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Assessment of quality of life three years from hematopoietic stem cell transplant

Avaliação da qualidade de vida durante três anos após o transplante de células-tronco hematopoiéticas

Evaluación de la calidad de vida después de tres años del trasplante de células madre hematopoyéticas

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Angela da Costa Barcellos Marques[1]
Celina Angélica Mattos Machado[1]
Dabna Hellen Tomim[2]
Paulo Ricardo Bittencourt Guimarães[3]
Jorge Vinicius Cestari Felix[4]
Luciana Puchalski Kalinke[4]

[1] Universidade Federal do Paraná, Complexo Hospital de Clínicas, Curitiba, PR, Brazil.

[2] Universidade Federal do Paraná, Curitiba, PR, Brazil.

[3] Universidade Federal do Paraná, Departamento de Estatística, Curitiba, PR, Brazil.

[4] Universidade Federal do Paraná, Departamento de Enfermagem, Curitiba, PR, Brazil.

ABSTRACT

Objective: To assess the domains of quality of life related to hematologic cancer patient health in the first three years from autologous and allogeneic hematopoietic stem cell transplantation. **Method:** A prospective cohort from September 2013 to February 2019 at a reference service in Latin America with 55 patients. The instruments Quality of Life Questionnaire Core C30 and Functional Assessment Cancer Therapy – Bone Marrow Transplantation were used. For data analysis, Generalized Linear Mixed Model was used. **Results:** The domains global and overall quality of life presented the lowest scores in the pancytopenia phase: 59.3 and 91.4 in autologous, 55.3 and 90.3 in allogeneic. The mixed method analysis has shown that there was a significant change in scores between the phases throughout the treatment ($p < 0.05$). **Conclusion:** Health-related quality of life presented significant changes in the domains between the phases throughout time. Understanding these results enables nursing interventions directed at the domains which were damaged during treatment.

DESCRIPTORS

Quality of Life; Hematopoietic Stem Cell Transplantation; Bone Marrow Transplantation; Hematologic Neoplasms; Oncology Nursing.

Corresponding author:
Luciana Puchalski Kalinke
Av. Pref. Lothario Meissner, 632
Bloco Didático II, 3º andar
80210-170 – Curitiba, PR, Brazil
kalinkeluciana@gmail.com

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INTRODUCTION

Quality of life (QOL) can be understood as a multi-dimensional construct, since it is subjective and encompasses different domains of an individual's life, such as physical, functional, social, spiritual, and emotional. For the World Health Organization (WHO), it is conceived as "the perception of an individual of their position in life according to their culture, system of values in which they live, their objectives, expectations, standards, and worries". The subjective aspect reinforces the conception that QOL must be measured by individuals themselves and when their life condition is affected by disease, the term Health-related Quality of Life (HRQOL) is also employed[1–2].

In the last decade, studies about HRQOL had a significant increase, mainly in oncology, since the technological advancement and development of new therapies has provided an increase in the population's life expectancy, with a growing interest in this theme, since knowledge on these changes throughout the treatment helps defining conducts[3]. Hematologic cancer, the focus of this research, is highly incident in Brazil and worldwide. According to data of the International Agency for Research on Cancer (IARC) of WHO, 1,186,598 new cases of hematologic cancer and 644,609 deaths occurred worldwide in 2018. In Brazil, there were 134,860 new cases with 74,092 deaths[4].

Hematopoietic stem cell transplantation (HSCT) is a possible therapeutic choice; however, this procedure is complex and aggressive. The treatment is relatively long due to encompassing some phases from hospitalization: pre-HSCT (conditioning, pancytopenia) HSCT itself, post-HSCT (bone marrow engraftment, outpatient follow up). After hospitalization, patients are submitted to high doses of chemotherapy, either associated or not to radiotherapy, whose objective is to eradicate cancer cells and then perform an infusion of healthy hematopoietic stem cells (HSC) so that the hematopoietic system can be rebuilt[5]. This transplant is classified as autologous (the HSC are from the patients themselves) or allogeneic (the HSC are from a donor, either a relative or not). The source of HSC may be bone marrow, peripheral blood, or umbilical cord blood[6].

Technological developments and improvements in support care during HSCT improve survival rates; however, this procedure also implies toxic effects which change HRQOL, leading to complications which cannot be ignored[7]. These are either acute or chronic, with a varied classification regarding severity and high potential for negatively impacting the domains of QOL, both in pre-HSCT and in post-HSCT[6,8]. The knowledge of changes in HRQOL in different phases of HSCT is important to subsidize patient care since the detection of these changes may help elaborating healthcare plans directed at the specific needs of each patient.

Given the above, a need for deepening studies that show the difficulties and changes of HRQOL of patients submitted to HSCT during treatment in different modalities is understood. Thus, the objective of this study was to assess the domains of HRQOL of patients with hematological cancer three years from autologous and allogeneic HSCT.

METHOD

Design of Study

Prospective cohort developed at a Bone Marrow Transplantation Service, reference in Latin America, located at a public hospital in South Brazil.

Selection Criteria

The included patients amounted to 55 and met the following inclusion criteria: aged 18 or higher, hematological cancer diagnosis, and submitted to HSCT. The adopted exclusion criteria were: patients with no physical condition for filling the questionnaires and/or who were submitted to any modality of HSCT. The discontinuation criteria were patients who, throughout the research, opted for withdrawing consent, loss to follow-up (absent from outpatient follow-up consultations), and death.

Sample Definition

Non-probabilistic sample corresponding to the total of patients who met the inclusion criteria from September 2013 to November 2015, the period of participant inclusion. Sample size was based on mean of hospitalization at the service from 2010 to 2012 (36.6 patients), with an extra 50% due to an expressive mortality rate throughout treatment. Retrospective study[9] performed with 278 patients submitted to HSCT in a university hospital in South Brazil had as a result 40.7% and 44.6% mortality in five and ten years, respectively, and emphasizes that HSCT is associated to a higher mortality rate throughout time.

Data Collection and Instruments

The data collection lasted from September 2013 to February 2019. The data were collected in the hospitalization and outpatient units of the transplant service in eight phases, three of which were during the hospitalization phase (pre-HSCT, pancytopenia, pre-hospital discharge), and five in the outpatient follow-up phase (post 100 days, post 180 days, post 360 days, post two years, and post three years from HSCT). After hospital discharge, collections were scheduled according to the return consultation protocol of the outpatient ward of the institution and took place at the waiting room while patients waited for their consultations. The researchers had contacted them previously through telephone to confirm their presence in the consultation.

The sociodemographic and clinical data were collected through an instrument developed by researchers in the pre-HSCT phase. To measure HRQOL, two instruments were used: one generic, applicable to patients with cancer in general, and another one specific for patients submitted to HSCT. These were, respectively, Quality of Life Questionnaire Core C30 (QLQ C30) version 3.0, developed by the European Organization for Research Treatment of Cancer (EORTC) and the Functional Assessment Cancer Therapy – Bone Marrow Transplantation (FACT-BMT) version 4.0, elaborated by the Functional Assessment of Chronic Illness Therapy (FACIT), both translated and

validated for Brazil[10–11] and authorized/made available through download directly for researchers upon registration of the research project.

The QLQ C30 of EORTC is composed of 30 questions distributed into five domains (physical functioning, role functioning, emotional functioning, cognitive functioning, and social functioning) with scores from 0 to 100. A higher score in the functional scale and in global QOL (global health status and QOL) represents a better assessment of HRQOL[12]. The FACT-BMT is composed of 50 questions and presented in five domains. Its score ranges from 0 to 28 for physical well-being, social and family well-being, and functional well-being; from zero to 24 for emotional well-being; from 0 to 40 for additional worries; 0 to 96 for *Trial Outcome Index* (TOI), which corresponds to the sum of scores for the domains physical well-being, functional well-being, and additional worries; 0 and 108 for FACT-G (sum of scores for the domains physical well-being, social and family well-being, emotional well-being, and functional well-being); 0 and 148 for overall QOL. Higher scores indicate a better HRQOL[13].

Data Analysis

The sociodemographic and clinical data were analyzed through descriptive statistics expressed in simple and absolute frequencies. The HRQOL data were organized and analyzed according to recommendations of the *Scoring Manual* of EORTC[12] and *Scoring Manual* of FACIT[13]. For a comparison of transplant modalities and between phases, the Generalized Linear Mixed Model (GLMM) was applied. Software SPSS 20 was employed for analysis.

The use of GLMM considers the totality of observations, including those of discontinued patients. The model enables the assessment of the factors time (eight phases) and group (autologous versus allogeneic), as well as a possible interaction effect between phases and group. The model was adjusted considering the patients as a random effect and covariance matrix AR1. The best adjustment was defined through AIC (Akaike Information Criterion). The presupposition of normality of residuals was verified with the graph QQ plot and the analysis of multiple paired comparisons was performed through the Sidak test[14].

Ethical Aspects

This research is inserted into the thematic project "Assessment of QOL of patients with hematologic neoplasia submitted to HSCT". This is a prospective cohort whose opinion, dated 2013, had an amendment approved in 2018 by the Research Ethics Committee of the Health Sciences Sector of Universidade Federal do Paraná, with number 2.853.160. This research met the ethical precepts of CNS Resolution 466/2012 and the participants signed the informed consent form.

RESULTS

Out of the 55 included patients, five were discontinued due to loss to follow-up, 14 progressed to death before completing 180 days, six before completing 360 days, five before completing two years, and three before completing three years from HSCT; in the last phase, 22 (40%) participated in the study.

The sociodemographic and clinical description showed that the mean age of the sample (n = 55) was 36 years old, with 53% (n = 29) male and 55% (n = 30) married or who reported being in a domestic partnership. In relation to diagnosis, 65% (n = 36) presented some type of leukemia and 71% (n = 39) were submitted to allogeneic HSCT.

When comparing between the phases, the lowest scores were observed to be those of the pancytopenia phase, in the HRQOL domains measured by QLQ C-30: global QOL, physical functioning, role functioning, and social functioning in both groups. The domain emotional functioning is also emphasized to have presented higher scores when compared to the basal phase until completing 360 days for both autologous and allogeneic. In the domain cognitive functioning, both groups presented lower scores in the last phase of the study compared to the initial phase (Table 1).

In Table 2, the item overall QOL assessed through FACT-BMT, for both groups, presented lowest scores in the pancytopenia period; however, the scores recovered, surpassing the basal levels after 180 days from HSCT. Nonetheless, the autologous group is emphasized to have had a gradual improvement up to the post 360 days and, from this phase onwards, presented lower scores in relation to the pre-HSCT phase. Domain measurement reveals that, except for emotional well-being, all others presented lower scores in the pancytopenia phase in both groups.

In relation to TOI (index of assessment of the result of treatment) which encompasses the domains physical well-being, functional well-being, and additional worries, and to FACTG, which encompasses the domains physical well-being, social and family well-being, emotional well-being, and functional well-being, in the last phase of the study, the autologous group presented a lower score in relation to that of the first phase, whereas the allogeneic group presented a higher score (Table 2).

In the analysis throughout time of the global QOL scores evolution (QLQ C-30) and overall QOL (FACT-BMT), the GLMM was used and adjusted considering the patients as random effect. The best adjustment was defined by the AIC (AIC: global QOL = 2576.07; overall QOL = 2495.86. The presupposition of normality of residues was verified through the QQ plot graph, with confirmatory results.

Table 3 presents the results of the final analysis of GLMM for the factors group, phase, and group/phase interaction. A significant difference in scores between the phases of this research was observed throughout time. There is no difference between autologous and allogeneic, not even in the group/phase interaction.

Figure 1 illustrates the behaviors throughout time for the index of global QOL measured by QLQ-C30, for total group (n = 55). A significant reduction of HRQOL was observed in the moment of pancytopenia, with a gradual reduction until the post 180 days from HSCT. However,

Table 1 – Health-related quality of life scores of Quality of Life Questionnaire – 30 of patients submitted to autologous and allogeneic transplant obtained in the eight phases of the study – Curitiba, PR, Brazil, 2013–2019 (n = 55).

Quality of Life Questionnaire – Core 30 (QLQ – C30)																
Scores	Pre-HSCT* n = 55		Pancytopenia n = 50		Pre-discharge n = 49		Post HSCT 100 days n = 41		Post HSCT 180 days n = 38		Post HSCT 360 days n = 32		Post HSCT 2 years n = 25		Post HSCT 3 years n = 22	
	Means SD		Means SD		Means SD		Means SD		Means SD		Means SD		Means SD		Means SD	
	Aut† n = 16	Alo‡ n = 39	Aut† n = 16	Alo‡ n = 34	Aut† n = 16	Alo‡ n = 33	Aut† n = 13	Alo‡ n = 28	Aut† n = 12	Alo‡ n = 26	Aut† n = 11	Alo‡ n = 21	Aut† n = 7	Alo‡ n = 18	Aut† n = 4	Alo‡ n = 18
Global QOL§	70.8 16.3	79.2 17.8	59.3 19.2	55.3 20.9	73.9 15.1	66.7 20.6	80.7 13.3	71.4 23.7	75.6 21.4	77.5 20.1	72.7 16.7	70.6 22.7	63.1 28.8	77.7 16.4	75.0 21.5	82.8 13.8
Funtional Scale																
Physical functioning	72.9 22.3	77.9 21.8	50.8 21.4	57.6 19.5	57.5 22.4	68.2 18.4	82.5 14.2	74.7 21.1	79.4 20.7	80.5 23.7	83.6 17.7	83.8 16.6	60.9 32.5	85.7 20.3	68.3 23.9	80.3 26.2
Role functioning	79.1 30.1	79 29.5	50 36	41.1 26.3	52 37.4	61.6 29.3	82 24	72.6 26.9	88.8 21.7	77.5 31.9	90.9 20.2	87.3 20.3	61.9 41.6	86.1 26.3	70.8 34.3	85.1 28.5
Emotional functioning	70.8 19.9	65.1 25.5	71.8 19.6	70.5 24	77.6 20.3	68.6 30.6	85.9 9.2	74 24.9	81.9 12.7	72.1 25.2	71.9 17.9	67.4 33.4	52.3 25.3	69.4 26.5	52 38.7	67.1 25.8
Cognitive functioning	81.2 18.3	84.1 21.9	85.4 19.1	74 16.6	91.6 18.2	83.3 24.6	91 12.9	82.1 29	91.6 11.2	80.7 21.9	83.3 23.57	80.9 28	61.9 36.9	84.2 25.8	70.8 25	82.4 23.2
Social functioning	62.5 33.6	52.1 31.1	46.8 29.3	33.3 31.5	46.8 28	35.8 35.3	71.7 32.1	52.9 40	86.1 18.5	67.9 36.7	81.8 26.3	75.4 29.6	59.5 40.6	85.1 22	66.6 40.8	79.6 33.1

Notes: *HSCT: Hematopoietic stem-cell transplant; †Aut: Autologus; ‡Alo: Allogeneic; §QOL: quality of life.

Table 2 – Health-related quality of life scores of Functional Assessment of Cancer Therapy Bone Marrow Transplantation of patients submitted to autologous and allogeneic transplant obtained in the eight phases of the study – Curitiba, PR, Brazil, 2013–2019 (n = 55).

Functional Assessment of Cancer Therapy Bone Marrow Transplantation (FACT-BMT).																
Scores	Pre-HSCT* n = 55		Pancytopenia n = 50		Pré-high n = 49		Post HSCT 100 days n = 41		Post HSCT 180 days n = 38		Post HSCT 360 days n = 32		Post HSCT 2 years n = 25		Post HSCT 3 years n = 22	
	Means SD		Means SD		Means SD		Means SD		Means SD		Means SD		Means SD		Means SD	
	Aut† n = 16	Alo‡ n = 39	Aut† n = 16	Alo‡ n = 34	Aut† n = 16	Alo‡ n = 33	Aut† n = 13	Alo‡ n = 28	Aut† n = 12	Alo‡ n = 26	Aut† n = 11	Alo‡ n = 21	Aut† n = 7	Alo‡ n = 18	Aut† n = 4	Alo‡ n = 18
Overall QV§ FACT-BMT	107.7 18.3	108.6 22.2	91.4 16.4	90.3 14.6	98.9 16.6	95 16.6	114.8 20.2	105 18.8	115.3 21	111.1 22.2	113.8 20.2	109.7 19	101.8 30.6	117.1 16.1	95.3 41.3	117.7 20.1
Physical well-being	21 5.9	22.3 6	16.4 4.9	14.5 6.3	19.9 5	18.7 6.3	23 4	21.2 5.4	23.9 3.7	22.7 6.4	24.2 2.5	23.4 5.4	17.1 10.4	24.8 3.5	19.5 8.7	24.1 5.7
Social and family well-being	20.8 6.9	21.1 4.4	17 6.5	18.6 4.3	16.7 6.7	17.6 4.69	19.9 7.9	20.1 5.2	20.8 5.7	21.2 5.9	20.7 7.9	19.7 4.4	21.5 4.8	21.6 3.1	16.8 11.3	21.3 4.1
Emotional well-being	19.4 4	17.7 4.4	20.1 2.9	19.5 3.7	20.5 3.1	19.7 3.8	21.3 2.2	19.8 3.2	20.7 2.3	19.4 4.1	19.1 3.1	19.1 3.7	15.5 6.1	20.2 3	17 4.5	19.9 4.6
Functional well-being	18.9 6	19.5 5.3	15.1 5.1	14.6 4.1	16.9 4.1	15.4 4.2	20.2 5.3	16.2 5.1	18.6 6	18.6 5.3	19.9 5	18.2 4	17.4 7.1	19.3 3.9	16 9.4	20.9 4.4
Additional worries	27.5 4.1	27.9 6.8	22.6 4.6	23 4.2	24.7 4.6	23.4 4.2	30.3 4.6	27.4 5.2	31.1 5.7	29 6	29.9 5.6	29.1 6.2	30.1 6.8	31 5.6	26 10.4	31.3 5
TOI**	67.4 13.5	69.7 15.9	54.2 13.1	52.1 11.9	61.6 12.3	57.6 12.2	73.6 12.6	64.9 12.7	73.7 14.5	70.4 15.8	74 12.4	70.8 12.9	64.7 21.3	75.3 12	61.5 27.7	76.4 13.8
FACTG††	80.2 15.4	80.7 16.5	68.8 12.7	67.3 11.8	74.2 12.8	71.5 13.1	84.4 16.2	77.5 14.5	84.1 15.8	82 16.9	83.9 16	80.5 14.4	71.6 26.2	86.1 11.3	69.33 32	86.3 15.3

Notes: *HSCT: hematopoietic stem cell transplant; †Aut: Autologus; ‡Alo: Allogeneic; §QOL: quality of life; **TOI – Index for the assessment of treatment result (physical well-being/functional well-being/additional worries).
††FACTG – Overall assessment (physical well-being/family and social well-being/emotional well-being/functional well-being).

a new reduction was observed upon completion of the first year.

In Figure 2, the behavior of the overall QOL index measured by FACT-BMT is verified throughout three years. An important reduction in scores in the pancytopenia phase is observed; however, there was a recovery throughout time, surpassing the baseline parameter of the phase after 180 days.

DISCUSSION

Patients with hematologic cancer, in addition to facing the severity of this disease, must face the complexity and aggressiveness of the treatment. It requires care so as to avoid intercurrences which may compromise HRQOL or even predispose them to a higher risk of death. However, in spite of these risks, the last decades have seen an increase in

Table 3 – Mixed Generalized Linear Model Analysis of the global QOL and overall QOL among groups (Autologous versus Allogeneic), phases (eight phases) and group/phase interaction – Curitiba, PR, Brazil, 2013–2019 (n = 55).

Factors	QLQ-C30* Global QOL‡		FACT-BMT† Overall QOL‡	
	F§	*p***	F§	*p***
Intercept	1362.54	0.00	1713.83	0.00
Groups	0.25	0.61	0.12	0.72
Phases	6.18	0.00**	12.45	0.00**
Groups/Phase	1.65	0.12	2.22	0.03

Notes: **Quality of Life Questionnaire-Core 30;* †*Functional Assessment of Cancer Therapy Bone Marrow Transplantation;* ‡QOL = Quality of Life; §F = F Snedecor statistics; ***p* < 0.05.

the number of HSCT, with improved results, following an increase in survival rates[15].

In this research, the results have shown that the mean age was 36 years. This is a relatively young public belonging to an age group which is representative of a productive period of life and who is unexpectedly caught in a situation of vulnerability, fighting with a severe disease whose treatment may damage their QOL in several different ways.

Regarding clinical data, leukemia diagnosis and allogeneic HSCT were prevalent. The high rate of this modality of HSCT may be related to the place where the research was conducted, since this is a worldwide reference center which also stands out for its number of allogeneic HSCT per year. This treatment is a curative therapeutic option for several malignant and nonmalignant diseases. Despite the reduction of early mortality due to some factors such as reduced intensity conditioning regimens and efficient anti-infectious treatments, the late mortality related to HSCT continues to be considered a setback[16].

The HSCT has high-complexity demands and variables to be controlled, since there is a preoccupation with the necessary compatibility between donor and receptor to obtain treatment success. Donor-provided HSC may significantly increase the risk of complications, such as the graft versus host disease (GVHD), implying changes to the domains of QOL[3,6]. By its turn, autologous HSCT requires no preoccupation with compatibility, since the HSC are the patient's; however, this does not make it less complex, since this procedure also has its specificities.

In relation to the HRQOL data, the measurement of the domains through instruments QLQ-C30 and FACT-BMT has enabled the identification of changes throughout the treatment. According to authors[17], this is a relevant assessment since, to appropriately provide integral care, patient satisfaction with life should be observed through the domains of QOL.

Global QOL (QLQ-C30) and overall QOL (FACT-BMT) of patients submitted to HSCT presented lower scores in the pancytopenia phase, coinciding with acute toxic effects of the chemotherapeutics used during conditioning. Similar results were shown by a study in South Korea with 89 patients who used HSCT as a treatment strategy[18] and a study conducted in China with 191 patients submitted to

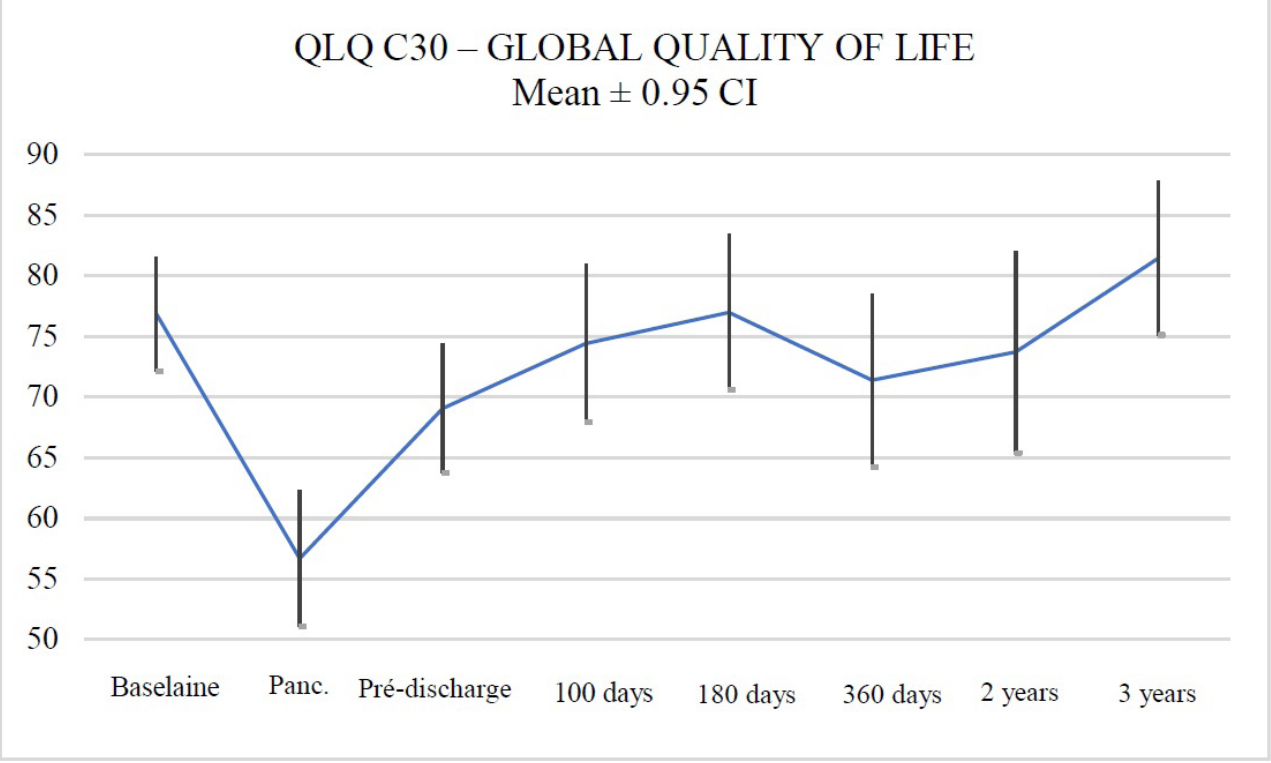

Figure 1 – Global QOL measured with Quality of Life Questionnaire – Core 30 (QLQ-C30) for patients submitted to autologous and allogeneic HSCT, in the eight study phases – Curitiba, PR, Brazil, 2013–2019 (n = 55).

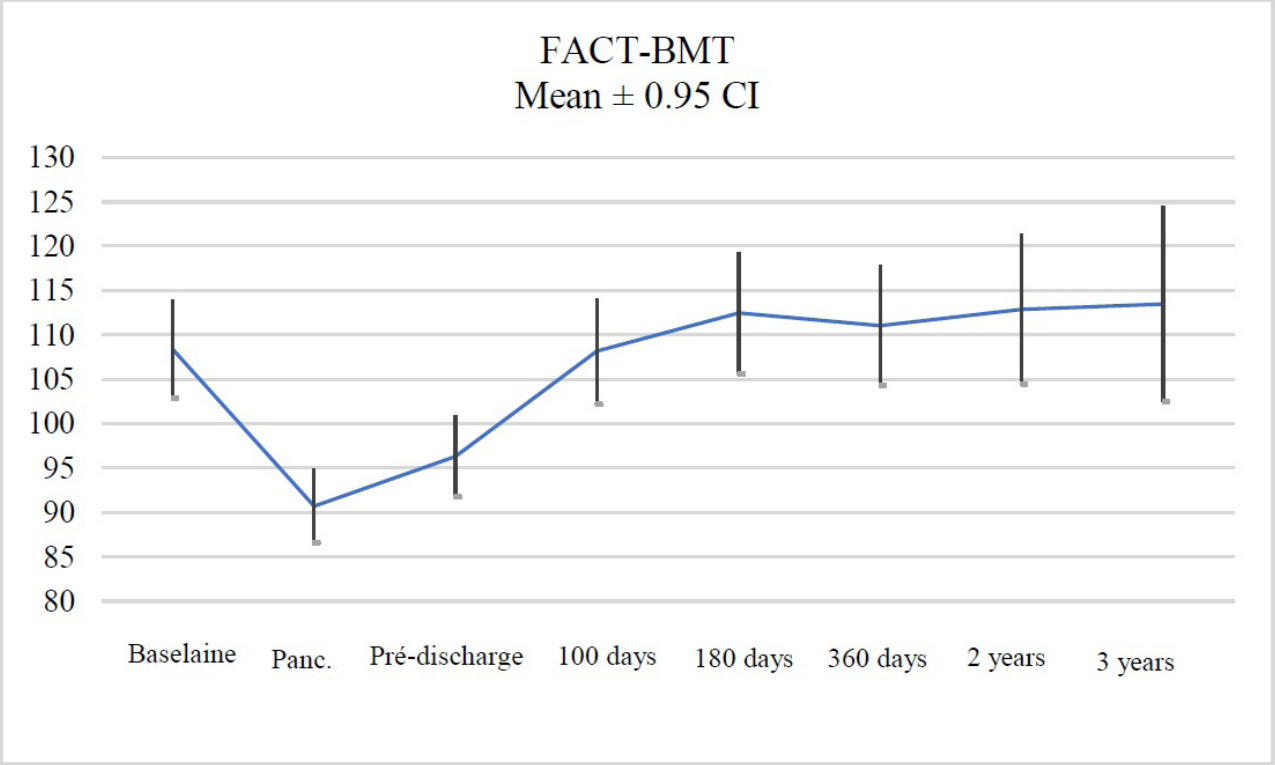

Figure 2 – Overall QOL measured with Functional Assessment of Cancer Therapy Bone Marrow Transplantation (FACT-BMT) of patients submitted to autologous and allogeneic HSCT, in the eight study phases – Curitiba, PR, Brazil, 2013–2019 (n=55).

the same therapy[19], both of which presented a more strongly compromised HRQOL in the first stages of the procedure.

Among the several physical events that the patient presents in the pancytopenia phase, which cause pain and discomfort and influence a compromised HRQOL, oral mucositis (OM) is commonly reported as a side effect which causes the reduction of HRQOL and important financial implications[19]. A study conducted in Germany, whose objective was to determine the impact of OM on HRQOL, has shown that patients suffered with more pain and more sensitivity in the oral cavity, lower functional capacity, and worse QOL[20].

After grafting, the patients started to present a gradual improvement of their health status and consequent recovery in HRQOL scores. There is a progressive and constant recovery throughout the subsequent phases of the procedure, presenting values over the baseline after three years, except for autologous HSCT, for which a new reduction of HRQOL scores was observed two and three years from HSCT. For allogeneic HSCT, the findings suggest that, despite treatment aggressiveness and lower means in the pancytopenia period, these patients presented a satisfactory performance and were able to recover their HRQOL with time.

In autologous HSCT, although there was a reduction in the overall QOL scores assessed by FACT-BMT, its indexes are still not considered satisfactory, with a positive assessment of HRQOL throughout time. This lower score may be related with lower scores for pre-HSCT assessment in the domains physical well-being, social and family well-being, functional well-being, as well as diagnosis, age, and other factors which may influence long term HRQOL, since this population presents its own characteristics upon treatment onset. These patients are suggested to be followed for a longer period so as to assess their behavior throughout time.

In the QLQ-C30 functional scale, patients submitted to allogeneic HSCT presented significant results for physical functioning, with a higher mean, as well as for the progression of scores throughout the phases after three years in the domains global QOL, physical functioning, role functioning, and social functioning, which suggests that, although there are late complications with changes of physical symptoms and other impairments, they seem to be well-controlled by the health team providing patient care. A study conducted in Poland with 188 patients, whose objective was to assess physical symptoms, concluded that there is a significant systematic reduction of symptoms throughout time. These results may indicate relatively good performance and adaptation to the treatment[21].

Cognitive functioning was significantly compromised for autologous transplant throughout the phases, with lower scores than in baseline, two years from HSCT, and three years from HSCT. A similar result was found in a study performed in the USA in which 71% of the participants reported cognitive impairment, with damage to daily life activities after HSCT with a negative association between cognitive impairment and QOL[22]. However, this study differs from a longitudinal study performed in the USA

with 477 participants, in which, for autologous HSCT, the cognitive domain was stable throughout the period[23].

Cognitive impairment may be related to age, increased distress, and lower QOL, as well as impaired self-management of symptoms, i.e., experiencing a reduction in efficient symptom management seems to lead HSCT survivors to cognitive impairment[22]. Also, potentially neurotoxic agents, including total body and cranial irradiation, high dose chemotherapy, immunosuppressive therapy, duration of hospitalization, and GVHD, put patients submitted to HSCT at risk for neurocognitive dysfunction, which has emerged as one of the main causes of post-transplantation morbidity and mortality[24].

The social functioning domain (QLQ-C30) presented the lowest scores during the assessed phases for both modalities of transplant with a significant result in the evolution throughout the phases. The performance improvement in the social domain is an expected result throughout time, given that, little by little, social interaction is resumed. The health team may stimulate social interaction, encouraging patients and their relatives to gradually return to the activities they performed before the diagnosis, with the objective of improving QOL in their multi-dimensional aspects. Despite the imposed need for social distancing, mainly during hospitalization, relatives and friends are noticed to be still present, showing their support for the patient's well-being[25].

Concerning FACT-BMT, the assessed domains physical well-being, functional well-being, and additional worries, index of assessment of treatment result (TOI) presented similar assessment results throughout the phases for allogeneic HSCT, which corroborates the results of the QLQ C-30 questionnaire. In both assessments, patients recover their QOL, even overcoming the baseline results. These findings may be used by health professionals, mainly nurses, who spend the most time with the patient, so as to promote hope and comfort regarding treatment expectations.

Authors[18] corroborate this study's findings, which has shown that QOL and its predictors change dynamically throughout time. In addition, they also conclude that the results may help advising patients who have an indication for HSCT, since they may demonstrate reasonable recovery expectations.

Concerning the mixed method analysis used for assessment of changes between phases (eight phases), groups (autologous versus allogeneic), and possible interaction between phase and group, a significant change was observed only between phases, which corroborates other studies which show that HRQOL changes with time[18,23].

Scientific evidence-based nursing interventions, such as integrative and complementary practices, which take into account the multi-dimensional aspect of the construct, may offer a possibility for promoting well-being and improving HRQOL.

This study is emphasized to be limited by its conduction in a single transplant center, which precludes result generalization.

CONCLUSION

The HRQOL of patients submitted to autologous or allogeneic HSCT is concluded to have presented a significant change throughout time. Pancytopenia is the phase in which the domains of the QOL construct presented the lowest scores. Nonetheless, throughout the treatment, a gradual improvement is observed in the allogeneic group, with better assessed domains in the third year when compared to baseline. However, in the autologous group, there is a gradual improvement after the pancytopenia phase, although the scores at the end of the third year do not surpass those obtained in the treatment onset.

This research provides evidence for clinical practice with a focus on domains which are damaged during HSCT phases. It also shows that, in addition to physical impairment, there is also emotional, social, and cognitive impairment, and that nursing interventions focused on multi-dimensional issues are necessary.

RESUMO

Objetivo: Avaliar os domínios de qualidade de vida relacionada à saúde de pacientes com câncer hematológico nos três primeiros anos após o transplante de células-tronco hematopoéticas autólogo e alogênico. **Método:** Coorte prospectiva realizada de setembro de 2013 a fevereiro de 2019, em um serviço de referência na América Latina, com 55 participantes. Foram utilizados os instrumentos *Quality of Life Questionnaire Core* C30 e *Functional Assessment Cancer Therapy – Bone Marrow Transplantation*. Para análise dos dados, foi utilizado o *Generalized Linear Mixed Model.* **Resultados:** Os domínios de qualidade de vida global e geral apresentaram os menores escores na etapa de pancitopenia: 59,3 e 91,4 no autólogo, 55,3 e 90,3 no alogênico. A análise de métodos mistos demonstrou que houve alteração significativa dos escores entre as etapas ao longo do tratamento ($p < 0,05$). **Conclusão:** A qualidade de vida relacionada à saúde apresentou mudança significativa nos domínios entre as etapas ao longo do tempo. Conhecer esses resultados possibilita intervenções de enfermagem direcionadas aos domínios prejudicados durante o tratamento.

DESCRITORES

Qualidade de Vida; Transplante de Células-Tronco Hematopoéticas; Transplante de Medula Óssea; Neoplasias Hematológicas; Enfermagem Oncológica.

RESUMEN

Objetivo: Evaluar los dominios de la calidad de vida relacionada con la salud de pacientes con cáncer hematológico en los tres primeros años después del trasplante de células madre hematopoyéticas autólogo y alogénico. **Método:** Cohorte prospectivo realizado de septiembre 2013 a febrero 2019 en un servicio de referencia en Latinoamérica con 55 participantes. Se utilizaron los instrumentos *Quality of Life Questionnaire Core C30* y *Functional Assessment Cancer Therapy – Bone Marrow Transplantation***.** Para el análisis de datos, se utilizó el *Generalized Linear Mixed Model*. **Resultados:** Los dominios de calidad de vida global y general presentaran las menores

puntuaciones en la etapa de pancitopenia: 59,3 y 91,4 en el autólogo, 55,3 y 90,3 en el alogénico. El análisis de métodos mixtos demostró que hubo un cambio significativo en la puntuación entre las etapas durante el tratamiento ($p < 0,05$). **Conclusión:** La calidad de vida relacionada con la salud presentó cambios significativos en los dominios entre las etapas a lo largo del tiempo. Conocer estos resultados posibilita intervenciones de enfermería direccionadas a los dominios afectados durante el tratamiento.

DESCRIPTORES

Calidad de Vida; Trasplante de Células Madre Hematopoyéticas; Trasplante de Médula Ósea; Neoplasias Hematológicas; Enfermería Oncológica.

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