to HSCT. Although HSCT is a complex and aggressive treatment, it is perceived that patients consider their general quality of life to be satisfactory throughout the therapeutic process.

The findings of this study highlight that a significant portion (69%) of the patients in the sample recover their QoL after the first six months of HSCT. Both those submitted to autologous and allogeneic HSCT reached relatively good overall and general QoL averages in the three study stages. However, the lack of national and international studies comparing QoL between autologous and allogeneic patients was a limiting factor of this research due to the inability to compare different results.

Nonetheless, by evidencing the changes in QoL of patients, this study contributes to the care team professionals (especially to nurses) closest to the patients throughout all stages of treatment, thus creating a foundation for building an effective and individualized action plan in order to meet patient needs, in addition to guiding further studies on quality of life in oncology that link to other theme subdivisions.

REFERENCES

1. Ministério da Saúde (BR), Instituto Nacional de Câncer José de Alencar Gomes da Silva (INCA). Estimativa 2016: incidência de câncer no Brasil. Rio de Janeiro (RJ): INCA, 2016 [cited 2016 May 30]. Available from: http://www.inca.gov.br/bvscontrolecancer/publicacoes/edicao/Estimativa_2016.pdf
2. Union for International Cancer Control. Cancer Today. Switzerland: UICC; 2015 [cited 2015 Jul 18]. Available from: <https://goo.gl/m4u8uA>
3. Públio GB, Silva KO, Viana GFS. Qualidade de vida de pacientes oncológicos submetidos à quimioterapia. Ciênc Desenvolv [Internet]. 2014 Jul-Dec [cited 2017 Jul 30]; 7(2):244-57. Available from: <http://srv02.fainor.com.br/revista237/index.php/memorias/article/view/329/209>
4. European Organization For Research And Treatment Of Cancer (EORTC). Bélgica: EORTC; 2015 [cited 2015 Jun 23]. Available from: <http://www.eortc.be>
5. Andrade V, Sawada NO, Barichello E. Quality of life in hematologic oncology patients undergoing chemotherapy. Rev Esc Enferm USP [Internet]. 2013 Apr [cited 2015 May 15]; 47(2):355-61. Available from: <http://dx.doi.org/10.1590/S0080-62342013000200012>
6. World Health Organization (WHO). WHOQOL Measuring quality of life. The world health organization quality of life instruments (The WHOQOL 100 and the WHOQOL Bref). Geneva, 1997 [cited 2015 May 29]. Available from: http://www.who.int/mental_health/media/68.pdf
7. Almeida MAB, Gutierrez GL, Marques R. Qualidade de vida: definições, conceitos e interfaces com outras áreas de pesquisa. São Paulo (SP): Escola de Artes, Ciências e Humanidades da Universidade de São Paulo; 2012 [cited 2015 Jun 15]. Available from: http://www.each.usp.br/edicoes-each/qualidade_vida.pdf
8. Mercês NNA das, Erdmann AL. Nursing and hematopoietic stem cell transplantation: scientific production from 1997 to 2007. Acta Paul Enferm [Internet]. 2015 Mar-Abr [cited 2015 Jun 15]; 23(2):271-7. Available from: <http://dx.doi.org/10.1590/S0103-21002010000200019>
9. Matias AB, Oliveira-Cardoso EA, Mastropietro AP, Voltarelli JC, Santos MA. Qualidade de vida e transplante de células-tronco hematopoéticas alogênico: um estudo longitudinal. Estud Psicol [Internet]. 2011 Apr-Jun [cited 2015 Jun 27]; 28(2):187-97. Available from: <http://dx.doi.org/10.1590/S0103-166X2011000200006>
10. Bonassa EMA, Mancusi FCM. Transplante de medula óssea e de células-tronco hematopoéticas. In: Bonassa EMA, Gato MIR. Terapêutica oncológica para enfermeiros e farmacêuticos. São Paulo (SP): Editora Atheneu; 2012.
11. Voltarelli JC, Pasquini R, Ortega ETT, organizadores. Transplante de células-tronco hematopoéticas. São Paulo (SP): Editora Atheneu; 2009.
12. Garnica M, Machado C, Cappellano P, Carvalho VVH, Nicolato A, Cunha CA, et al. Recomendações no manejo das complicações infecciosas no transplante de células-tronco hematopoéticas. Rev Bras Hematol Hemoter [Internet]. 2010 [cited 2016 May 25]; 32(1):140-62. Available from: <http://www.scielo.br/pdf/rbhh/v32s1/aop26010.pdf>
13. Funke VM, Flowers MED. Complicações tardias pós-transplante de células tronco hematopoéticas. In: Voltarelli JC, Pasquini R, Ortega ETT, organizadores. Transplante de células-tronco hematopoéticas. São Paulo (SP): Editora Atheneu; 2009.
14. Guimarães RCR, Gonçalves RPF, Limas CA, Torres MR, Silva CSO. Ações de enfermagem frente às reações a quimioterápicos em pacientes oncológicos. J Res: Fundam Care Online [Internet]. 2015 Abr-Jun [cited 2015 Jun 27]; 7(2):2440-52. Available from: <http://dx.doi.org/10.9789/2175-5361.2015.v7i2.2440-2552>

15. Fayers PM, Aaronson NK, Bjordal K, Groenvold M, Curan D, Bottoomley. On behalf of the EORTC quality of life group. The EORTC QLQ-C30 Scoring Manual. 3^a ed. Brussels (BE): European Organization for Research and Treatment of Cancer; 2001.
16. Eremenco SL, Cella D, Arnold BJ. A comprehensive method for the translation and cross-cultural validation of health status questionnaires. *Eval Health Prof* [Internet]. 2005 Jun [cited 2015 Jan 23]; 28(2):212-32. Available from: <http://ehp.sagepub.com/content/28/2/212.full.pdf>
17. Cohen MZ, Rozmus CL, Mendoza TR, Padhye NS, Neumann J, Gning I, et al. Symptoms and quality of life in diverse patients undergoing hematopoietic stem cell transplantation. *J Pain Symptom Manage* [Internet]. 2012 Aug [cited 2015 Oct 11]; 44(2):168-80. Available from: <https://dx.doi.org/10.1016/j.jpainsymman.2011.08.011>
18. Ferreira Júnior MA, Ivo ML, Pontes ERJC, Carvalho DPSRP, Vitor AF. Perfil sociodemográfico e clínico de portadores de síndromes mielodisplásicas. *Biosci J* [Internet]. 2014 Jul-Aug [cited 2015 Aug 21]; 30(4):1269-77. Available from: <http://www.seer.ufu.br/index.php/biosciencejournal/article/view/23749/14779>
19. Braamse AM, van Meijel B, Visser O, Huijgens PC, Beekman AT, Dekker J. Distress, problems and supportive care needs of patients treated with auto or allo-SCT. *Bone Marrow Transplant* [Internet]. 2015 Oct [cited 2016 Jul 21]; 49(2):292. Available from: <https://dx.doi.org/10.1038/bmt.2013>
20. Kenzik K, Huang IC, Rizzo JD, Shenkman E, Wingard J. Relationships among symptoms, psychosocial factors, and health-related quality of life in hematopoietic stem cell transplant survivors. *Support Care Center* [Internet]. 2015 Mar [cited 2016 Jul 21]; 23(3):797-807. Available from: <https://dx.doi.org/10.1007/s00520-014-2420-z>
21. El-Jawahri A, Traeger LN, Kuzmuk K, Eusebio JR, Vandusen HB, Shin JA, et al. Quality of life and mood of patients and family caregivers during hospitalization for hematopoietic stem cell transplantation. *Cancer* [Internet]. 2015 Mar [cited 2016 Aug 08]; 121(6):951-9. Available from: <https://dx.doi.org/10.1002/cncr.29149>
22. Ovayolu O, Ovayolu N, Kaplan E, Pehlivan M, Karadag G. Symptoms and quality of life before and after stem cell transplantation in cancer. *Pak J Med Sci* [Internet]. 2014 May-Jun [cited 2016 Aug 29]; 29(3):803-8. Available from: <http://dx.doi.org/10.12669/pjms.293.3290>
23. Seixas MR, et al. Calidad de vida relacionada con la salud en pacientes con trasplante de progenitores hematopoyéticos. *Index Enferm* [Internet]. 2014 Oct-Dec [cited 2015 Aug 02]; 23(4). Available from: http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1132-12962014003300004
24. Shah CA, Karanwal A, Desai M, Pandya M, Shah R, Shah R. Hematopoietic stem-cell transplantation in the developing world: experience from a center in western India. *J Oncol* [Internet]. 2015 [cited 2016 May 04]; 2015:710543. Available from: <http://dx.doi.org/10.1155/2015/710543>
25. Shokouhi S, Brays S, Bakhtiyari S, Sayehmiri K, Alimoghadam K, Ghavamzadeh A. Effects of aGVHD and cGVHD on survival rate in patients with acute myeloid leukemia after allogeneic stem cell transplantation. *Int J Hematol Oncol Stem Cell Res*. [Internet]. 2015 Jul [cited 2016 Set 12]; 9(3):112-21. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4529677/pdf/IJHOSCR-9-112.pdf>
26. Palmer J, Chai X, Martin PJ, Weisdorf D, Inamoto Y, Pidala J. Failure-free survival in a prospective cohort of patients with chronic graft-versus-host disease. *Haematologica*. [Internet]. 2015 May [cited 2017 Jul 30]; 100(5):690-5. Available from: <http://www.haematologica.org/content/100/5/690.full.pdf+html>
27. Silva JB, Póvoa VCO, Lima MHM, Oliveira HC, Padilha KG, Secoli SR. Nursing workload in hematopoietic stem cell transplantation: a cohort study. *Rev Esc Enferm USP* [Internet]. 2015 [cited 2016 Jul 08]; 49(Esp):93-100. Available from: <http://dx.doi.org/10.1590/S0080-623420150000700014>
28. Sun CL, Kersey JH, Francisco L, Armenian SH, Baker KS, Weisdorf DJ, et al. Burden of morbidity in 10+ year survivors of hematopoietic cell transplantation: a report from the bone marrow transplant survivor study. *Blood Marrow Transplant* [Internet]. 2014 Jul [cited 2017 Jul 30]; 19(7):1073-80. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3691346/pdf/nihms467933.pdf>
29. Grulke N, Albani C, Bailer H. Quality of life in patients before and after haematopoietic stem cell transplantation measured with the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Core Questionnaire QLQ-C30. *Bone Marrow Transplant* [Internet]. 2012 [cited 2015 Sep 01]; 47(4):473-82. Available from: <https://dx.doi.org/10.1038/bmt.2011.107>
30. Fiuza-Luces C, Simpson RJ, Ramírez M, Lucia A, Berger NA. Physical function and quality of life in patients with chronic graft-versus-host-disease: a summary of preclinical and clinical studies and a call for exercise intervention trials in patients. *Bone Marrow Transplant* [Internet]. 2016 Jan [cited 2017 Jul 30]; 51(1):13-26. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4703521/pdf/nihms724761.pdf>
31. Machado SM, Sawada NO. Avaliação da qualidade de vida de pacientes oncológicos em tratamento quimioterápico adjuvante. *Texto Contexto Enferm* [Internet]. 2008 [cited 2016 May 15]; 17(4):750-7. Available from: <http://www.scielo.br/pdf/tce/v17n4/17.pdf>

32. García CM, Mumby PB, Thilges S, Stiff PJ. Comparison of early quality of life outcomes in autologous and allogeneic transplant patients. *Bone Marrow*

Transplant [Internet]. 2012 Dec [cited 2015 Sep 01]; 47(12):1577-82. Available from: <https://dx.doi.org/10.1038/bmt.2012.77>

Correspondence: Luciana Puchalski Kalinke
Av. Prefeito Lothário Meissner, 632 - Bloco Didático II, 3 andar
80210-170 - Jardim Botânico, Curitiba-PR, Brasil
E-mail: lucianakalinke@yahoo.com.br

Received: December 26, 2016
Approved: July 03, 2017