



ORIGINALES

Quality of life of patients submitted to autologous and allogeneic stem cell transplant in hospitalization

Qualidade de vida dos pacientes submetidos ao transplante de células-tronco autólogo e alogênico na hospitalização.

Calidad de vida de los pacientes sometidos al trasplante de células madre autólogo y alogénico en la hospitalización

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ABSTRACT

Objective: To evaluate the quality of life of adult patients with hematologic cancer according to the modality of hematopoietic stem cell transplant during hospitalization stages.

Method: A quantitative, observational, longitudinal and analytical study with 55 adult participants diagnosed with hematologic cancer who underwent hematopoietic stem cell transplant between September 2013 and November 2015. Three instruments were used, one for sociodemographic and clinical characterization, and two instruments for quality of life assessment, as follows: the Quality Of Life Questionnaire - Core30 (QLQ-C30), version 3.0 in Portuguese developed by the European Organization Research Treatment of Cancer (EORTC) and the Functional Assessment Cancer Therapy- Bone Marrow Transplantation (FACT-BMT) questionnaire, version 4.0 in Portuguese developed by the Functional Assessment of Chronic Illness Therapy (FACIT), both validated for Brazil.

Result: The results showed the mean age for autologous hematopoietic stem cell transplant was 45 years, the prevalence of multiple myeloma diagnosis and for allogeneic stem cell transplant was 31 years, and leukemia was the predominant diagnosis. The quality of life assessment with both

questionnaires and modalities showed a significant decrease in values in all domains evaluated, with predominance of worse scores in the pancytopenia period, except for the emotional function.

Conclusion: The present study concludes that hematopoietic stem cell transplant changes the quality of life during hospitalization for both transplant modalities. The promotion of interventions to improve patients' quality of life by covering physical, emotional, social and functional domains is the nurses' role.

Keywords: Quality of Life; Hematopoietic stem cell transplantation; Oncology Nursing; Hospitalization.

RESUMO

Objetivo: Avaliar a qualidade de vida dos pacientes adultos com câncer hematológico de acordo com a modalidade de transplante de células-tronco hematopoética durante as etapas de hospitalização.

Método: Estudo quantitativo, observacional, longitudinal e analítico, com 55 participantes adultos, diagnosticados com câncer hematológico que se submeteram ao transplante de células-tronco hematopoéticas de setembro de 2013 a novembro de 2015. Foram utilizados três instrumentos, um para caracterização sociodemográfica e clínica e dois instrumentos para avaliação da qualidade de vida: o *Quality Of Life Questionnaire - Core30 (QLQ-C30)*, versão 3.0 português, desenvolvido pela *European Organization Research Treatment of Cancer (EORTC)* e o questionário *Functional Assessment Cancer Therapy- Bone Marrow Transplantation (FACT-BMT)*, versão 4.0 português, desenvolvido pela *Functional Assessment of Chronic Illness Therapy (FACIT)*, ambos validados para o Brasil.

Resultado: Os resultados demonstraram que a média de idade para o transplante de células-tronco hematopoéticas autólogo foi 45 anos e predomínio do diagnóstico mieloma múltiplo e para o transplante de células-tronco alogênico foi 31 anos e como diagnóstico predominante a leucemia. A avaliação da qualidade de vida com ambos os questionários e modalidades demonstrou que há queda significativa dos valores em todos os domínios avaliados, com predomínio de piores pontuações no período de pancitopenia, exceto para a função emocional.

Conclusão: A presente pesquisa conclui que o transplante de células-tronco hematopoéticas altera a qualidade de vida durante a hospitalização para ambas as modalidades de transplante. Cabe à enfermeira promover intervenções para melhorar a Qualidade de Vida dos pacientes, abrangendo domínios físicos, emocionais, sociais e funcionais.

Palavras-Chave: Qualidade de Vida; Transplante de Células-Tronco Hematopoéticas; Enfermagem Oncológica; Hospitalização.

RESUMEN

Objetivo: Evaluar la calidad de vida de los pacientes adultos con cáncer hematológico de acuerdo con la modalidad de trasplante de células madre hematopoyéticas durante las etapas de hospitalización.

Método: Estudio cuantitativo, observacional, longitudinal y analítico con 55 participantes adultos diagnosticados con cáncer hematológico sometidos al trasplante de células madre hematopoyéticas desde septiembre de 2013 hasta noviembre de 2015. Se utilizaron tres instrumentos, uno para caracterización sociodemográfica y clínica y dos instrumentos para evaluar la calidad de vida: el *Quality Of Life Questionnaire - Core30 (QLQ-C30)*, versión 3.0 portugués, desarrollado por la *European Organization Research Treatment of Cancer (EORTC)* y el cuestionario *Functional Assessment Cancer Therapy- Bone Marrow Transplantation (FACT-BMT)*, versión 4.0 portugués, desarrollado por la *Functional Assessment of Chronic Illness Therapy (FACIT)*, ambos validados para Brasil.

Resultado: Los resultados demostraron que el promedio de edad para el trasplante de células madre hematopoyéticas autólogo fue de 45 años, el predominio del diagnóstico mieloma múltiple y para el trasplante de células madre alogénico fue de 31 años y como diagnóstico predominante la leucemia. La evaluación de la calidad de vida con ambos cuestionarios y modalidades demostró descenso significativo de los valores en todos los dominios evaluados, con predominio de peores puntuaciones en el período de pancitopenia, excepto para la función emocional.

Conclusión: La presente investigación concluye que el trasplante de células madre hematopoyéticas altera la calidad de vida durante la hospitalización para ambas modalidades de trasplante. Los enfermeros deben promover intervenciones para mejorar la calidad de vida de los pacientes, abarcando dominios físicos, emocionales, sociales y funcionales.

Palabras clave: Calidad de vida; Trasplante de células madre hematopoyéticas; Enfermería Oncológica; Hospitalización.

INTRODUCTION

The number of new cases of cancer will rise from 14.1 million in 2012 to 21.6 million in 2030. More than 70% of the deaths caused by cancer occur in low and middle-income countries ⁽¹⁾. It is estimated that 600 000 new cases will emerge in Brazil during 2016 and 2017; especially hematologic cancers such as lymphoma and leukemia, representing 10 010 and 12 710 new cases respectively ⁽²⁾.

Immunotherapy, chemotherapy associated or not with radiotherapy and hematopoietic stem cell transplantation (HSCT) are options of treatment for hematologic cancer. The latter was consolidated as a therapy in December 2012, when one million procedures were made all over the world ⁽³⁾, and it is significantly growing according to the Worldwide Network of Blood and Marrow Transplantation (WBMT)⁽⁴⁾.

HSCT is a category of treatment whose purpose is the cure or remission of many pathologies. HSCT may be classified as autologous, when the hematopoietic stem cells (HSC) are derived from a person's own stem cells; and allogeneic, when the HST are from a donor related or unrelated to the patient ⁽⁵⁾. The choice of the cell source and the type of HSCT takes account of the disease, the patient's condition and the donor's availability ⁽⁶⁾.

HSTC is considerate as an extensive therapy and it is divided into stages, from the first day of hospitalization. The first stage is the conditioning, whose aim is to eradicate the disease, inducing immunosuppression in order to receive the graft and to enable the hematopoietic reconstitution. This stage lasts on average seven to ten days before HSC infusion ⁽⁷⁾; the infusion occurs on day "zero".

After HSC infusion, the patients face the pancytopenia stage (simultaneous decrease of all figurative elements of the blood- red blood cells, white blood cells and platelets), and they become vulnerable to various infections and to the toxic effects of chemotherapy ⁽⁸⁾. The largest number of physical, emotional and social alterations occurs during this stage ⁽⁹⁾. The hematopoietic reconstitution and repopulation of the bone marrow happens between 10 and 28 days after infusion, during hospitalization. The type of HSCT, the number of HSC infused and the absence of complications determine the success of these stages ⁽⁸⁾.

In this context, the hospitalization becomes a landmark in a series of modification that will accompany the patient, interfering with daily activities and altering the quality of life (QOL). WHO defines QOL as "individuals' 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" ^{(10 (pp1))}. Evaluating QOL during the different stages and types of HSCT enables the increasing of actions and orientations to improve clinical management and to identify populations on high risk of complications ⁽¹¹⁾.

The assessment of QOL, according to the multidimensional aspect (physical, psychological and social) and to the patient's perception, may give information that helps to make a decision on treatment and its results ⁽¹²⁾. Additionally, it may provide support to the nursing actions to improve the QOL, aiming physical, emotional and social aspects. Thus, the aim of this study was to assess the QOL during the stages of hospitalization in adult patients with hematologic cancer, according to the type of HSCT.

METHOD

This observational study of a quantitative approach was performed at the HSCT Service in a tertiary referral public hospital in Brazil.

Patients over 18 years old, with hematologic cancer, before undergoing HSCT, were included. It was excluded those with no physical conditions to fill in the questionnaires or discontinued those who have given up or have died.

The period of data collection was from September 2013 to November 2015. Fifty-five adult patients composed the non-probabilistic, yet based on the number of transplants between 2012 and 2014 sampling. In this basal stage, 55 (100%) patients participated of the study, in the second stage, the pancytopenia period, between five and ten days after HSC infusion, 50 patients, and in the third stage, the pre-discharge, 49 participants filled in the questionnaire. There were six deaths.

Instruments

Three instruments were used to data collection: one to assess sociodemographic and clinical data and two to assess QOL. The Quality of Life Questionnaire Core C30 (QLQ C30), 3.0 Portuguese version, developed by the European Organization Research Treatment of Cancer (EORTC) and the Functional Assessment Cancer Therapy – Bone Marrow Transplantation (FACT-BMT), 4.0 Portuguese version, specific to assess QOL in HSCT, developed by the Functional Assessment of Chronic Illness Therapy (FACIT), both translated and adapted to Brazil.

The QLQ C30 is composed by 30 questions about Global QOL, functional scale (physical, emotional, cognitive and social function and personal performance) and a scale of symptoms, whose data are expressed in punctuations from 1 to 100. A higher score in the functional scale and in the Global QOL represents a better evaluation of QOL; for the symptoms scale, the higher the punctuation the worst the QOL⁽¹³⁾.

The FACT-BMT is composed by five domains; four are general for all patients with cancer, totaling 27 questions: physical well-being (seven questions encompassing lack of energy, nausea and pain; social and family well-being (seven questions encompassing friends and family's proximity and support); functional well-being (seven questions encompassing working and enjoying life); emotional well-being (six questions encompassing sadness, concern with the worsening of the health and death). The additional concerning domain (23 questions) is related to specific aspects of HSCT⁽¹⁴⁾.

Data analysis

Sociodemographic and clinical data were analyzed by descriptive statistic and expressed in simple and absolute frequency. The non-parametric Friedman test supplemented by the least significant difference for multiple comparisons was used for assessment of the QOL questionnaires' scores for each stage. The stages (basal, pancytopenia and pre-discharge) were compared to each other. Non-parametric tests were used due the lack of normality of data, attested by Shapiro Wilk test. The statistic software 7.0 was used.

Findings

Sociodemographic and clinical results

The mean age of the patients for autologous HSCT was 45 years old, 11 (68.75%) were married or in a consensual union, five (31.25%) had no children or only one and seven (43.75%) declared themselves as economically active. The mean age of the patients for allogenic HSCT was 31 years old, 20 (51.28%) were single and did not have children and 28 (71.79%) declared themselves as economically active. With respect to clinical characteristics, 39 (70%) performed allogenic HSCT and 21 were from a donor unrelated to the patient (Table 1).

Table 1: Sociodemographic and clinical data of the patients undergoing HSCT- Curitiba, PR, Brazil, 2013-2015.

Variable	Autologous HSCT n=16 (%)	Allogenic HSCT n=39 (%)
Age		
18-30 years	5 (31.25)	21(53.84)
31-40 years	2 (12.5)	7(17.94)
41-50 years	-	8 (20.53)
Over 50 years	9 (56.25)	3 (7.69)
Medium age	45	31
Gender		
Female	7 (43.75)	19 (48.72)
Male	9 (56.25)	20 (51.28)
Marriage status		
Married/ Consensual union	11 (68.75)	19 (48.72)
Separated	2 (12.5)	-
Single	3 (18.75)	20 (51.28)
Children		
No children	5 (31.25)	20 (51.28)
1 child	5 (31.25)	4 (10.25)
2 children	2 (12.5)	8 (20.53)
3 or more children	4 (25)	7 (17.94)
Occupation		
Economically active	7 (43.75)	28 (71.79)
Retired	4 (25)	1 (2.56)
Housekeeper	3 (18.75)	2 (5.12)
Student	2 (12.5)	8 (20.53)
Family Income*		
Up to 1 minimum income	7 (43.75)	4 (10.25)
1 to 3 minimum income	5 (31.25)	22 (56.41)
4 to 10 minimum income	4 (25)	10 (25.64)
10 to 20 minimum income	-	3 (7.70)
Receiving allowance from government**		
No	13 (81.25)	29 (74.35)
Yes	3 (18.75)	10 (25.65)
Type of Transplant		
Autologous	16 (100)	
Allogenic donor related	-	18 (46.15)
Allogenic donor unrelated	-	21 (53.85)

* National minimum income current during data collection \$ 284.00

** Example of allowance from the government: aid for treatment away from home, transport aid

QOL EVALUATION RESULTS

Table 2 shows the Global (QLQ C30) and General (FACT-BMT) QOL evaluation during each stage for both types of HSCT. During basal stage, the mean scores were considered satisfactory for both types of HSCT but they get worse during pancytopenia stage, where the results are statistically significant among the stages for both questionnaires.

Table 2: Comparison among stages- significant scores - Curitiba, PR, Brazil, 2013-2015.

Domain	Mean (SD)			Comparison among stages (p-value)		
	Basal Au *(n=16) Al **(n=39)	Pancytopenia Au (n=16) Al (n=34)	Pre-discharge Au (n=16) Al (n=33)	1 ^a x 2 ^a	1 ^a x 3 ^a	2 ^a x 3 ^a
QLQ C30						
Au	70.83 (16.39)	59.38 (19.21)	73.96 (15.18)	-	-	p<.05
Al	79.27 (17.82)	55.39 (20.91)	66.67 (20.62)	p<.05	-	-
FACT-BMT						
Au	107.70 (18.34)	91.47 (16.40)	98.97 (16.68)	p<.05	-	-
Al	108.68 (22.26)	90.33 (14.65)	94.40 (17.73)	p<.05	p<.05	-

*Au: Autologous HSCT; **Al: Allogenic HSCT

The functional scale (Table 3) shows that the physical function, the personal performance and the social function presented the lower means, statistically significant for both types of HSCT, during pancytopenia. The emotional function for both types of HSCT presented higher means during pancytopenia and continued to increase during pre-discharge stage.

Table 3: Comparison among stages for autologous and allogenic HSCT- QLQ C30 functional scale significant scores - Curitiba, PR, Brazil, 2013-2015.

QLQ C30 Domains	Mean (SD)			Comparison among stages (p-value)		
	Basal Au* (n=16) Al** (n=39)	Pancytopenia Au (n=16) Al (n=34)	Pre-discharge Au (n=16) Al (n=33)	1 ^a x 2 ^a	1 ^a x 3 ^a	2 ^a x 3 ^a
Physical Function						
Au	72.92 (22.37)	50.83 (21.48)	57.50 (22.43)	p<.05	-	-
Al	77.09 (21.83)	57.65 (19.55)	68.28 (18.49)	p<.05	p<.05	-

Personal Performance						
Au	79.17 (30.12)	50 (36)	52.08 (37.45)	p<.05	p<.05	-
Al	79.06 (29.55)	41.18 (26.35)	61.62 (29.31)	p<.05	p<.05	p<.05
Emocional Function						
Au	70.83 (19.95)	71.88 (19.69)	77.60 (20.35)	-	-	-
Al	65.10 (25.50)	70.59 (24.03)	68.69 (30.62)	-	-	-
Cognitive Function						
Au	81.25 (18.13)	85.42 (19.12)	91.67 (18.26)	-	-	-
Al	84.19 (21.95)	74.02 (25.36)	83.33 (24.65)	-	-	-
Social Function						
Au	62.50 (33.61)	46.88 (29.32)	46.88 (28.03)	-	-	-
Al	52.14 (31.11)	33.33 (31.52)	35.86 (35.39)	p<.05	p<.05	-

*Au: Autologous HSCT; ** Al: Allogenic HSCT

The FACT-BMT (Table 4) shows that, for both types of HSCT, the physical and functional well-being, the additional concerning, the treatment outcome index (TOI) - mean of physical/functional well-being/additional concerning- and FACTG- mean of physical/social and family/emotional/functional well-being- presented lower means during pancytopenia compared to the basal stage; with gradual improvement during pre-discharge, except for social and family well-being, which did not improve.

Table 4: Comparison among stages for autologous and allogenic HSCT- FACT significant scores - Curitiba, PR, Brazil, 2013-2015.

FACT Domains	Mean (SD)			Comparison among stages (p-value)		
	Basal Au (n=16) Al (n=39)	Pancytopenia Au (n=16) Al (n=34)	Pre-discharge Au (n=16) Al (n=33)	1 ^a x 2 ^a	1 ^a x3 ^a	2 ^a x3 ^a
Physical well-being						
Au	21 (5.97)	16.44 (4.93)	19.94 (5.03)	p<.05	-	-
Al	22.35 (6.03)	14.53 (6.33)	18.73 (6.35)	p<.05	p<.05	p<.05
Social and family well-being						
Au	20.86 (6.97)	17.09 (6.59)	16.78 (6.73)	-	-	-
Al	21.15 (4.46)	18.65 (4.37)	17.64 (4.69)	p<.05	p<.05	-
Emotional well-being						
Au	19.40 (4.08)	20.13 (2.94)	20.56 (3.16)	-	-	-
Al	17.74 (4.48)	19.56 (3.74)	19.73 (3.81)	-	-	-
Functional well-being						
Au	18.94 (6.05)	15.19 (5.11)	16.94 (4.11)	p<.05	-	-
Al	19.54 (5.31)	14.60 (4.13)	15.42 (4.21)	p<.05	p<.05	-
Additional concerning						
Au	27.50 (4.12)	22.63 (4.63)	24.75 (4.65)	p<.05	-	-
Al	27.90 (6.84)	23 (4.21)	23.48 (4.25)	p<.05	p<.05	-
TOI						
Au	67.44 (13.56)	54.25 (13.11)	61.63 (12.37)	p<.05	-	-
Al	69.79 (15.92)	52.13 (11.92)	57.03 (13.62)	p<.05	p<.05	-

FACTG						
Au	80.20 (15.49)	68.84 (12.75)	74.22 (12.81)	p<.05	-	-
Al	80.79 (16.54)	67.33 (11.86)	70.92 (14.17)	p<.05	p<.05	-

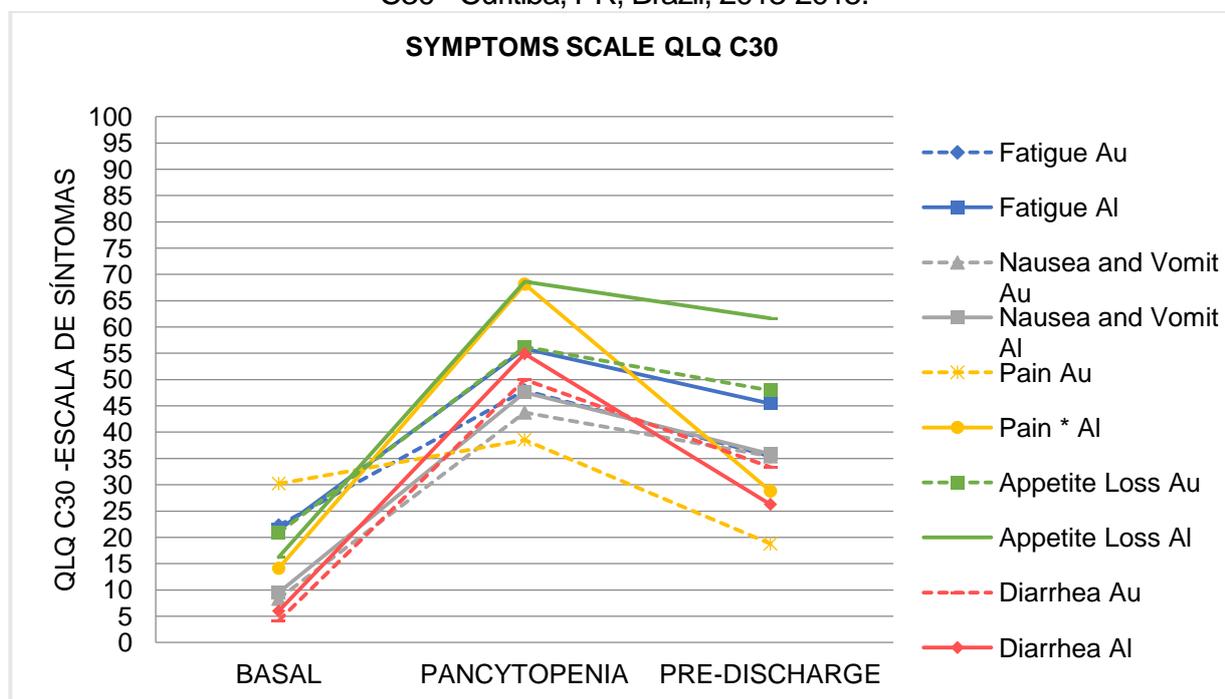
* Friedman Test

** Au: Autologous HSCT; *** Al: Allogenic HSCT

Regarding the symptoms (Figure 1), the comparison among stages shows a similar behavior for both types of HSCT, which enhanced during pancytopenia.

In the comparison of HSCT modalities, using both questionnaires and when the Mann-Whitney test was applied, there was statistical significance in the QLQ-C30 questionnaire, in the pain item of the symptom scale, during the pancytopenia period, higher in the allogenic HSCT.

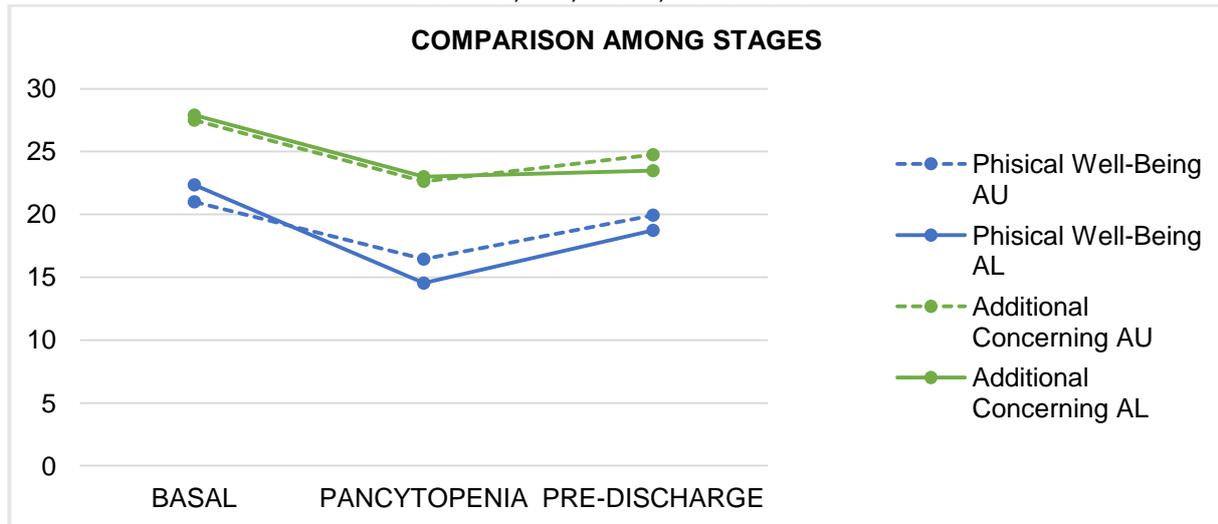
Figure 1: Comparison of symptoms among stages for autologous and allogenic HSCT - QLQ C30 - Curitiba, PR, Brazil, 2013-2015.



Au: Autologous HSCT Al: Allogenic HSCT

Figure 2 shows the physical well-being and the comparison among stages, with unsatisfactory results during pancytopenia stage.

Figure 2: Comparison among stages for autologous and allogenic HSCT – FACT-BMT - Curitiba, PR, Brazil, 2013-2015.



Au: Autologous HSCT Al: Allogenic HSCT
 Additional concerning includes body image, fatigue, sexuality, appetite

DISCUSSION

Hematologic cancer diagnosis and the indication for HSCT have impact on life and QOL of patients and their family, resulting in physical and psychological changes over time. Nursing professionals must follow these changes, in order to provide assistance when it comes to modifications of life functions.

In the present research, there was predominance of married and in consensual union patients for autologous HSCT; in allogenic HSCT, this difference was almost not seen among groups. These results are similar to the patients' profile found in a study performed in Korea ⁽¹⁵⁾ and in the United Kingdom ⁽¹⁶⁾. Having a partner, a person who can provide support to the patient, is fundamental to face the treatment.

Hospitalization results in changes of the family dynamics which can pull away the patients from their beloved ones, it may bring isolation and concern with the impact of their absence in the family environment, education, children growing and other situations related to the social coexistence. Thus, the presence of a partner acts as a bond between patients and their social context and it brings peace, support, safety and protection during this moment of fragility. The partner's presence may booster, albeit indirectly, social interaction, thus, reducing the hospitalization obstacles.

On the other hand, there are cases where the partners present unbalanced, shaken behavior, due the state of health they are watching, and they are overloaded with activities, which were shared in the past. The nurses, aware of the signals of lack of emotional control, may forward the partners to family support services, to minimize the discomfort and the worsening of the clinical status of the patient.

Another factor that may influence the QOL during hospitalization is the removal from professional activities. This study's data show that 63% of the patients were economically active, similarly to the study performed in Chicago, USA ⁽¹²⁾. The cancer diagnosis may change the patients' role inside the family structure and they may become financially dependent on the others and dependent on the maintenance of basic needs, reflecting on social, emotional and functional domains.

The financial difficulty, also called financial toxicity ⁽¹⁷⁾ is an area that suffers from negative reflex of the illness' emergence because the patient is required to step back from their professional activities to undergo the treatment. In addition, the costs of the treatment are high, even with state support; the expense with prescribed and not standardized medication, transport, food and specific needs due the therapeutic, change the family budget. The sum of all these expenses influences the treatment's maintenance and adherence, and may induce post-transplant complications.

This vulnerability gets higher when the patient is the home financial provider, requiring family's adaptation to a new family budget. Studies show that financial questions and concern with returning to work affect the physical and psychological well-being of the patients after transplant ^(17, 18).

Comorbidities, the period between diagnosis and HSCT, stage of the disease, clinical conditions and other factors must be considered when comparing types of HSCT and QOL. For allogenic HSCT the considerations are the donor and receptor's compatibility, risk of graft rejection and development of graft versus host disease (GVHD); for autologous HSCT the considerations are the prevalent age group and the impact on prognosis.

A study performed in Brazil has shown that for both types of HSCT, the severity was similar during the conditioning day, infusion day and the engraftment. Autologous patients presented higher severity during pancytopenia stage compared to allogenic ⁽¹⁹⁾. Other studies performed in Spain ⁽²⁰⁾ and EUA ⁽²¹⁾ suggest that there is no difference between the types of HSCT.

In this research, 70% of the patients underwent allogenic HSCT, as well as the study performed in New York, USA ⁽²²⁾. However, differently from the studies performed in the USA ^(21, 12) and from the report of transplants performed in Brazil in 2016, which demonstrated a higher number of autologous (1,385) compared to the allogenic (802). The prevalence of allogenic HSCT in this study is related to the research's location, which is pioneer and a referral center for this type of HSCT in Latin America ⁽²³⁾.

Researches should be able to identify alterations for both types of HSCT. Although the allogenic patients may be more symptomatic, the global QOL is not significantly different from autologous patients. Thus, the same attention must be given for both patients ⁽²¹⁾, similarly to the study performed in Spain ⁽²⁰⁾ and in the USA ⁽²⁴⁾.

By comparing QOL for both types of HSCT, based on EORTC QLQ C30 and FACIT FACT-BMT questionnaires, it was observed that during basal stage, separately for each type of HSCT, autologous (n=16) and allogenic (n=39), the patients scored their global QOL as good, without significant difference between the types. The same result was found in other studies in the USA, with higher scores for global QOL for both questionnaires and independently of the type of HSCT ^(21, 22). Possibly, these results are related to hope and possibility of cure due the therapeutic.

During pancytopenia, between day five and ten after HSC infusion, the global QOL score was significantly lower than during basal and pre-discharge stages, independently of the questionnaire and the type of HSCT. The study performed in the USA adds that, during hospitalization, the enhancement of physical and depressive symptoms lead to the loss of QOL ⁽²⁵⁾. This is a critical stage for the patient that suffers with the chemotherapy effects and with physical and emotional impairment. It is the nurse's responsibility to stimulate the patient to remain resilient during all the treatment.

The five domains of the QLQ C30- functional scale were significantly lower during pancytopenia than during basal stage. Highlighting the personal performance and social function, whose means were smaller in each type of HSCT. The same result was seen on functional well-being (FACT-BMT), lower scores during pancytopenia.

The ability to conduct the daily activities and satisfaction with the QOL are part of the personal performance domain (QLQ C30) and functional well-being (FACT-BMT). Low scores of QOL during this stage may be due the deleterious effects of chemotherapy and the social isolation. This functional incapacity may make the patient more likely to depression ⁽²⁶⁾. Similar results were seen in the study performed in Massachusetts (USA), which evaluated QOL, depression, anxiety and risk factors to development of posttraumatic stress disorder after HSCT ⁽²⁷⁾. Other study from the same author, which evaluated QOL of patients and their family caregivers during hospitalization, mentions that for both types of HSCT, there is a marked deterioration on QOL and worsening of fatigue and depression during hospitalization ⁽²⁴⁾.

The social function has presented the worst QOL score in this research, for both types of HSCT and instruments. This item includes questions such as having a good relationship with friends, receiving emotional support from the family, acceptance of the disease by the family, proximity of the partner or person who gives main support. Studies show that patients with satisfactory social support present the lowest affliction scores ^(28, 29).

The patients suffer a series of disorders during hospitalization due their immune system fragility, making them vulnerable to infections and post-transplant complications. The isolation negatively contributes to low scores for social function. In the study performed in Chicago (USA) there were no significant alterations in this function, especially during the initial stages of the transplant. The author suggests that the patients' stability may be related to their perception of social support, regardless of the severity of the symptoms, and emphasizes that the clinical staff must provide guidance to patients and family, reinforcing their roles during the treatment ⁽¹²⁾.

Emotional function and well-being (QLQ C30/FACT-BMT) presented high scores mainly during pancytopenia and pre-discharge stages. The hope for cure may promote high scores in the emotional domain, for example, patients undergoing allogenic TSCH may feel joy of finding a compatible donator.

During the second stage, it is observed worsening in QOL or increasing of the symptoms for both types of HSCT. Highlighting the appetite loss, pain, diarrhea, and fatigue. These symptoms may be related to the toxic effects of chemotherapies used during the conditioning stage.

Appetite loss was the prevalent symptom, especially during pancytopenia stage, for both types of HSCT. Similar result was found in studies in Turkey ⁽³⁰⁾, Germany ⁽³¹⁾ and Korea ⁽¹⁵⁾. Gastrointestinal manifestations are common symptoms during hospitalization, due the high-dose chemotherapy and complication post-transplant, related to GVHD. Diarrhea was the third most reported symptom for both types of HSCT. Similar data were found in the study performed in the USA ⁽²⁴⁾ and Pakistan ⁽³⁰⁾.

Pain was the second symptom that most influenced the QOL for both types of HSCT. Authors highlight that pain is one of the symptoms most feared by oncologic patients and its control is a challenge due the magnitude and subjectivity ⁽³²⁾.

By comparing both types of HSCT, using Mann Whitney test, there is a statistical significance in the pain item, during pancytopenia stage; it was higher allogenic TSCH, thus, showing that there are few differences found on QOL in each TSCH type.

Gastrointestinal manifestations are common symptoms during hospitalization, due to the high chemotherapy doses, as well as post HSCT complication related to GVHD. Diarrhea was the third most reported symptom for both TSCH types. Similar data was found in a study performed in the USA⁽²⁴⁾ and Paquistan⁽³⁰⁾.

The additional concerning item englobes body image, fatigue, sexuality, appetite, and corroborates with the findings of the symptoms scale of QLQ C30, presenting low means during pancytopenia stage. These variants decrease the QOL, weakening the patient and impacting on the emotional, social and functional domains. The detection and early action of the nurse team and other health professionals may stabilize the clinical status, relieve the damage on QOL and provide comfort. Supervised and systematic conversation between patient and family helps promoting comfort and may contribute to motivation during treatment.

The professionals, who act with transplanted patients, especially the nurse, need to know the domains that may alter and affect the patients' life, to promote orientation, referral to other professionals such as psychologist, physiotherapist and nutritionist. The partnership and the continued change of information between professionals may help on making a decision, planning assistance, enhancing the plan of individualized care.

In this study, the reduced number of patients was a limiting factor, and it has not enabled the comparison of the results found in other studies. This possibility is due the reduced number of beds available for HSCT in the hospital where the research was performed, difficulty of finding a compatible donor for allogenic HSCT, as well as the long hospitalization period until hematopoiesis recovery.

CONCLUSION

The patients who undergo HSCT show significant alterations in their QOL during hospitalization in all assessed domains and the worst scores were prevalent during pancytopenia, independently to the type of HSCT.

Thus, nurses are responsible for promoting interventions to improve patients' QOL, including not only the physical domains but also the sociodemographic characteristics and other alterations (emotional, social and functional) which may negatively affect the evaluation.

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